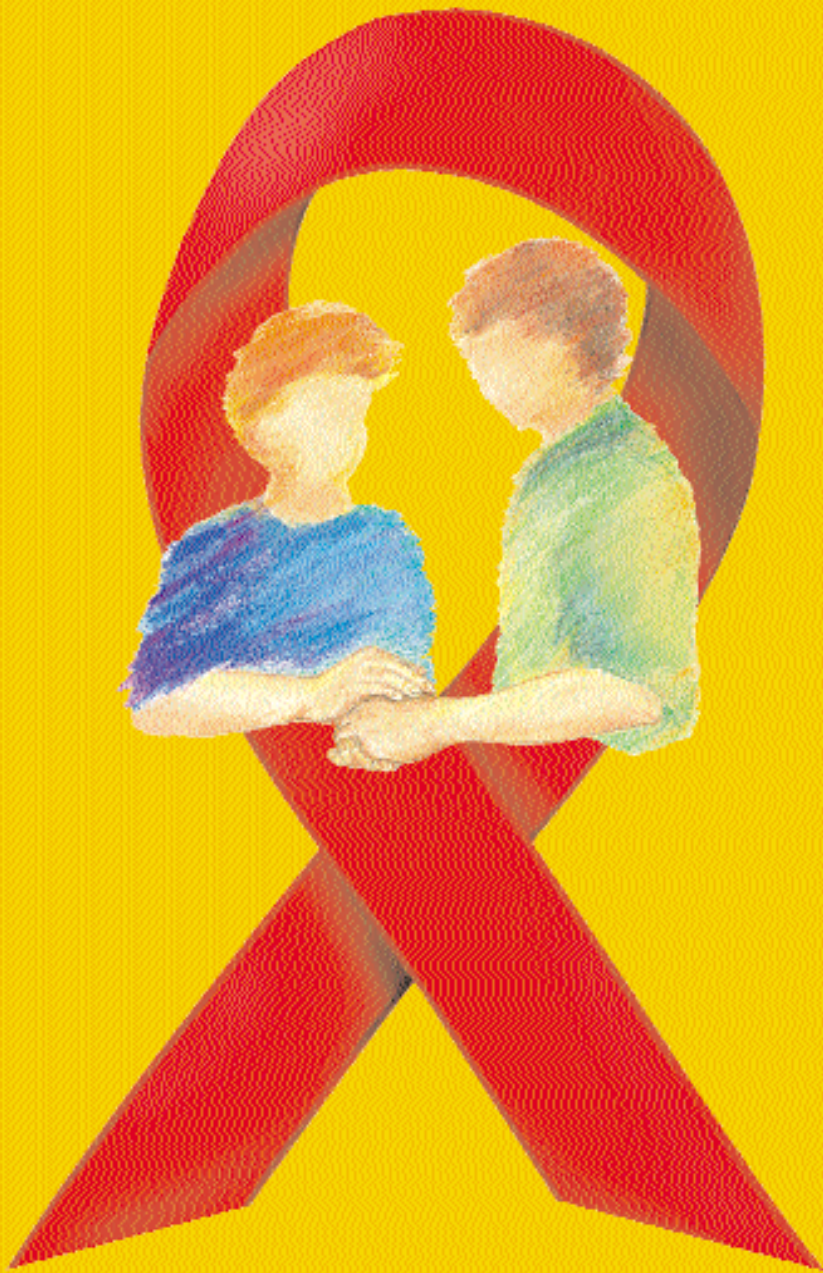




Caring for
Information
for friends,
relatives,
household members
and others caring
for a person
with AIDS
with AIDS
at home.

