



UNDERSTANDING  
invasive fungal infection

# Doctor discussion guide for caregivers

Helpful information, topics, and questions to  
consider bringing up with your child's doctors.



## Information to tell your child's doctors

Unfortunately, your child is at risk for an invasive fungal infection (IFI). The doctors may have already explained why. They may have explained that your child is at risk for other types of infections, too.

**Follow the instructions of the health care team if your child has any of the following, which could be signs of infection:**

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|--|---|
| <input type="checkbox"/> Fever of 100.5°F (38°C) or higher                       | <input type="checkbox"/> Sores or a white coating in their mouth or on their tongue         |
| <input type="checkbox"/> Chills  | <input type="checkbox"/> Swelling or redness, especially where a catheter enters their body |
| <input type="checkbox"/> Cough or sore throat                                    | <input type="checkbox"/> Urine that is bloody or cloudy, or pain when they urinate          |
| <input type="checkbox"/> Diarrhea  | <input type="checkbox"/> Any other signs of infection                                       |
| <input type="checkbox"/> Ear pain, headache or sinus pain, or stiff or sore neck |   |
| <input type="checkbox"/> Skin rash   |   |
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## What doctors may do

The doctor might give your child medicine to help prevent an IFI or other infections. This is called **prophylaxis**. Your child may need to take an **antifungal medicine** for weeks or months.

If your child is at risk, the doctors will watch for signs of infection. They will watch for IFI. They also will watch for bacteria and viruses. Fever and changes in blood work are often the first signs of infection.

If your child is in the hospital, a nurse may take their temperature or a blood sample often. If your child is at home, you may need to go to the doctor's office for tests. If there are signs of infection, the doctors may then do other tests. This is to see if there really is an infection, and what kind it is.

# Questions to consider asking your child's doctors

You may have a lot of questions for your child's doctors. But, it can be hard to remember all of your questions when you see a doctor. Here are some questions you may consider asking.

## General questions

**Why is my child at risk for infection from a fungus?**

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**How will you know if my child has an IFI?**

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**What tests did you or will you use to check for IFI?**

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**What can I do to help reduce my child's risk for an IFI?**

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**Where can I get more information about IFI?**

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## Questions to consider asking your child's doctors (cont'd)

### Questions about treatment

What kind of treatment will my child get to help prevent IFI?

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If my child will be taking an antifungal medicine, what should we know about it?

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Are any additional tests needed while my child is taking antifungal medicine?

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How will you know if the treatment is working?

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Other questions:

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# Medicine tracker

Use these pages to help keep track of the medicines your child is taking.

**IT IS IMPORTANT THAT YOUR CHILD TAKE ALL MEDICINES AS PRESCRIBED BY THE DOCTOR. BE SURE TO FOLLOW SPECIFIC DOSING SCHEDULES AND DIRECTIONS, INCLUDING WHETHER YOUR CHILD SHOULD BE TAKING MEDICINES WITH OR WITHOUT FOOD. CHECK WITH THE DOCTOR OR PHARMACIST IF YOU HAVE ANY QUESTIONS ABOUT YOUR CHILD'S MEDICINES.**

Medicine: \_\_\_\_\_

How Much to Give: \_\_\_\_\_

How Often to Give It: \_\_\_\_\_

When to Give It: \_\_\_\_\_

Who Prescribed It: \_\_\_\_\_

Prescriber's Phone #: \_\_\_\_\_

Other Notes: \_\_\_\_\_

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Medicine: \_\_\_\_\_

How Much to Give: \_\_\_\_\_

How Often to Give It: \_\_\_\_\_

When to Give It: \_\_\_\_\_

Who Prescribed It: \_\_\_\_\_

Prescriber's Phone #: \_\_\_\_\_

Other Notes: \_\_\_\_\_

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Medicine: \_\_\_\_\_

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Medicine: \_\_\_\_\_

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Who Prescribed It: \_\_\_\_\_

Prescriber's Phone #: \_\_\_\_\_

Other Notes: \_\_\_\_\_

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# Emergency contact information

Use this page to help keep track of the contact information of whom you would contact in case of an emergency.

## Emergency Contact #1:

Cell Phone #: \_\_\_\_\_

Other Phone #: \_\_\_\_\_

Email Address: \_\_\_\_\_

Address: \_\_\_\_\_

## Emergency Contact #2:

Cell Phone #: \_\_\_\_\_

Other Phone #: \_\_\_\_\_

Email Address: \_\_\_\_\_

Address: \_\_\_\_\_

Other:

Cell Phone #: \_\_\_\_\_

Other Phone #: \_\_\_\_\_

Email Address: \_\_\_\_\_

Address: \_\_\_\_\_

## Nearest Emergency Room:

Phone #: \_\_\_\_\_

Alternative Phone #: \_\_\_\_\_

Email Address: \_\_\_\_\_

Address: \_\_\_\_\_

## Nearest Emergency Room:

Phone #: \_\_\_\_\_

Alternative Phone #: \_\_\_\_\_

Email Address: \_\_\_\_\_

Address: \_\_\_\_\_

Other:

Cell Phone #: \_\_\_\_\_

Other Phone #: \_\_\_\_\_

Email Address: \_\_\_\_\_

Address: \_\_\_\_\_

# Care team contact information

Use this page to help keep track of the contact information of whom you can contact if you have questions about your child's care or therapy.

