

Caregiver Basics

This section addresses several basic but important aspects of home care: organizing home-care responsibilities efficiently and providing a safe and healthy household both for you and for the person for whom you are caring. This material will help you:

- Get organized
- Prevent infection (control the spread of germs and their transmission)
- Prevent accidents in the home

Getting Organized

Taking time to organize care-giving responsibilities before you actually begin home care can make your work much easier. It is not always possible to plan ahead, however. You may find yourself in the middle of providing care for someone without much warning or time to prepare. Whatever your situation, the following suggestions may help you become more organized. Try to adapt whatever you find useful to your current situation.

- If you are one of several caregivers, try to plan a time when you can all meet together. Scheduling "time off" and "time on" in advance may avoid confusion later about who is doing what when.
- Appoint people to be responsible for specific jobs. For example, one person could be in charge of shopping for food, while another could be responsible for making sure medications and medical supplies don't run out.
- Keep a journal or notebook that can be shared among the caregivers in order to keep track of the day-to-day needs of the patient. Write down how he/she is feeling each day, what medications seem to be working, what foods seem to be well tolerated. You may not be able to pass on this information orally to the other caregivers.
- Ask the health-care provider about equipment that could possibly make your job easier. For example, a walker, a cane, a hospital bed, or a portable toilet could ease the situation for the patient and, as a result, for you.
- Keep track of complicated medication schedules with a medication dispenser. Available at most pharmacies, medication dispensers are usually plastic boxes with times and dates that allow you to organize up to a two-week supply of medications. These dispensers are especially

helpful when more than one person is in charge of making sure that the patient is taking all of his/her medications correctly. You may wish to keep a written schedule as backup.

Always include the patient in his/her care. You may, under stress, forget to consult with the person for whom you are caring, particularly if he/she is extremely ill. Helping the patient maintain some control over his/her care is always important—and frequently makes your job easier.

Preventing Infection

Infection control refers to the prevention of the possible spread of germs (bacteria, viruses, or other microorganisms that can cause infection). Germs can spread through direct contact or through the air: from person to person, from animal to person, from object to person, or from food to person. People with cancer or whose immune systems are weakened by age or another illness or condition are more vulnerable to infection. If they should become ill from an infection, they are less able to fight it off and it could further weaken them, worsen their illness, and add to the burden of the caregiver.

General Household

Household bleach is a low-cost, widely available disinfectant for general cleaning. When mixed with water (one part bleach to nine parts water), bleach makes an excellent cleaning solution that kills germs on contact (including HIV, the virus that causes AIDS). Note: You must prepare a new batch of bleach/water solution every day. You should wear rubber or vinyl household gloves whenever you clean to protect your hands, especially when you are using a strong disinfectant.

Following are some guidelines for general household cleaning.

Kitchen

- Clean the sink, refrigerator, floor, and counter tops regularly using the bleach/water solution. Molds and fungi grow readily in the kitchen and can be harmful.
- Wash dishes with hot, soapy water and let them air dry. Alternatively, you may use an automatic dishwasher if one is available.
- Wash the kitchen floor at least once a week. Clean all spills immediately. Pour dirty water down the toilet, not the sink.
- Keep the mops and sponges used to clean the kitchen separate from the ones used to clean the bathroom.
- After use, soak sponges, rags, and mops in the bleach/water solution for five minutes to disinfect them. Soaking them any longer could cause them to disintegrate.
- Line all trash and garbage containers with plastic bags and keep them covered. Empty them regularly.

Bathroom

- Clean the sink, tub, and shower with the bleach/water solution regularly-daily if necessary.
- Clean the toilet bowl regularly. An effective way to do this is to pour undiluted bleach directly into the toilet bowl. If you use a toilet brush, soak it afterwards in the bleach/water solution.
- Clean any spills or splashes of blood, feces, urine, or vomit immediately with the bleach/water solution. Wear gloves.
- If the patient uses a urinal, bedpan, or commode, flush all wastes down the toilet, then scrub and disinfect the container. Wear gloves.
- Feminine personal hygiene products, sanitary pads, tampons, Chux, (Chux brand pads are moisture-proof, disposable pads that are used to protect linens from being soiled.) and diapers should be double bagged and disposed of in regular trash.
- Flush solid wastes from a soiled Chux or diaper down the toilet. Wrap the Chux or diaper in a plastic bag, secure the bag in a second plastic-lined container, and discard immediately.
- Do not share toothbrushes and razors. Discard used blades and disposable razors in a puncture-proof container, such as a coffee can, to avoid injury.

Pet Care

Do not allow the patient to come in contact with animal feces or urine. Clean cat litter boxes every day.

Do not allow the patient to clean birdcages, fish tanks, or turtle bowls. People with weakened immune systems are more vulnerable to diseases that these animals might carry.

Keep all pets clean and free of ticks and fleas to prevent any possible animal-to-person infection.

Laundry

Wear gloves when handling linens or clothing soiled with blood or other body fluids. Otherwise, you do not need to wear gloves when doing the patient's laundry.

Wash linens and clothing, including those soiled with blood or other body fluids, in the washing machine with hot, soapy water. These soiled items do not have to be discarded.

If a washing machine is not available, soak linens and clothing in hot, soapy water and scrub.

Add liquid bleach to the wash for items that can be bleached (check laundering instructions on labels). For items that cannot be bleached, use another disinfectant, such as Lysol, which is equally effective.

Dry clothes in an automatic dryer or by air-drying; either method is fine.

After you have washed linens, towels, and so on, other members of the household may use them.

Food Preparation

Wash hands before and after handling food.

Start with clean utensils, and wash them before reusing them with other food.

Make sure cutting boards and counter tops are clean. Use separate cutting boards for meats and vegetables. Use only pasteurized dairy products (milk, cream, cheese). Unpasteurized dairy products have been associated with salmonella infections.

Avoid dishes with uncooked eggs as ingredients (such as homemade Hollandaise, Eggnog, or Caesar salad) because of their potential to carry Salmonella.

The precautions described in this section for providing direct care to a patient are designed to protect not only you but also the patient, whose immune system is suppressed. Taking the following precautions ultimately protects both of you.

Hand-washing

The most important part of infection control is hand washing. You should wash your hands before and after handling food, after using the bathroom, after handling soiled items, after blowing your nose, and after covering your face with your hands during a sneeze or cough.

Wash your hands:

- Before you touch the person for whom you are caring.
- After you finish the care provided.
- Before you put gloves on and as soon as you take them off.
- After you clean any soiled object.
- Before you prepare food.

Protective Clothing

Aprons, gloves, and masks are referred to as protective clothing. They act as barriers to prevent body fluids, such as blood, that have left one person's body from entering another person's body-thus preventing infection. When caring for a patient it is recommended that

you use these barriers in certain situations, defined in this section. Most of what you do to and for the patient does not call for the use of gloves, masks, or aprons.

Wear gloves only when:

- You are doing direct, hands-on care for someone who has open cuts or skin sores.
- You have open cuts or sores on your hands.
- You are in contact with a person's blood, wound drainage, semen, or vaginal secretions.
- You are cleaning up vomit, feces, urine, or sputum.
- You are changing a Chux, diaper, or sanitary pad.

You do not have to wear gloves when:

- You are feeding someone.
- You are giving someone a bath.
- You are giving someone a back rub or combing his/her hair.
- You are helping someone get dressed or are changing the bed linens (unless they are soiled with blood or other body secretions).
- You are holding someone or assisting him/her in walking.

Wear a mask only when:

- The person you are caring for may have tuberculosis, is coughing, and is unable to use a tissue. This precaution is to prevent the spread of TB.
- You have a cold or a cough or are sneezing. This precaution is to protect the patient.

Wear an apron only when:

- You may be splashed with vomit, diarrhea, blood, or other body secretion.

