

C1 Esterase Inhibitor

Learning about intravenous self infusion

C1 Esterase Inhibitor, also called C1 Inhibitor or C1-INH. C1 inhibitor is a concentrated protein that replaces what is missing in your body. It is used to treat hereditary angioedema (HAE). This handout provides information on how to give yourself an infusion of C1 Inhibitor.

Where do I pick up my C1 Inhibitor?

You pick up your C1 Inhibitor from the Transfusion Medicine (TM) Department.

- Telephone Number: 905-521-2100, ext. 76281
- Location: Transfusion Medicine Department, 2nd floor, Blue section, McMaster University Medical Centre

Order on time so you do not run out

- The Transfusion Medicine (TM) Department needs 2 business days from the time the C1 Inhibitor is ordered until it is picked up.
 - Place your order with TM at least one week before the end of your supply and tell them when you will be picking up the C1 Inhibitor.
 - Place your order during the day from Monday to Thursday.
 - Bring an insulated bag to transport the C1 Inhibitor.
 - The C1 Inhibitor must be stored at temperatures between 2°C and 25°C.
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When you first get started with C1 Inhibitor infusions.

1. On the first day of training in Medical Day Care (MDC) the nurse will go over:
 - why you are receiving C1 Inhibitor
 - how to store and travel with the C1 Inhibitor
 - the ABCs of giving yourself C1 Inhibitor
 - troubleshooting
 - side effects of C1 Inhibitor, safety and emergency procedures
 - other resources available to you
2. You will be given 1 infusion of C1 Inhibitor and the log book to keep track of your infusions when completed.
3. You will be given a C1 Inhibitor kit to practice with at home. Do not use the practice kit supplies to give yourself the infusion. The practice kit is only to learn how to become comfortable with the steps leading up to the infusion.
4. An appointment for follow-up teaching will be made according to your doctor's order.
5. The nurse will continue teaching you how to give C1 Inhibitor until you are comfortable with giving yourself the infusion.
6. When you are comfortable with giving yourself the infusion the nurse will arrange for a one month supply of C1 Inhibitor for you to take home.

Supplies needed

Sharps container

Your pharmacy may supply sharps containers free of charge. Full containers may be dropped off at the pharmacy and may be replaced with empty ones. Ask your pharmacy if they offer this service.

Travel bag

Travel bag to pick up your C1 Inhibitor from Transfusion Medicine, and to travel with the C1 Inhibitor . Remember the C1 Inhibitor must be kept between 2°C and 25°C.

Infusion supplies

Type of supply	Medical Mart catalogue number	Approximate price
Box of 200 alcohol pads, or use cotton balls and rubbing alcohol instead.	204-MM-05507	\$1.79/box
Box of 40, 60 mL luer lock syringes OR Box of 56, 30 mL luer lock syringes	308309653 308302832	\$46.99/box \$48.00/box
1 inch paper tape (box of 12 rolls)	238-A5110	\$10.00/box
2 x 2 gauze (200 per package)	211052113	\$1.69/package

Where do I order the supplies?

You will need to set up an account. These items will be delivered to your home. If you spend \$100, delivery is usually free. After your first day of training at MDC:

- Call Medical Mart at 905-624-2011 or toll-free 1-800-379-4780

You may also try other websites for supplies.

Cost and insurance

The cost of supplies is about \$40 a month if you are doing a C1 Inhibitor infusion every day. Check with your insurance company for coverage. If you are not covered through insurance and you cannot afford the cost, the C1 inhibitor supplier may cover the cost.

C1 Inhibitor infusions at home

Tips for success

1. Make up kits of supplies (11 things) in plastic bags – 1 month supply.
 2. Use rubbing alcohol and cotton swabs if you like instead of alcohol swabs. Alcohol swabs are not covered by insurance.
 3. Have 2 kits on hand at all times.
 4. Have a C1 Inhibitor infusion buddy (support person), especially for the first month. Have your support person come to the training with you.
 5. Inject at a maximum rate of 4 mL per minute. It should not hurt.
 6. Remember to fill out your log pages. Photocopy more when you start to run out.
 7. Keep track of your C1 Inhibitor vials. Consider colour coding or dating the top of the boxes so they will not be expired when you are ready to do the infusion.
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Side effects

Side effects from C1 Inhibitor are low, but could include: nausea, headache, abdominal pain, or changes in taste. The most serious side effect is an increase in the severity of pain from hereditary angioedema.

What if the needle hurts or I notice some swelling?

If you have discomfort with the needle or notice swelling or a bubble around the needle site it may not be in your vein. Continue the infusion in another vein with a new butterfly needle.

Call us. Medical Day Care is available 8:00am to 4:00pm, Monday through Friday for any troubleshooting issues or advice. Phone 905-521-2100, ext. 75250.

Emergency procedures

Seek immediate emergency treatment for:

- being unable to start your IV
- no improvement or worsening of your HAE attack
- throat swellings
- severe side effects from the C1 Inhibitor infusion

If you have a medical emergency call 911 or go to the Emergency Department.

Traveling tips for C1 Inhibitor

- Gather your supplies of 11 things together, or more if you are giving yourself many infusions while away.
 - Make sure that you have your travel letter.
 - Always travel with C1 Inhibitor in the passenger compartment of the car. Never store it in your trunk as the temperature changes too much.
 - Always carry C1 Inhibitor in your carry on bag when flying. It will freeze in the airplane's hold.
 - Be prepared to take the vials out of their boxes and place them in a plastic bag to show security. Keep the boxes in your carry on bag and place the vials back into the boxes once through security. This will help prevent them from breaking while travelling.
 - If you are concerned about travelling with your C1 Inhibitor and supplies check with your airline before you fly.
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Notes:
