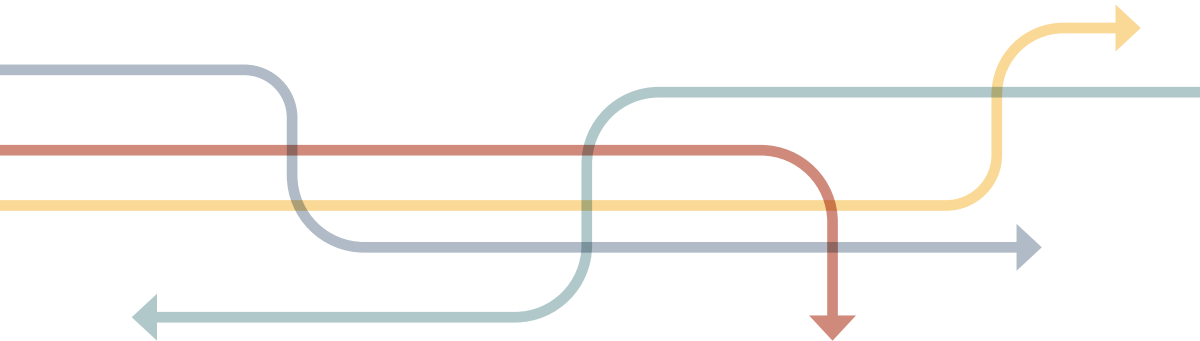




# Journey Navigator

A helpful resource to guide your child's transitions of care



## Dear parents and other caregivers:

The *myIFI* Journey Navigator is an easy-to-use resource highlighting information that may be helpful to know as a caregiver of a child with an invasive fungal infection (IFI). It also features a possible roadmap of what transitions of care from one stage to the next might look like. The intention of this navigation resource is to help you better understand the health care journey and ask appropriate questions of the right health care providers during care transitions. You are encouraged to share this resource with members of the health care team.

## A note to health care professionals:

If a caregiver has shared this resource with you, it means that they wish to partner with you and other members of the health care team in order to more easily navigate their child's transitions of care.

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My child's name: \_\_\_\_\_

My name (caregiver): \_\_\_\_\_

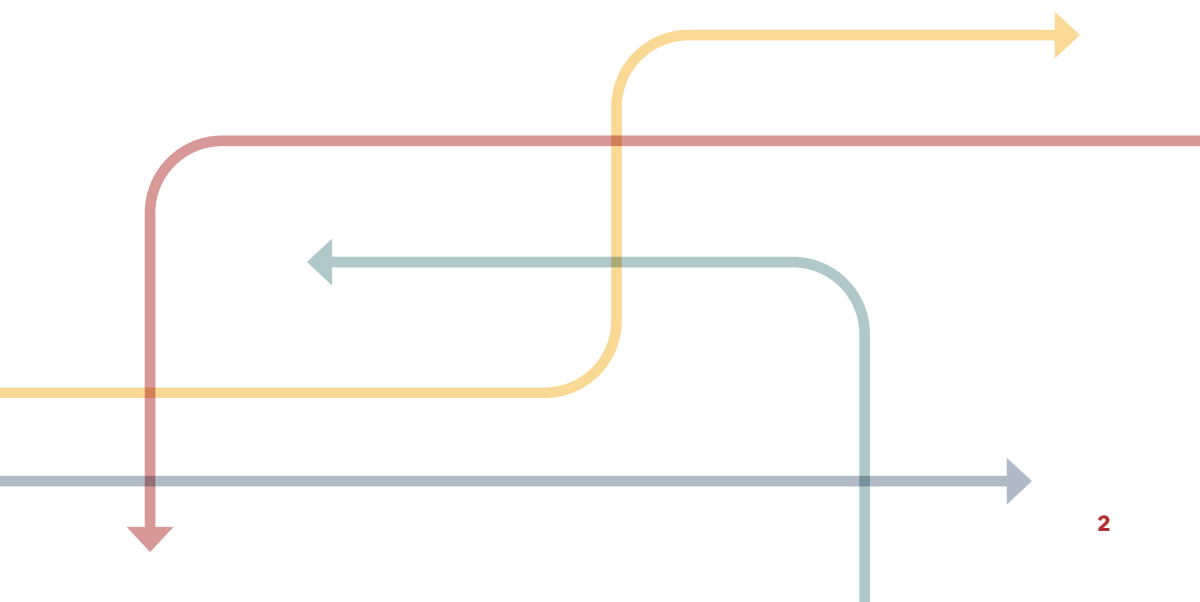
# myifi

## Journey Navigator



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## Invasive fungal infection (IFI): The basics