Handling Needles Safely

If you are caring for someone who is receiving injections or infusions at home, you must take care to prevent the possibility of a needle stick injury. Make sure that you and anyone else who gives the injections or infusions always follows these precautions:

- Wash hands and put on gloves before you begin.
- Place a puncture-proof container close by before you give the injection or infusion so that you do not have to move to discard the needle after use.
- Following the injection or infusion, never recap, bend, or clip the needle.
- Discard the needle and syringe as a unit immediately into the puncture-proof container next to you.

Make sure that everyone who gives injections and infusions properly disposes of all needles and any other equipment that might contain blood or have sharp edges. A coffee can is a perfect puncture-proof container. When it is full of discarded needles and syringes:

Bake the coffee can (without the top) in the oven at 400° for 10 minutes. The needles and syringes will melt.

When the coffee can has cooled, double bag it and discard it in the trash.

Treating Accidental Exposure to HIV

An accidental exposure to HIV is extremely rare. In cases where health-care providers have been exposed, their chance of becoming infected with HIV has been 1 in 300. The most common way exposure occurs is during the handling of sharp objects, when the risk of actually penetrating the skin is greatest. (See Handling Needles Safely) The risk of infection is minimal when the blood, semen, or vaginal fluids of someone infected with HIV come in contact with skin that has no cuts, scrapes, or rashes. The risk is higher if the blood, semen, or vaginal fluids get into a cut, the mouth, or the eyes.

The instructions that follow are to be used only in the unlikely event of accidental exposure to blood, semen, or vaginal fluids.

To treat accidental exposure via broken skin or puncture wound:

- Squeeze out some blood from the wound.
- Wash the affected area immediately with soap and water.
- Report the accident immediately to your health-care provider. He or she may make recommendations on possible follow-up care to reduce the risk of infection.
- To treat accidental exposure via mouth or eyes:
- Bathe the eyes or rinse the mouth thoroughly with water.
- Discuss the accident with your health-care provider to determine the level of risk involved.

To treat accidental exposure via unbroken skin:

Wash the affected area immediately with soap and water. If your skin has no cuts, scrapes, or rashes, you do not need to do anything further.

Safeguarding the patient from accidents is an important part of caregiving. The two most common accidents that occur in the home are falls and burns. People who are physically weak as a result of illness are at a much greater risk for such accidents. Also, unfamiliar aids,

such as wheelchairs or walkers, can add to the risk of accidents. The guidelines in this section will help you prevent injuries from falls, burns, and wheelchairs.

Preventing Falls

Follow these precautions to help prevent falls:

- If the patient would like to walk after being in bed for some time, make sure that he/she sits on the side of the bed for few minutes to avoid dizziness.
- When he/she is getting out of bed or up from a chair, offer to stand next to him/her to help in case of any dizziness.
- When he/she is seated or in bed, make sure that frequently used personal belongings are close at hand (glasses, tissues, books, and so on). Unnecessary reaching can increase the risk of falls.
- If the patient wears glasses, make sure he/she has them on before attempting to walk.
- Make sure that the room is well lit.
- Make sure the patient uses slippers with rubber soles. Socks are very slippery!
- Remove throw rugs from the patient's path unless the rugs are skid-proof. Clear all obstacles from the patient's path (toys, electrical cords, and so on).
- Avoid long bathrobes or nightgowns because they can cause the wearer to trip, particularly when going up or down steps. Untied or long shoelaces are also dangerous.
- If the patient uses a walker, cane, or crutches, check the tips regularly. Worn or missing rubber tips can cause the user to slip.

Preventing Wheelchair Accidents

Follow these precautions to help prevent wheelchair accidents:

- If the patient has a cover over him/her, make sure it cannot become caught in the wheels.

Always set the brakes when:

- Assisting the patient into the wheelchair.
- Assisting the patient out of the wheelchair.
- The patient is to remain stationary.
- Make sure to put the footrests up when the patient is getting into or out of the wheelchair.
- If you are moving the patient down a ramp, take the chair down backwards. Glance over your shoulder to be sure of your direction.

