

Children's Hospital of Illinois
BURKHOLDERIA CEPACIA
INFORMATION SHEET

WHAT IS BURKHOLDERIA CEPACIA?

Bacteria and viruses are the most important types of germs that cause infection in people with cystic fibrosis (CF). Bacteria are probably the major cause of lung infection and lung damage in people with CF. Usually the number of bacteria in the lung of a person with CF is low because the body's immune system can keep these bacteria under control. This is referred to as bacterial colonization. When the bacteria grow out of control, it becomes an infection. There are several bacteria that most often colonize the lungs of people with CF. They are, *Haemophilus influenzae* (sometimes known as H. flu, which is different than the influenza virus), *Staphylococcus aureus*, and *Pseudomonas aeruginosa*. Other bacteria include, *Escherichia coli*, *Stenotrophomonas maltophilia*, *Alcaligenes xyloxydans*, *methicillin resistant Staphylococcus aureus (MRSA)* and *Burkholderia cepacia*.

WHY IS BURKHOLDERIA CEPACIA IMPORTANT?

Burkholderia cepacia complex is a family of bacteria that can colonize and infect the breathing tubes of people who have CF. Years ago it was thought that all *Burkholderia cepacia* were very dangerous for people with CF. This was believed because some people who were colonized with *Burkholderia cepacia* developed a very quick drop in their health and lung function. In fact, a number of people developed something called "cepacia syndrome". Cepacia syndrome is a very dangerous, overwhelming infection that can cause severe, life threatening complications. Although cepacia syndrome occurs in some cases, we now know that not all types of *Burkholderia cepacia* are associated with this very dangerous complication. In fact, some forms of *Burkholderia cepacia* are no worse than some of the other bacteria that colonize the breathing tubes of people with CF. The biggest problem with *Burkholderia cepacia* is we do not know enough about it. What we do know is that it can get very resistant to antibiotics and it can cause a lot of lung damage.

HOW DO YOU GET BURKHOLDERIA CEPACIA ?

It is known that *Burkholderia cepacia* can be passed on from one person with CF to another person with CF. Plants and soil may be other sources of *Burkholderia cepacia*. However, it is unknown how all people who have *Burkholderia cepacia* complex actually acquired it. Studies are currently underway to determine all the environmental sources of *Burkholderia cepacia*.

With CF there are problems with salt and water balance in the lining of the breathing tubes. This imbalance causes thick, sticky mucus. This mucus then traps bacteria, like *Burkholderia cepacia*, in the lungs making it hard to clear. This leads to infection and damage to the lung lining. This leads to more mucus production and further trapping of *Burkholderia cepacia*.

HOW DO YOU AVOID GETTING BURKHOLDERIA CEPACIA?

Most CF experts agree that the best way to avoid the spread of *Burkholderia cepacia* is to limit contact with others who have CF. Bacteria enter the lungs through your mouth and nose. You should, therefore, avoid direct (kissing, physical intimacy) and indirect (standing next to someone who is coughing or sneezing, prolonged close (<3 feet distance) contact, sharing food, utensils or respiratory therapy equipment) contact with others with who have CF. As always, it is important to make sure you wash your hands frequently, take your medications and do your therapies as prescribed.

WHAT ARE THE SYMPTOMS OF BURKHOLDERIA CEPACIA INFECTION?

Symptoms of *Burkholderia cepacia* infection are similar to the symptoms you would experience with any other bacteria. These symptoms include increased cough, congestion, difficulty breathing and possibly fever. If someone develops “cepacia syndrome” the symptoms will be very severe and include a high fever.

HOW DO YOU TREAT A BURKHOLDERIA CEPACIA INFECTION?

Antibiotics are the most effective way to fight bacteria. Some types of *Burkholderia cepacia* are sensitive to trimethoprim-sulfamethoxazole (Bactrim), doxycycline, ceftazidime and meropenem. The benefit of Bactrim and doxycycline is that they can be taken by mouth.