Québec 

Caring for someone with AIDS

**Informations
for friends,
relatives,
household
members and
others caring
for a person
with AIDS
at home**



Gouvernement du Québec
**Ministère de la Santé
et des Services sociaux**

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Coordination

Claudette Lafrenière - Direction générale de la santé publique, Centre de coordination sur le sida, ministère de la Santé et des Services sociaux

Communications

Michelle Rompré - Direction générale de la santé publique, Centre de coordination sur le sida, ministère de la Santé et des Services sociaux

Contributors

Dr. Anne-Marie Bourgault - Saint-Luc Hospital, Microbiology Department

Monique Boulard, caregiver

Marie Charron - CLSC Plateau Mont-Royal

Dr. Louis-Gilles Cloutier - Direction de la protection de la santé publique, MSSS

Francine Comptois - CLSC Plateau Mont-Royal

Michèle Cossette, dietician - CLSC Centre-Ville

Xavier Côté - Maison d'Hérelle

Lucie Dandurand-Raby, caregiver

Monique Delorme - APPI

Jacques Grégoire, person living with AIDS

Louis Letellier de St-Just, attorney - Roy, Perron, Goyette, Letellier de St-Just

Nicole Marois - CQCS

Dr. Pierre Robillard - PHU Montréal General Hospital

Ghislain Roux, caregiver

Dr. Élise Roy - PHU Montréal General Hospital

Marie-Jan Seille, caregiver

Sylvie Venne - CQCS

Forewords

This brochure was designed to help friends and relatives providing home care for people with AIDS. It is not a medical document, but a practical guide full of helpful tips regarding your everyday routine. Above all, it stresses the precautions and preventive measures that should be taken for the benefit of all involved.

Table of contents

Foreword	
1 Home Care	7
2 Things You'll Need to Do	9
3 Providing Emotional Support for the Person with AIDS	11
4 Protecting Yourself Against the AIDS Virus in Your Daily Routine	13
5 Protecting Yourself Against Other Infections	21
6 Protecting the Person with AIDS Against Infection	25
7 Support for the Caregiver	31
8 Do You Need More Information?	32
9 Index	33
10 Basic Hygiene and Preventive Measures (summary)	35

Most people with AIDS — men, women and children — can continue to lead an active life for a long time. Usually, there is no need for them to be hospitalized. In fact, a person with an AIDS-related illness will often recover more quickly at home, with the loving support of friends and relatives. Also, home care is generally less stressful than hospitalization.

People with AIDS often have a hard time with such ordinary things as **shopping, dealing with the mail, paying bills and tidying up around the house.**

You can be of great help in all these areas. But remember that the person with AIDS must accept your assistance. People with AIDS must have control over all decisions that affect them for as long as they are capable of expressing their wishes. You must always take care to respect the person's privacy and individual rights, and ensure complete confidentiality.

YOU ARE NOT ALONE

Many other people have done what you're doing. Talk to them: their experiences can be a great source of information, encouragement and strength.

Things you'll need to do

Every person with AIDS is an individual with a distinct personality. Also, each person is affected by the disease in different ways, and to different degrees.

If you're planning to care for a person with AIDS at home, you should contact your local CLSC or a community AIDS organization to find out what kind of home assistance and support services are available in your area.

While it's not always possible, it's nice to get to know the person's doctor, nurse, social worker and other caregivers.

These people can help you prepare a home care plan. Ask them for clear written instructions about medication and how it should be administered, and make sure you know about any adverse reactions that may occur. You should also find out whom to call in an emergency.

At the end of this guide you'll find a handy checklist where you can enter information about the person you are caring for.

You should inform the person's doctor or nurse immediately if you notice any change in behaviour or condition. For example, coughing, fever, diarrhea and confusion may be symptoms of an infection or complication requiring special treatment or hospitalization. Be prepared in case the doctor or nurse tells you that these changes indicate that home care may not be the best option.

It is important for the person with AIDS to prepare a "Mandate in case of inability," which is like a power of attorney for personal care, to be used in the event that the person becomes unable to express his or her wishes or make decisions.

3 Providing emotional support for the person with AIDS

It's extremely important to consider the emotional well-being of the person you are caring for. Of course, emotional needs vary from one individual to the next, and there is no single approach that works for everyone.

Here are a few ways you can offer emotional support to the person with AIDS.

- **Encourage the person to become involved in his or her care.** Setting a daily schedule and making as many decisions as possible will help the person feel more independent and in control.

- **Don't avoid the person with AIDS. Include him in your activities wherever possible.** You don't always have to talk; **your company can be more important than your words.** Just being there while the person is reading or watching television can be of great comfort. In fact, you should deliberately allow for **quiet time.** The person with AIDS is an ordinary people who may feel all kinds of emotions, including depression, anger and frustration.