Preventing Burns

Follow these precautions to reduce the risk of injury from burns:

- If the patient smokes, make sure he/she uses a large, deep ashtray. If the patient is weakened, has vision problems, or is confused, you should remain close by when he/she is smoking.
- If the patient uses a hot water bottle or heating pad, check the skin periodically for any redness or irritation. Loss of sensation related to the illness may make the patient unaware of overexposure to heat.

Not all accidents can be prevented, but taking precautions can certainly decrease the incidence.

The Importance of Routine

As a caregiver, you may find that you begin to develop a routine of care that becomes comfortable both for you and for the person in your care. For the person with neurological problems, any alteration in this routine can be very difficult. With this in mind, the following suggestions may be helpful:

- Although it is not always possible, try to avoid sudden changes in the daily routine. If you change the daily routine, you may have to explain what these changes are many times.
- Explain any new procedure that you may have to perform. Proceed slowly.
- Try to keep the person's belongings in the same place. Rearranging his/her personal belongings (clothing, telephone, radio, and so on) may cause confusion.
- Write down anything that the patient needs to keep track of (appointments, medications, and so on).
- Avoid too much stimulation. A lot of company, visitors, or activities may be difficult.

Safety Issues

Confused or dis-oriented people should not be left alone. Do not make sharp instruments, medications, cigarettes, and other potentially dangerous items available to the patient who is experiencing neurological changes. Remove locks from bathroom and bedroom doors. Use plastic instead of glass containers.

With all the tasks you have to do as the caregiver, it is often easy to neglect providing for the emotional well-being of the person you are caring for as well. Emotional support is, however, at least as important as all those "tasks" referred to throughout this manual.

Ways to Provide Support

Since every person's emotional needs are different and may vary during the course of the illness, no single approach to providing emotional support can work for everyone. You may find a number of the following suggestions helpful:

- Encourage the patient to become more involved in his/her care whenever possible. Allow him/her to be independent as possible in decision making and scheduling. This empowerment will give the person a sense of control over his/her care.
- Don't be afraid to discuss the disease. A patient may feel more comfortable talking to you, the caregiver, about how he/she really feels than talking with friends or members of the family.
- Don't be afraid to touch the patient. Holding a hand, giving a hug, or giving a back rub can convey many messages: that you care, that you are not afraid, and that the patient is not alone.
- Remember that your company is important. You don't always have to be doing something. Allow for quiet time. Share a TV show, read, or sew. Talking isn't always necessary. Your quiet presence can be more important than words.
- The person you are caring for may become difficult and demanding. Like anyone else, he/she may feel frustrated, angry, or depressed. You, the caregiver, may be the target of these emotions. Try not to take it personally. Try to be patient and understanding. Set your limits. If you find certain behaviors unacceptable, make sure you say so.
- If you feel that the person you are caring for could benefit from counseling or from talking with the hospice social worker, chaplain, or nurse, mention this to him/her. Encourage the patient to discuss this with his/her hospice team.

The Need for Intimacy

A topic rarely discussed among families is the patient's ongoing need for intimacy. Addressing this issue may be uncomfortable for some. To ignore it, however, is to deny a very basic part of the person for whom you are caring.

We are all sexual beings. Sexual expression is more than a physical activity. It is a form of communication and self-expression. It may be a way of achieving comfort and closeness, of expressing love and concern. Touching or holding someone can represent caring, needing, or continued commitment. It can also mean fun, joy, and relaxation. It is often thought that when someone is ill, he/she no longer needs or wants to express his/her sexuality. Contrary to this belief, sexuality may continue to be an important part of life. Needs may change or desires may be reduced, depending on how one feels, but the need for intimacy on some level remains very real.

