

Transmissible Infections in Patients with Cystic Fibrosis - Frequently Asked Questions -

TRANSMISSIBLE BACTERIA & CLINICAL IMPLICATIONS

What is *Burkholderia cepacia* complex and will my health be affected if I have *Burkholderia cepacia* complex?

Burkholderia cepacia (*B. cepacia*) complex is a family of bacteria, or germs, which live in damp or wet places, and cause rot in plants such as onions. This organism rarely causes infection in healthy people, but can be a problem for people with cystic fibrosis (CF), and other individuals who cannot fight infections properly. To date, 17 different strains of *B. cepacia* complex have been identified.

A few people who culture positive for *B. cepacia* complex may develop “*cepacia* syndrome”. “*Cepacia* syndrome” involves the spread of *B. cepacia* complex into a person’s bloodstream results in severe chest problems, accompanied by a fever and a rapid decline in health.

Many patients with *B. cepacia* complex infections can live for a long time without developing a rapid decline in lung function or overall health. Nonetheless, patients with *B. cepacia* complex infections do not live as long on average as those who never acquire *B. cepacia* complex.

What is MRSA and will my health be affected if I have MRSA?

Methicillin-resistant *Staphylococcus aureus* (MRSA) are strains of *S. aureus* that are resistant to commonly used antibiotics. MRSA strains are not only resistant to the antibiotic called methicillin, but also to many other types of antibiotics.

S. aureus is found on the skin of many individuals and seems to cause no major health problems. However, if it gets inside the body, for instance under the skin or into the lungs, it can cause infections.

MRSA is dangerous if it spreads to individuals who are very ill with weakened immune systems that cannot fight off the infection. MRSA infections occur most frequently among persons (with or without CF) in hospitals and health care facilities. These healthcare-associated MRSA infections include surgical wound infections, urinary tract infections, bloodstream infections, and pneumonia. MRSA may now be found in the community as well.

MRSA can be present in the nose, throat, lungs, on the skin, moist areas, such as armpits and groins, or in the blood or urine. If the organism is on the skin, then it can be passed

around by physical contact. If the organism is in the nose, or is associated with the lungs rather than the skin, then it may be spread by droplets from the mouth and nose.

Over the years, MRSA has emerged as a potentially more serious cause of morbidity among patients with CF, especially infants and young children. A UK study reported an increase in the frequency of CF severe infections in people who have MRSA. Among children with CF, MRSA infection was shown to be related to significant deterioration in weight, height, and body mass index, compared with controls. Chest radiographs revealed worsening signs after one year among patients who had test results positive for MRSA.

The 2009 Canadian Patient Data Registry (CPDR) report shows 3.8% of individuals with CF are infected with MRSA, and the numbers have been rising since 2003. In the United States, approximately 22.6% of adults with CF are colonized with MRSA. In general, MRSA is more common in the US than in Canada.

What is *Pseudomonas aeruginosa* and will my health be affected if I have *Pseudomonas aeruginosa*?

Pseudomonas aeruginosa (*P. aeruginosa*) is a bacterium that causes chronic lung infections in 60% to 70% of adults with cystic fibrosis. It is commonly found in soil, water, vegetation, on our skin, and in most man-made environments.

Infection with *P. aeruginosa* is associated with increased severity of CF symptoms and, in some cases, increased rates of death or need for lung transplant. Outcomes vary from person to person and may depend on the strain of *P. aeruginosa* and an individual's health. Some people with CF experience a rapid decline in lung function following infection, while others may be infected for extended periods of time without any worsening of symptoms.

Transmissible (also known as epidemic or clonal) *P. aeruginosa* means that the identified strain is genetically identical in two or more persons who are unrelated and don't live in the same household, and therefore likely to have been transmitted from person to person.

A study on adults with CF in Ontario has shown that persons with CF infected with certain strains of transmissible *P. aeruginosa* have twice the risk of dying or requiring a lung transplant over the three-year study period.

ACQUISITION & TRANSMISSION

What activities increase my risk of cross-infection?

Activities involving prolonged or close contact with other people with CF or infected materials, including:

- Kissing or other sexual contact
- Sharing medical equipment or exercise facilities
- Sharing living space
- Riding in a car
- Face-to-face meetings where the majority of participants are individuals with cystic fibrosis
- Riding in an elevator
- Clinic waiting rooms
- Eating from a buffet

In general, the risk appears to be proportional to the extent and nature of exposure to other cystic fibrosis patients who are colonized with harmful bacteria. Studies have shown that prolonged close contact (such as used to occur in CF summer camps) increases the likelihood that microorganisms will be spread from one person to another. Any activity which increases the chance of prolonged contact with infected materials (such as sputum, saliva, etc.) also increases the risk that you will become infected. Bacteria can be transmitted by coughing, so being in close contact with another CF patient who is coughing is likely a risk factor for becoming infected with bacteria from that person.