Care Team Member:

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Cell Phone #: \_\_\_\_\_

Other Phone #: \_\_\_\_\_

Email Address: \_\_\_\_\_

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Address: \_\_\_\_\_

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Care Team Member:

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Cell Phone #: \_\_\_\_\_

Other Phone #: \_\_\_\_\_

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Care Team Member:

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Care Team Member:

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## Terms related to IFI that you may not know

**Antifungal medicine**—A medicine that fights a fungus infecting the body. The medicine prescribed depends on the specific type of fungal infection.

**Aspergillosis**—An infection caused by the fungus *Aspergillus*, which is a type of **mold**. This infection usually starts in the lungs.

***Aspergillus***—A mold that can infect the lungs, sinuses, or other organs in people with a weakened immune system. It is one of two types of **fungi** that most often cause an **invasive fungal infection**.

**Bronchoscopy**—Placement of a tube into the lungs to check for disease or take a tissue sample for diagnosis.

***Candida***—A yeast that can infect the bloodstream or body organs in people with a weakened immune system. It is one of two types of **fungi** that most often cause an **invasive fungal infection**.

**Candidemia**—An infection in the blood caused by the fungus *Candida*, which is a **yeast**.

**Candidiasis**—A general term for an infection by the yeast *Candida* anywhere on the skin or in the body.

**Central venous catheter**—A tube that is inserted into one of the body's central veins to give a person fluids or medicines.

**Computerized tomography (CT) scan (also called CAT scan)**—A type of imaging test that may be used to check for infection of the lungs, head, or other body areas. It gives more information than an x-ray.

**Culture**—A test that is used to see if any bacteria or fungi are in the body. A sample of blood or other body tissue is placed in a special dish to see what grows in it.

**Drug interactions**—Effects that one drug has on another drug in the body. Doctors typically pay close attention to how different drugs react to each other. Some of these reactions can make treatment less effective or cause side effects.

**Fungal infection**—An infection that happens when a fungus gets into the body and makes a person sick. Many types of fungal infection are not serious, but some types (IFI) can be very dangerous.

**Fungi (plural of Fungus)**—From mushrooms to mold to baker's yeast, fungi are all around us. They live in the air, soil, plants, water, and even the human body. Most fungi are harmless. Some fungi can cause minor infections like athlete's foot and vaginal yeast infections. But in people who are already sick or have a weakened immune system, some fungi can cause very serious infections (IFI).

**Imaging test**—A test such as an x-ray or **computerized tomography (CT) scan** that looks at what is happening inside your body. Doctors often use imaging tests to check for infection and/or see if a treatment is working.

**Infectious disease (ID) specialist**—A doctor who has had special training to learn how to care for people with different kinds of infections. They are likely to be very involved in the diagnosis and treatment of IFI.

**Intravenous (IV) medicine**—A medicine that is given as a liquid into a vein. Many people who get an IFI will receive IV medicine for at least some of their treatment.

**Invasive fungal infection (IFI)**—A term that is usually used to refer to a type of fungal infection where the fungus spreads inside the blood or to body organs, causing serious illness.

**Invasive mold infection**—A type of **invasive fungal infection** caused by a **mold** such as *Aspergillus*.

**Microbiologist**—A medical expert who looks at blood and tissue samples taken from patients to see if they have an infection, and if so, what type. Also see **Pathologist**.

**Microscopy**—The act of looking at a blood or tissue sample under a microscope, to see if a patient has an infection, and if so, what type.

**Mold**—A type of fungus that can be found in many places, from shower tile to damp basements to old bread. It is normally harmless to healthy people, but can cause serious infection in people with a weakened immune system.

**Mucorales** —A group of molds that are rare but can sometimes cause very serious infections.

**Mucormycosis**—A rare type of **invasive mold infection** that is very serious and can be very hard to treat.

**Opportunistic infection**—An infection that typically only happens to people who are very sick or who have a weakened immune system. Opportunistic infections can spread quickly throughout the body.

**Oral medicine**—A medicine that is taken by mouth, such as by swallowing a pill or liquid. Some people who need antifungal medicine are able to take it in oral form.

**Pathologist**—A medical expert who looks at blood and tissue samples taken from patients to identify disease. Also see **Microbiologist**.

**Prophylaxis**—Prevention. Specific to IFI, prophylaxis is the giving of antifungal medicine to someone who does not yet have a fungal infection. The idea is to try to prevent an IFI in someone who is at risk of getting one.

**Radiologist**—A doctor who helps identify and treat disease by looking at the results of **imaging tests** such as x-rays and **computerized tomography (CT)** scans.

**Spores**—Specific to IFI, tiny pieces of a fungus that break off and can travel through the air. When breathed in, spores can cause infection in people who are very sick or have a weakened immune system.

**Thrush**—A usually harmless infection of the mouth caused by yeast.

**Ultrasound**—An imaging test used to help diagnose some kinds of IFI.

**Yeast**—A common type of **fungus**. Yeast can be harmless and even helpful, like baker's yeast. But yeast can also cause infections. Some of these infections are not serious. But in people who are sick or have a weakened immune system, the yeast *Candida* can cause serious infection (IFI).

Access additional *myIFI* resources at  
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