A person with serious illness who has experienced physical changes as a result may have a hard time adjusting to his/her new image. He/she may see himself/herself as unattractive, "not the same," and unappealing to his/her partner. A common reaction to this concern is for the patient to distance himself/herself both emotionally and sexually. This withdrawal can, in turn, result in loneliness or depression.

A common misunderstanding for the partner of a person with serious illness is that sexual expression will hurt or disturb the patient. This is usually not the case. After talking with the patient, the partner will usually find out that now, more than ever before, the patient is in need of the comfort, closeness, and relaxation that touching, kissing, and other forms of intimate sexual expression have provided in the past.

A patient's sexual needs and how these needs can be expressed may vary with the course of the illness. Sexual intercourse may not always be possible, but this should not eliminate all the other wonderful ways in which to express sexuality and love. Touching, caressing, hugging, and massage provide warm, affectionate, and safe intimacy. The imaginative use of loving hands can relax, soothe, or excite.

Remember that the person you care for has sexual needs. Providing the privacy and opportunity for sex should be honored.

As we stated in the introduction, the purpose of this manual is primarily to help you take care of someone with living at home with serious illness. This is no easy task; the demands placed on the caregiver can be overwhelming. This section of the manual is dedicated to you.

Glossary of Terms –

AIDS: Acquired immune deficiency syndrome. AIDS is the last stage of a disease caused by the human immunodeficiency virus (HIV), which attacks and weakens the body's immune system. Without a working immune system, the body is vulnerable to infections and cancers that it would normally be able to fight off.

Antibiotic: A drug, such as penicillin, that kills disease-causing organisms.

Antifungal: A drug that kills or stops the growth of a fungus.

Asymptomatic: Infection without symptoms. A person can be infected with HIV but not have symptoms of the infection for many years.

Attends: A brand of adult disposable diapers.

Bacteria: A group of tiny organisms, many of which can cause disease when they infect someone.

Candida: A type of fungus that often grows in the mouth or stomach of people with AIDS. Candida infection in the mouth is also called thrush. The whitish patches can be painful and can make it difficult to swallow.

Catheter: A thin tube; can be placed in a vein to infuse commercially prepared nutritional solutions, or in the bladder for emptying urine.

Chronic: Lasting a long and undetermined time. Some physicians consider HIV to be a chronic disease.

Chux: A brand of moisture-proof, disposable pads used to protect linens from being soiled.

Diagnosis: The process of determining the cause and nature of an illness.

Diarrhea: Unusually frequent, loose, or watery stools.

Enteral feeding: Feeding commercially prepared, blended foods through a feeding tube, which takes the food directly into the digestive tract.

Herpes: Herpes Simplex Virus I and Herpes Simplex Virus II are viruses that can cause blisters on the mouth or genital region and are often transmitted through sex. Herpes infections in people with AIDS can spread throughout the body, causing severe damage, including blindness, ulcers, mental problems, and liver failure.

HIV: Human immunodeficiency virus, the virus that causes AIDS.

Immune system: The natural defense mechanisms of the body, where certain cells and proteins in the blood and other body fluids work together to rid the body of invading organisms such as viruses and bacteria.

Immunosuppression: A weakening of the immune response that happens with HIV infection and with some antiviral or anticancer treatments.

Lactose: A type of sugar found in most dairy products, including milk, butter, and cheese. Some people are allergic to it.

Neurological problems: Problems with the brain and spinal cord; affecting anything from thought processes to coordination. In HIV disease, these may be caused by other infections, by HIV, or by medications.

Neuropathy: The name given to a group of disorders involving nerves. Symptoms range from a tingling sensation or numbness in the toes and fingers to paralysis.

Side effect: An unanticipated effect of a drug. Some side effects are unwanted, harmful, or poisonous.

Systemic infection: Infection throughout the body.

Thrush: See Candida.

Virus: The smallest of disease-causing organisms, a virus is made up of genetic material (RNA or DNA) surrounded by a protein envelope. It can reproduce only within the living cell of a larger organism.