Living with cystic fibrosis (CF) or raising a child with CF can put heavy demands on your daily routine. Medicines and treatments take a lot of time, but will help you or your child stay healthy. There are some other simple things that people with CF can do to decrease the risk of catching germs (bacteria or viruses) that cause infections. This pamphlet lists ways that people with CF can stop the spread of germs to stay in the best possible health. As with any health-care information, be sure to talk with your CF care team to decide what is best for you or your child.

Clean Hands Are Important!
One of the best ways to keep from catching or spreading germs is hand cleaning or hand hygiene. Clean your hands often (see “When to Clean Your Hands”), and after touching anything that has been in contact with mucous membranes, sputum or phlegm. There are two ways to clean hands: One is to wash with soap and water. Antibacterial soap is the best to use (see “Handwashing Steps”). The second way is to use an alcohol-based hand gel. These hand gels are often called antiseptic handrubs or hand sanitizers. They can work better than soap and water to kill germs. To decide which method to use, follow this rule: if you see dirt on your hands, wash with soap and water; if you do not see dirt, use hand gel. It is a good idea to carry hand gel with you to use before eating and after blowing your nose, coughing, sneezing or shaking hands.

When to Clean Your Hands
• After coughing or sneezing
• After blowing your nose
• Before eating
• After going to the bathroom
• Before and after breathing treatments
• Before and after airway clearance
• Before taking medicine
• If your hands look dirty, use soap and water

*Words that appear in bold italic are defined at the end of this pamphlet.*
Cleaning Your Respiratory Equipment

Germs can get on respiratory equipment and cause lung infections. Clean and disinfect all equipment used for inhaled medicines or airway clearance using the manufacturer’s instructions. It is vital to clean and disinfect equipment that has been in contact with mucous membranes, sputum or phlegm, like nebulizers!

To clean and disinfect your nebulizer, follow these steps:

1) Clean your hands.

2) Clean the nebulizer parts. The parts cannot be disinfected until they are cleaned. With a new paper towel, wash the inside and outside of the nebulizer parts with liquid dish soap and hot water. Be careful not to damage any of the parts. Throw the paper towel away, then rinse the nebulizer parts with water. Clean the nebulizer right after it is used to keep the medicine and debris from drying. Once debris dries, it is difficult to wash off. You also can clean the nebulizer parts in an automatic dishwasher, if the nebulizer’s manufacturer’s instructions allow.

3) Disinfect the nebulizer parts. DO NOT USE VINEGAR. Vinegar is not strong enough to kill the germs a person with CF might get. Instead, if the manufacturer’s instructions allow, disinfect the nebulizer parts using one of these options:

- Boiling for 5 minutes;
- Microwaving (in water) for 5 minutes;
- Dishwasher, if the water is hotter than 158° F for 30 minutes;
- Soaking in a solution of 1 part household bleach and 50 parts water for 3 minutes;
- Soaking in 70% isopropyl alcohol for 5 minutes; or
- Soaking in 3% hydrogen peroxide for 30 minutes.

Ask your care center team what might work best for you. Read the manufacturer’s instructions to see what option is best for your nebulizer. Do not use a nebulizer that cannot be disinfected using one of these options.

Time-Saving Tip

Boiling the nebulizer is a way to disinfect and rinse in one step. Read the manufacturer’s instructions to find out if your nebulizer can be boiled.

Steps to Clean and Disinfect Nebulizers

1. Clean hands.
2. Clean nebulizer parts.
3. Disinfect nebulizer parts.
4. Rinse nebulizer parts.
5. Air-dry nebulizer parts.

Handwashing Steps

1. Wet hands with warm water.
2. Apply soap: liquid, antibacterial soap is best.
3. Rub hands together to lather.
4. Scrub hands well, back and front, up to wrist, and between fingers. Clean under nails. This should take 15 seconds to complete.
5. Rinse in warm, running water.
6. Use a clean towel to dry your hands. Paper towels are best.
7. Turn off the faucet using the paper towel.
4) Rinse the nebulizer parts. If you disinfect using bleach, isopropyl alcohol or hydrogen peroxide, rinse all parts well. Use sterile water for the final rinse. **DO NOT USE WATER FROM THE FAUCET, BOTTLED, OR DISTILLED WATER.** You can make water sterile by boiling it for 5 minutes. Use this water once, then throw it out. If you disinfect by boiling, you do not need to rinse the nebulizer.

5) Air-dry the nebulizer parts. After the final rinse, drain the parts on a clean surface covered with new paper towels. Replace wet paper towels with dry ones and fully air-dry all parts. Remember, germs will grow on anything that stays wet, so store the dry nebulizer in a clean, dry bag in a clean, dry place.

Follow the manufacturer’s care and cleaning instructions for all equipment used for inhaled medicines or airway clearance. Some respiratory equipment may need to be cleaned but not disinfected. These items can be cleaned often with liquid soap and hot water. Ask the physical or respiratory therapist, or the physician or nurse at your CF care center, how often to clean your equipment and the best way to do so. Do not share nebulizers, PEP devices, spacers or anything that has been in contact with mucous membranes, sputum or phlegm.