The most prudent approach to protecting yourself is to follow proper hygienic practices and avoid close and prolonged contact with other individuals with cystic fibrosis.

How can I minimize my risk?

There is nothing you can do to make the risk zero. However, the best measures for preventing the spread of these bacteria are to practice good personal hygiene and follow the infection control measures listed below:

- Wash your hands frequently, particularly after touching infected materials, such as sputum or saliva and before eating.
- Avoid close and prolonged contact with other individuals with CF
- Keep a distance of at least three feet apart from other individuals with CF.
- Cover your mouth when you cough.
- Throw away tissues immediately after use.
- Do not share physiotherapy or respiratory equipment, such as nebulizers, aerochambers, PEP masks, etc.
- Follow the appropriate cleaning instructions for aerosol equipment and nebulizers and PEP masks to minimize contamination.
- Do not share eating utensils, cans, cups or bottles.
- Cover skin scrapes or cuts with a clean, dry bandage until healed.
- Maintain your general overall health, and follow your prescribed therapy, physiotherapy and nutrition regimens.

Are CF patients infected with these bacteria at risk of spreading these bacteria to other people who don't have CF?

No. CF patients can spread bacterial lung infections to other patients with CF, however, these infections do not generally spread from CF patients to people who don't have CF. Therefore, your friends, colleagues, and family members are not at risk, and your bacteria are not 'contagious' except to other people who also have CF.

If I am colonized/infected with one bacterium, and I am doing well, can I become colonized/infected with another strain of bacteria?

Yes.

What level of protection do masks provide for people with cystic fibrosis?

There are different levels of protection that masks can provide. Wearing a mask is certainly a risk-reducing measure - large droplets are contained in the mask. However, masks provide imperfect protection against transmission of microorganisms and are impractical in many settings, such as prolonged use and use outside hospitals.

After coughing, how long do transmissible bacteria survive in the air, and on surfaces such as chairs, tables, and countertops?

If *B. cepacia* lands on a stainless steel surface and then dries, it can be dead within one to two hours. If the droplet stays moist, it can survive for hours, even up to 24 hours.

After coughing, *P. aeruginosa* may live for up to eight days on a dry surface. Non-mucoid (less resistant) strains of *P. aeruginosa* can live for 24 hours, and mucoid strains can survive for 48 hours on a moist surface.

Should CF clinics segregate individuals with CF receiving care?

Each CF clinic is regulated by infection control policies in place at each individual institution. However, in general, CF clinics do not use waiting rooms and patients with CF do not share rooms.

As well, the general practice in CF clinics is to hold separate clinic days for patients with CF that also have *B. cepacia* complex, and in some cases MRSA. Each clinic determines if the number of patients infected with harmful bacteria warrant a separate clinic. In situations where separate clinics are impractical or cannot be accommodated, patients who are colonized should be scheduled at the very end of the clinic to avoid unnecessary contact with patients without *B. cepacia*. Otherwise, infected patients should attend clinic visits individually.

LUNG TRANSPLANTS & TRANSMISSIBLE BACTERIA

What is the risk of cross-infection to CF patients that have received lung transplants?

CF patients that have received a lung transplant have suppressed immune system, and could be infected by transmissible bacteria. They may also spread bacteria to other individuals with CF, as their sinuses and upper airways may be infected with transmissible bacteria.

Will I be eligible for a transplant if I am infected with harmful bacteria?

Currently, most but not all, transplant centres will reject individuals with CF who test positive for *B. cepacia*. Each transplant centre will have its own approach to assessing the suitability of MRSA or *B. cepacia*-positive individuals for transplantation; transplant centres will not reject individuals with CF who have transmissible strain of *P. aeruginosa*.

TESTING

How can I find out if I am colonized with harmful bacteria?

Currently, in Canada, microbiology laboratories associated with the CF clinics can test for bacteria such as *P. aeruginosa*, MRSA and *B. cepacia*. Further genetic testing is required to identify transmissible strains of *P. aeruginosa* and this test is not available as a routine test. If you are an adult with CF living in Ontario, and you participated in the Ontario study, then contact your CF clinic to determine your status.