- **Don't be afraid to discuss the disease.** In fact, people with AIDS often need to talk about it in order to work out their own feelings. Offer to help find professional counselling if it is desired. And let the doctors, nurses and social workers know about your relationship to the person with AIDS and your role as a caregiver.

■ **Do not be afraid to touch a person with AIDS.** Hugs, back rubs and even just holding hands can do much to raise the person's spirits. However, be sensitive to the person who does not want physical closeness.

The virus that causes AIDS can damage the brain and cause psychological problems, particularly confusion, contradictory feelings and mood changes. Mental disorders can be manifested in a variety of ways: forgetfulness and difficulty concentrating; a slowing down of movements, speech and thought processes; decreased alertness; a loss of interest and pleasure in work and most other activities; and unpredictable or exaggerated mood swings.

These problems can be very disturbing to the person with AIDS and to others in the house. They may also upset the home care routine and procedures that protect the person with AIDS from infection. If these or other psychological problems arise, you should discuss them with the person's doctor, nurse, social worker or other health professional, being sure to respect the privacy of the person with AIDS.

4 Protecting yourself against the AIDS virus in your daily routine

In a few very rare cases, people have contracted the AIDS virus in the care environment. That's why it is very important that you know how to protect yourself against AIDS and other types of infection when you are caring for a person with the disease. We recommend that you follow **basic hygiene and the preventive measures** explained in detail in this brochure. A summary appears on page 34.

You will not get AIDS through everyday contact. You can't get AIDS from the air, water, food, insects or animals, or through contact with dishes, toilet seats or children's toys.

The virus that causes AIDS is the *human immunodeficiency virus*, commonly known by its initials, HIV. Studies have shown that HIV is present in the blood, semen, vaginal secretions and other body fluids of infected persons and is usually transmitted:

- by unprotected sex (without a condom) with an HIV carrier;
- by direct contact with HIV-infected blood, i.e. accidentally pricking yourself with an object contaminated by the blood of an infected person, or using a needle or syringe that has been used by or for a person infected with HIV (the risk of infection via blood transfusions have been virtually eliminated, because since November 1985, all donated blood is carefully screened and infected blood is destroyed);

■ by an infected mother to her child during pregnancy, delivery or breast-feeding.

All blood and other body fluids that contain visible blood (a bloody stool, for example), as well as semen, vaginal secretions and discharges from open sores must be considered potential sources of infection.

However, despite caregivers' frequent contact with HIV-infected blood, transmission of the disease is extremely rare. Such cases have resulted from an accidental needle prick, or when blood was splashed onto an open cut, scratch or mucous membrane (in the mouth, nose or eyes).

**BASIC HYGIENE
AND A FEW SIMPLE
PRECAUTIONS
CAN PROTECT YOU
FROM INFECTION.**



■ Always wash your hands with soap and water before and after providing care.



■ Wear gloves if you are going to be in contact with blood or blood-tinged body fluids, or if you are dressing sores.



■ Wash your hands with soap and water if you have been in contact with blood, even if you were wearing gloves.

Two types of gloves can be used, depending on the task. You can use disposable hospital-type latex gloves to prevent contact with blood when you provide care to a person with AIDS. These gloves should be used once and then thrown away. For household chores that involve possible contact with blood, you can use ordinary rubber gloves. These should be cleaned and disinfected before being used again. Make sure they are in good condition. Do not use gloves that are peeling, cracked, or have holes in them.

In order to prevent yourself from other types of infection, always use gloves when handling objects soiled by urine, feces or vomit to avoid contact with other germs.



■ If you have any cuts, sores or breaks on exposed skin, cover them with a bandage.



■ In addition to wearing gloves, if large amounts of blood are present, you may want to wear an apron or smock to protect your clothing. If the person with AIDS is bleeding frequently or heavily, contact the doctor or nurse, as home care may no longer be adequate. Remove blood from surfaces and containers using soap and water or a household cleaning solution, then disinfect with a solution of household bleach and water. The same precautions should be taken with semen and vaginal secretions.



■ You may have to handle syringes to administer medication if the person with AIDS suffers from diabetes or hemophilia, or receives special treatment at home. Always handle syringes carefully so as not to prick yourself.