**Important Note**
You should not give a nebulizer treatment through a Positive Expiratory Pressure (PEP) device unless that PEP device can be taken apart and cleaned, disinfected and dried just like your nebulizer. Examples of PEP devices are: TheraPEP®, Resistex® and Acapella®. Talk with your CF care center respiratory therapist or care team about cleaning your airway clearance equipment.

**Living Together**
- Do not share:
  - Respiratory equipment
  - Airway clearance devices
  - Toothbrushes
  - Eating utensils
  - Drinking cups
- Do airway clearance in separate rooms.

**When People With CF Live Together**
People with CF who live together can “share” the same CF germs. To decrease the spread of germs, they should limit contact with each other’s mucous membranes, sputum or phlegm. People with CF should not share respiratory equipment, airway clearance devices, toothbrushes, eating utensils or drinking cups or anything that has been in contact with mucous membranes, sputum or phlegm. When coughing, germs can spread up to three feet (about an arm’s length). Performing airway clearance at different times and in different rooms can help decrease the spread of germs.

People with CF who do not live together should also avoid activities that spread germs, such as hand shaking, hugging or kissing. They should also try to keep at least three feet (an arm’s length) between each other.
People with CF should clean their hands often, especially after coughing, sneezing, or blowing their nose. When coughing, sneezing or coughing up sputum, use a tissue and throw it away in a trashcan. Then, clean your hands!

Get Vaccinated (Shots)

EVERYONE should get the vaccinations or shots recommended by the Centers for Disease Control and Prevention. These vaccines help prevent illness. People with CF have the same risk of a viral infection as people without CF. However, when people with CF catch a respiratory virus, they can get much sicker. Influenza or “the flu” is a viral illness that can cause pneumonia in people with CF. Flu outbreaks often occur between December and March. People with CF older than six months should get a flu shot every year. Make a clinic appointment in the fall to get your or your child’s flu shot, or to find out where to get one. The relatives, day care and health care staff and close friends of those with CF also should get regular shots to prevent the flu and other infections. If you or your child did not get a flu shot and are exposed to someone with the flu, call your CF care center to see about starting medicine that may keep you or your child from getting sick.

Another germ that anyone can get is called “RSV” or respiratory syncytial virus. RSV can make babies, young children and the elderly very sick. There is a special shot to prevent RSV in children, but there are no current guidelines for giving it to children with CF. Good hand cleaning reduces your, or your child’s, risk of getting RSV and other germs.

Germs in Public

There are many different types of germs out there. You may have heard a lot about Pseudomonas aeruginosa (sue-da-moan-us a-ridge-a-no-sa) (Pseudomonas) and Burkholderia cepacia complex (bur-cold-air-ee-ah sa-pay-sha) (B. cepacia). Pseudomonas and B. cepacia are both types of bacteria that people with CF can catch. There is medical evidence that B. cepacia can be passed between people with CF. It is important for those with CF to keep their hands clean, stay at least three feet away from each other, and limit contact with each other’s mucous membranes, sputum and phlegm. Hand cleaning is the best way to keep from catching and spreading most germs (see “Preventing Germs in Public”).

Remember: clean your hands often and after touching things that

Remember

Clean your hands before touching medicines and equipment so that you do not put germs on them. Also, the place where you clean and disinfect the nebulizer and prepare medicines should be clean.

Recommended Vaccines

- Diphtheria, Tetanus, Pertussis (DPT)
- Haemophilus B (Hib)
- Hepatitis B
- Influenza (flu)
- Measles, Mumps, Rubella (MMR)
- Pneumococcal
- Polio
- Varicella (Chickenpox)
School: Health information is private unless you tell someone, or ask your CF care center to provide others with your health information or your child’s health information. If your child has CF, consider letting the school nurse know. Work with your CF care team to decide what information to tell the school. Members of the CF care team can talk to the school about CF.

More than one child with CF may attend the same school. When possible, they should not share the same classroom. To lower exposure to germs, they should try to stay at least three feet apart. Ask the school to schedule common activities, such as gym, at different times. Again, hand cleaning can help prevent the spread of germs that cause infections.

Camps: There is medical evidence that CF germs have been passed between people with CF at CF-specific camps. People with CF should not attend CF-specific camps. The risks outweigh the benefits. Because it is vital to exercise, make friends, and build support systems, people with CF are encouraged to join in camps, social groups and sports activities that are not specifically for people with CF.

Preventing Germs in Public

- Clean your hands often.
- Stay at least three feet away from others with CF.
- Use and throw away tissues when coughing, sneezing and blowing your nose.
- Avoid hot tubs and spas.
- Avoid CF-specific camps.
- Don’t be with others with CF in enclosed or poorly ventilated spaces like small rooms, hotel rooms, or cars.