If I test negative for *B. cepacia* complex, can I be sure that I really don't have it?

The current laboratory tests are good but not perfect for detecting *B. cepacia* complex. There are examples of undetected infection, but the exact frequency of this is not known.

Once I test positive for MRSA, will I continue to be infected?

Each person handles infection differently, and it is impossible at the time of first evidence of infection to predict how long the MRSA infection will last. Infection with MRSA can be temporary or more permanent. For instance, a study from the US showed that about half of CF patients who tested positive with MRSA were infected transiently and half developed persistent MRSA infections over 10 years.

TREATMENT

Are there treatments for transmissible bacteria?

Antibiotics are used to fight infection-causing bacteria and may be given as an inhaled, oral or IV medication. The type of antibiotic (or combination of antibiotics), the dosage, and the length of time the drug is taken all vary for each individual and depend on the severity of the infection.

The microbiology labs associated with the Canadian CF clinics provide the testing needed to determine the best antibiotics to treat infections with all bacteria seen in people with CF. It is not necessary to have the results of genetic testing of the strain of *P. aeruginosa* to determine which antibiotic therapy to use. Transmissible strains of *P. aeruginosa* are also relatively resistant to antibiotics but there are antibiotics (and combinations of antibiotics) that can successfully treat these infections.

What is being done to find new ways of treating infections?

Cystic Fibrosis Canada supports research looking at novel ways to prevent or eliminate lung infections, including alternatives to antibiotics. Funds also support studies investigating the characteristics of different bacteria in the human body to learn how to tailor treatments specific for an individual's "bacterial profile".

INFECTION CONTROL POLICY

What is Cystic Fibrosis Canada's infection control policy?

It is the policy of Cystic Fibrosis Canada that persons with CF who have tested positive in the last 12 months for *B. cepacia* complex and/or Methicillin-resistant *Staphylococcus aureus* (MRSA) should not attend, in person, any Cystic Fibrosis Canada-sponsored meeting and event where persons with CF may be in attendance. Individuals *without* CF, who are colonized with MRSA in the nasal cavity or on the skin, but who *are not actively sick* may attend.

Furthermore, persons with CF should not attend Cystic Fibrosis Canada-sponsored meetings and events held indoors since the risk of close or prolonged contact between persons with CF is increased. Participation is encouraged through alternative methods, such as teleconferencing, webconferencing, or other remote applications.

For the complete Infection Control Policy & Guidelines, visit www.cysticfibrosis.ca, or speak with your CF clinic health care team for more information.

Do infection control policies work?

Yes. Since the adoption of the infection control policy the incidence of *B. cepacia* acquisition in the Canadian CF population has declined. The existence and persistence of transmissible bacteria threaten to undermine many of our successes in improving the quality and length of life for people with cystic fibrosis. As we learn more about the risks of harmful bacteria and how they are transmitted, stronger steps will be taken to ensure the health of the CF community. Successful infection control can only occur when everyone is aware of the risks and ways to minimize the spread of harmful bacteria.

How does infection control impact the lives of people with cystic fibrosis?

Heightened awareness of the bacteria in our environment, particularly in health-care settings such as hospitals, could lead to feelings of anxiety and fear. Socially, people with cystic fibrosis may limit contact such as hand-shaking and hugging with peers and colleagues. There may also be emotional implications that arise from being isolated, including depression and feelings of loneliness.

How can people with cystic fibrosis stay connected?

From Facebook and email, to texting and video chatting, technology and social media provide many options to connect with individuals worldwide.

Cystic Fibrosis Canada continues to identify ways all people with cystic fibrosis can participate, interact, and exercise leadership. In response to the revised Cystic Fibrosis Canada Infection Control Policy & Guidelines, several possible solutions/technologies are being explored to ensure persons with cystic fibrosis remain closely connected with the organization and within the Canadian CF community.

Cystic Fibrosis Canada welcomes your thoughts and ideas on how the CF community can stay engaged with the organization and remain connected. Please send your suggestions to afernandes@cysticfibrosis.ca.

ADDITIONAL RESOURCES

Where can I learn more about transmissible bacteria?

For additional information on *B. cepacia* complex, visit the International *Burkholderia cepacia* Working Group Web site at: <http://go.to/cepacia>.

For more information on transmissible strains of *P. aeruginosa* you can read the article abstract describing the Ontario study online at www.jama.ama-assn.org.

You may also use the search function on the Cystic Fibrosis Canada Web site (www.cysticfibrosis.ca) or speak with your CF Clinic health care team to get more information or answer any questions you may have.

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