A SIMPLE DISINFECTANT.

To clean floors, showers, bathtubs, wash basins and other items, such as mops and sponges, use a freshly prepared solution of one part bleach (the 5% kind) to 100 parts water (for example, one tablespoon (15 ml) of bleach in one quart (1.14 litres) of water). Always wear gloves when you mop up blood and wash your hands with soap and water afterwards. Discard the bleach solution after 24 hours because it is less effective when it is old. Be sure to keep it out of the reach of children.

Do not put caps back on needles, do not remove needles from syringes, and avoid breaking, bending or otherwise handling them to avoid being pricked accidentally.

When you handle a used syringe, pick it up by the barrel and carefully drop it into a puncture-proof container. The doctor or nurse can provide you with a container specially designed for this purpose. If such a container is not available, you can use any puncture-proof container with a plastic lid, such as a coffee tin.

Keep the syringe disposal container in the room where needles and syringes are used, but well out of the reach of children and visitors.

Dispose of the container before it is overflowing with needles. Ask the doctor, nurse or your CLSC about the proper disposal procedure.

If you prick yourself with a used needle, make the wound bleed without pressing on the area immediately around it, and carefully wash it with soap and water. Then contact a hospital, public health unit or CLSC as soon as possible to find out what you should do, and if you should be examined and treated.

Laundry

You can wash the clothing and household linen used by a person with AIDS as you normally would. If you use an automatic washer, you can use either hot or cold water and ordinary soap or detergent, according to the regular instructions on the package.

If clothes or linens are stained with blood, semen or vaginal secretions, soak them in cold water and a little bleach. It is not necessary to add bleach to the washing machine to kill the virus. Clothing may also be washed by hand or dry-cleaned.

If you cannot do the laundry immediately, keep the soiled linen and clothing in a separate plastic bag.

Dishes

A person with AIDS need not require separate dishes and utensils, and no special measures are necessary when cleaning them. Simply wash them in the usual manner with hot water and soap or detergent.

Food

A person with AIDS may prepare food for others, provided that he or she does not have diarrhea caused by a germ that can be transmitted through food. Everyone who prepares food, including the person with AIDS, should wash their hands before beginning.

Personal hygiene

A person with AIDS should not share razors or toothbrushes with anyone else, since these items sometimes draw blood. Toothbrushes and razors should be clearly identified with the name of the user.

Waste

Flush any liquid waste that might contain blood down the toilet. Take care not to splash any blood when pouring the waste into the toilet. Tissues and other flushable objects containing blood, semen or vaginal secretions can be disposed of in the same way.

Non-flushable items such as paper towels, tampons and sanitary napkins, bandages and other articles soiled with blood, semen or vaginal secretions, must be put into a plastic bag. Close the bag securely and put it into a trash container. Check with your doctor, nurse or local health services to make sure you are following garbage disposal regulations for your area.

Protecting yourself against other infections

Because a person with AIDS may also carry other types of infection, everyone in the household, and visitors, too, must take certain precautions. If the person with AIDS does contract another type of infection, call the doctor or nurse to find out how this can affect others. These precautions are particularly important if you yourself are HIV-positive.

Use the checklist at the back of this guide to enter information about any infection the person you are caring for may have.

Diarrhea

Diarrhea in a person with AIDS may be caused by an infection (gastro-enteritis). **You should wear gloves** if you come into contact with diarrheal discharge of a person with AIDS, **and wash your hands carefully afterwards**. A person with AIDS or anyone else who has diarrhea due to an infection should never prepare food for others.

Cough

If the person with AIDS has a cough that persists for more than a week or two, **he or she should see a physician** to check for infection (pneumocystis carinii, tuberculosis, etc.). If tuberculosis (TB) is diagnosed, you, everyone else in the household, and visitors **should be checked periodically, even if you are not coughing**. Discuss this and other precautions with your doctor, nurse or local health department.