Spas, hot tubs and pools: Pseudomonas has been found in spas and hot tubs with low chlorine levels. People with CF should avoid spas and hot tubs without enough chlorine to kill Pseudomonas!

Pseudomonas has not been found in swimming pools with proper chlorine levels. Your city or county public health department can tell you what chlorine levels kill germs and meet public health standards. Ask the pool maintenance crew how often the chlorine level is checked and if the pool meets public health standards.

CF Education Days: There have been no reports of CF germs being passed from one person with CF to another at CF Education Days. If you have questions, talk with your CF care team. Again, hand cleaning is the best way to keep from catching and spreading germs (see “Preventing Germs in Public”). Once again, clean your hands after touching things that have contacted mucous membranes, sputum or phlegm!

GREAT STRIDES: Based on medical evidence, there have been no reports of CF germs being passed from one person with CF to another at CF GREAT STRIDES walks. However, the CF Foundation has a policy that states that people with CF who have B. cepacia should not attend events sponsored by the
CF Foundation (see CF Foundation B. cepacia Policy at www.cff.org) because of the increased risk of spreading the germ.

There Is Support for You and Your Family!
Your CF care center is a great place to look for support to help you and your family deal with the challenges of CF. Educate yourself and your family about why these actions are vital to the health of someone with CF. Share your questions or concerns with your CF care team. Some centers have parent support groups. In these groups, parents can help each other. Ask your CF care center where you can find support in your area. If there is not a parent support group in place, ask how you can start one.

Living with CF or raising a child with CF is challenging. But just as the daily medicine and treatment demands can be time consuming, knowing and using these guidelines to stop the spread of infections can help everyone stay healthier. The benefits of close contact must be weighed against the risk of infections. Think of these guidelines as a key to help you and your family stay healthier. Remember, your CF care team is a good resource for questions about changes in your home and school routine that can help you lower the risk of catching and spreading germs.

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**GLOSSARY**

Antibacterial: Something that kills or stops bacteria growth

Antiseptic handrub: A substance that, when put on the hands, kills germs

Bacteria: A tiny organism that can cause infections; antibiotics can kill bacteria

*Burkholderia cepacia* complex (bur-cold-air-e-ee-ah sa-pay-sha): A group of bacteria that can be spread between people with CF; it can cause a serious lung infection

Debris: Remains of something; for inhaled medicine, this could be medication or sputum

Disinfect: To kill most of the germs

Germs: Organisms, like bacteria and viruses, that can cause infections

GREAT STRIDES: The CF Foundation’s annual walkathon, which raises money to fund CF research and care

Hand gel: A substance that has alcohol to kill germs as it dries

Hand cleaning: Includes using soap and water or alcohol-based hand gels (see hand hygiene)

Hand hygiene: A general term for cleaning hands; this includes the use of soap and water or an alcohol-based hand gel (see hand cleaning)

Hand sanitizer: See hand gel

Mucous membranes: Places in the body that produce mucus; these are found in the nose, mouth, lungs, esophagus, stomach and intestine

PEP – Positive Expiratory Pressure: an airway clearance technique

Phlegm: Lung mucus or sputum

*Pseudomonas aeruginosa* (sue-da-moan-us a-ridge-a-no-sa): Bacteria often found in the lungs of people with CF; it is a cause of many lung infections

Sputum: Lung mucus or phlegm

Sterile: The complete absence of all germs

Vaccine: A solution to put into the body to build a defense against a disease

Vaccination: Giving a vaccine (shot)

Viral: An illness caused by a virus

Virus: A tiny organism that can cause infections
Resources

The information in this pamphlet is based on “Infection Control Recommendations for Patients With Cystic Fibrosis: Microbiology, Important Pathogens, and Infection Control Practices to Prevent Patient-to-Patient Transmission” by Lisa Saiman, M.D., M.P.H.; Jane Siegel, M.D.; and the participants of the CF Foundation’s Consensus Conference on Infection Control. This document is available as a supplement to Infection Control and Hospital Epidemiology (ICHE), May 2003, Volume 24, Number 5 (http://www.ichejournal.com) and as a supplement to American Journal of Infection Control (AJIC), May 2003, Volume 31, Number 3 (http://www.apic.org).

These Web sites have more information about preventing infections:

- Information about hand cleaning for adults and children:
  [www.cdc.gov/cleanhands](http://www.cdc.gov/cleanhands)
  [http://www.microbeworld.org/know/important.aspx](http://www.microbeworld.org/know/important.aspx)

- Questions and answers for swimmers and information about chlorine treatments:
  [www.cdc.gov/healthyswimming](http://www.cdc.gov/healthyswimming)

- Teenagers & Germs

- For hand cleaning tips, the Henry the Hand Foundation is a fun way to encourage children to clean their hands:
  [www.henrythehand.com](http://www.henrythehand.com)

- Infection control

- Vaccinations

- The CF Foundation’s Web-site has information: www.cff.org. You can contact the CF Foundation at (800) FIGHT CF or info@cff.org.
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