Hepatitis B

If the person with AIDS develops hepatitis B or is a carrier of the virus, you and any children and adults living with the person, and especially any current or recent sexual partners of the person with AIDS, should **ask your doctor about receiving treatment and/or being vaccinated to prevent the disease.**

Chickenpox or shingles

If the person with AIDS has chickenpox or shingles, anyone who has never had chickenpox **should not be in the same room** with the person with AIDS. If this cannot be avoided, **wear a surgical mask** and gloves, and wash your hands before and after providing care. Continue to take these precautions until the chickenpox or shingles are completely crusted over. **You should also consult your doctor.** There is a special drug that can help prevent serious complications resulting from chickenpox.

Herpes

If the person with AIDS has herpes (genital or oral herpes simplex, also known as cold sores) **around the mouth or nose, you should avoid kissing or touching the sores.** If you must touch them with your hands, **wear gloves and wash your hands carefully afterwards.** This precaution is especially important if you have eczema (allergic skin), because the herpes simplex virus can cause severe skin disease in people with eczema.

Cytomegalovirus (CMV)

Many people with AIDS are carriers of cytomegalovirus (CMV), which may be present in urine and saliva. **You should therefore wash your hands carefully after coming into contact with saliva or urine.** This is especially important for women who are or might be pregnant, since a pregnant woman who becomes infected with CMV may transmit the virus to the baby she is carrying.

**REMEMBER TO RECORD THIS
INFORMATION IN YOUR CHECKLIST.**

6

Protecting the person with AIDS against infection

A person with AIDS or an AIDS-related illness has great difficulty combatting certain infections. A person with AIDS must therefore avoid close contact with anyone who has a contagious disease until all symptoms have disappeared. This includes colds, flu and stomach flu (gastro-enteritis).

Cold or flu

If you have a cold or the flu and there is no one to replace you, you must wear a surgical mask and **wash your hands before touching the person with AIDS**. Anyone who lives with a person with AIDS or who provides care for such a person should be vaccinated against the flu to minimize the risk of getting sick and transmitting the infection to the person with AIDS. Flu shots must be taken every year to be effective.

Boils, fever blisters and shingles

If you have a skin infection, such as boils, cold sores (herpes simplex) or shingles (herpes zoster), you should avoid close contact with the person with AIDS. If this is impossible, cover the sores with a bandage and wash your hands before touching the person. Wear gloves if you have a rash or sores on your hands.

Chickenpox and shingles

Chickenpox can make a person with AIDS very sick, and can even be deadly. If the person with AIDS has already had chickenpox, he or she will probably not get it again. However, the following precautions should be taken in any case:

- *Under no circumstances* should a person with chickenpox be in the same room with a person with AIDS until all the chickenpox have completely crusted over.

- Anyone who has never had chickenpox and who has recently been *exposed* to the virus should not be in the same room with the person with AIDS from the 10th through the 21st day following exposure. If the person cannot stay out of the room, exposure time should be kept to an absolute minimum. The exposed person should wear a surgical mask and wash his or her hands before and after providing care.

- Most adults have had chickenpox, but caregivers should be particularly alert and make sure that any children visiting or living with the person with AIDS and who have never had chickenpox have not been exposed to it recently.

■ If you have shingles (herpes zoster), you should not care for the person with AIDS until the shingles have healed over. This is because contact with shingles can cause chickenpox in someone who has never had it. If there is no one else to take care of the person with AIDS, keep the shingles completely covered and wash your hands carefully before providing care.

■ If the person with AIDS is exposed to chickenpox or shingles, call the person's doctor within 24 hours. There is a special drug which, if administered promptly, can help prevent serious complications from chickenpox in the person with AIDS.

Vaccination

Everyone living with a person with AIDS should be up to date on all their shots against such childhood diseases as measles, mumps, German measles and polio, not only for their own protection but in order to avoid getting any of these diseases outside the home and then transmitting them to the person with AIDS. There are special drugs that can be used in certain situations; consult your doctor.

Food

Handling food for the person with AIDS

requires hygienic practices to prevent food poisoning. Because the immune system of the person with AIDS is so weak, he or she is more vulnerable to food-borne infections, which are more difficult to treat.

- Keep cold foods cold and hot foods hot.

- Make sure that all meat, poultry, fish, seafood and eggs are well cooked. Do not serve such foods as steak tartare or uncooked smoked salmon. Avoid Caesar dressing, hollandaise sauce, eggnog and homemade mayonnaise, if they contain raw eggs.

- Avoid contact between cooked and uncooked foods.

- Store uncooked meat, poultry, fish and seafood separately in plastic bags to prevent drips that may contaminate other foods.

- Always wash your hands with soap and hot water before touching food and after handling raw meat, poultry, fish, seafood or eggs.

- Wash and rinse in very hot water any dishes and utensils that have been in contact with uncooked meat, poultry, fish, seafood and eggs.

- Use a hard plastic or marble cutting board. The cracks in wooden boards are a breeding ground for bacteria.

- Wash all fresh fruits and vegetables, even if you are going to cook them.

- Avoid serving the person with AIDS unpasteurized milk, soft cheeses like Brie and Camembert, Feta cheese, blue cheeses like Roquefort, unpasteurized cheeses and liver paté. These foods are all more likely to contain bacteria that are harmful to a person whose immune system is weak.

Pets

If there are pets in the house, the person with AIDS should always wash his or her hands with soap and water after touching them, particularly after cleaning the litter box or living areas (cage, aquarium, etc.). This is to protect against diseases the animals may be carrying.

Litter boxes should be completely emptied, not just sifted, very frequently.

Birds should be examined by a veterinarian to make sure they do not have psittacosis, a disease that can be very harmful to a person with AIDS. Sick animals should be examined promptly by a veterinarian.

A person with AIDS should not touch sick animals or their litter. If the person with AIDS is a child, there should be no pets in the house.

Plants

Ordinary dirt and the earth in which house plants grow contain all kinds of germs. If you garden, wash your hands immediately afterwards. A person with AIDS who gardens or works with plant should wear rubber gloves.

Support for the caregiver

Caring for a person with AIDS at home can be stressful and emotionally trying. You may feel very frustrated when the person with AIDS deteriorates despite all your efforts. Sharing your feelings with others can help. Contact your CLSC or other community organization to find out what services are available.

When caring for a loved one who is very sick, it is important not to ignore your own needs. Unless you take care of yourself, you will not have the inner resources you need to care for the person with AIDS

Make arrangements for some occasional back-up help so that you can have some free time. This is especially important when the person with AIDS is seriously ill. You need a break from your responsibilities to recharge your batteries and maintain your energy level.

8

Do you need more information?

If you need more information about how to care for a person with AIDS, if you'd like to volunteer, or if you just want more information about AIDS, consult your doctor, your local health department, a CLSC or a community volunteer service for people with AIDS.

INDEX

Boils.....	25
Chickenpox.....	22-26
Colds	25
Cough	21
Cytomegalovirus	23
Diarrhea	21
Dishes	18
Disinfectant	16
Fever	25
Flu	25
Food.....	28
Hepatitis	22
Herpes.....	23
Hygiene.....	19
Laundry.....	18
Pets	29
Plants	30
Shingles.....	22-25-26
Vaccination.....	27
Waste	19

10

Basic hygiene and preventive measures (summary)



Wash hands in soap and water before and after providing care.

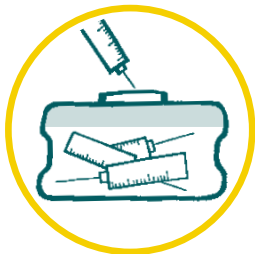


You don't have to wear latex or rubber gloves all the time. You should definitely wear them when you must be in contact with blood, blood-tinged body fluids, semen, vaginal secretions or running sores.



Since other body fluids may carry pathogens, you should also wear gloves when you must be in contact with urine, feces or vomit.

Remember to always wash your hands immediately upon removing your gloves after being in contact with blood or other body fluids.



Handle syringes with care. Do not replace caps on needles and do not remove needles from syringes. Dispose of needles and syringes in a puncture-proof container. Keep all needles and syringes out of the reach of children and visitors.



Clean all traces of blood and body fluids with a solution of one part bleach (5%) to 100 parts water.



If you or the person with AIDS has any cuts, scratches or open sores, keep them covered with a bandage.

CHECKLIST

SPECIAL PREVENTIVE MEASURES TO BE
TAKEN when caring for...

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CHECKLIST

PARTICULAR INFECTIONS

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CHECKLIST

[illegible]

CHECKLIST

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