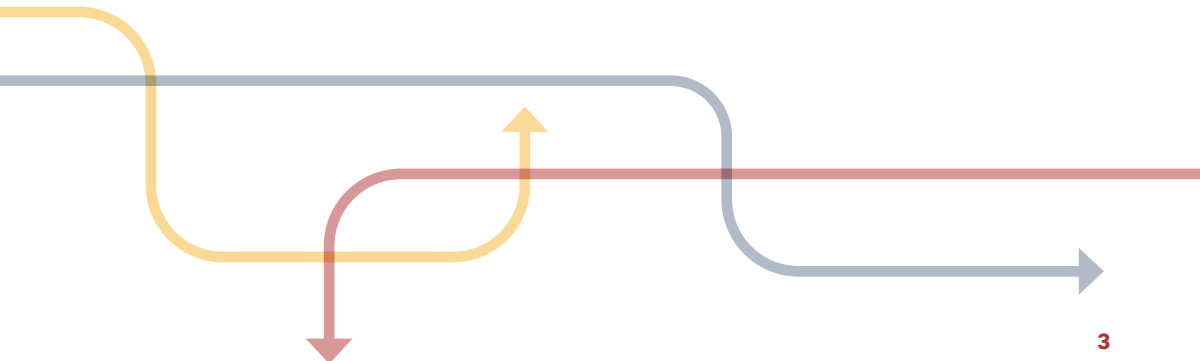
### What is IFI?

- **Invasive fungal infection** is called **IFI** for short. It is the name for many serious infections caused by a fungus. IFI is important to understand because it can be very harmful to your child.
- IFI usually affects people (including children) who are already sick or have a weakened immune system. IFI can make getting better much harder.

### Why IFI happens

- Although **fungi** are all around us, most people do not get sick from them. This is because of the immune system.
- The immune system stops the fungi from making children sick. But children who are already sick or taking some medicines can have weakened immune systems. Then the body has a harder time fighting the fungi. When a fungus causes disease in someone who is already sick, this is sometimes called an **opportunistic infection**.
- The fungi may enter the body through cuts or breaks in the skin. Or the child may breathe fungi into their lungs. Or fungi in the digestive tract that are normally harmless may spread to the blood.
- Children who are most at risk for getting an IFI include those who:
  - o Have certain blood cancers, such as leukemia, lymphoma, or myeloma
  - o Have severe aplastic anemia
  - o Have had a stem cell transplant or an organ transplant
  - o Have human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS)
  - o Have a weakened immune system due to a genetic disease or premature birth
  - o Are taking certain kinds of medicines, such as some cancer medicines or steroid medicines
  - o Are receiving nutrition through an **intravenous (IV)** line in a vein

Having diabetes or extensive burns also can put you at risk for some types of IFI.



## How IFI may affect your child

- If your child is already sick, having an IFI can make it harder to fight their other illness. And if their immune system is weakened, this fight can be even harder. Doctors may treat both illnesses at the same time. But sometimes when a person gets an IFI, doctors will stop other treatments that affect the immune system.
- IFI can be very dangerous. But with the right treatment, many people can recover. If your child is still taking medicine to treat the IFI when they get out of the hospital, it is important that they take it as prescribed.
- Your child's IFI is not likely to spread to others. Some fungi can live on the skin and might spread to other people. But these fungi are not likely to cause IFI in a person without any risk factors for infection.

## How it's often diagnosed

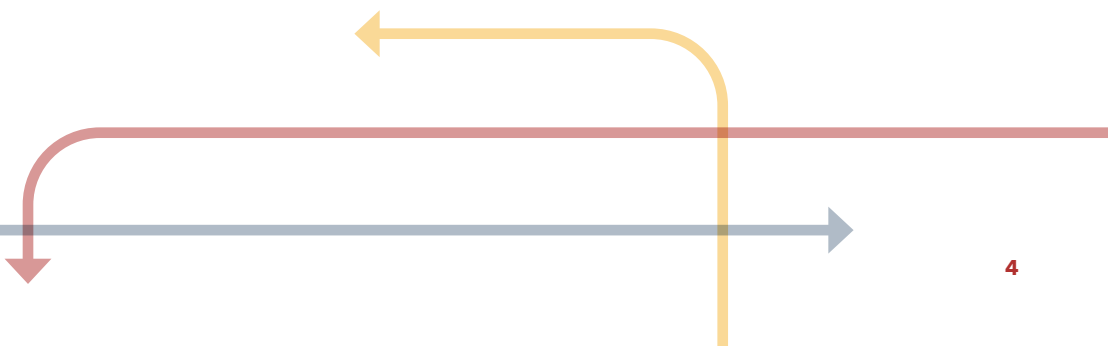
- The first signs of IFI are often fever and changes in blood work. But these signs also could be due to a bacterial or viral infection. So the health care team may take a sample of blood, other body fluid, or tissue from your child. These samples go to a lab, where one or more tests are done. The team also may look at your child's lungs or other body areas to find infection. They may take an x-ray, use **ultrasound**, or perform a **computerized tomography (CT) scan**.
- All of these tests together can show what is causing the infection. If a fungus is the cause, the team will try to find out what kind it is. Different types of IFI get different treatments.

## How it's often treated

- Your child will probably be given medicine to help stop the fungus. This is called **antifungal medicine**. Some people also need surgery to help get rid of some types of IFI.
- Your child's immune system may be weakened. If so, the doctor may give them medicine to help make the immune system stronger. The goal is to help the body fight off the IFI.

## The possible treatment team

- Your child may already have a few people caring for them. Some team members may specifically treat infections. A doctor who focuses on infections is called an **infectious disease (or ID) specialist**. However, other health care providers also may help treat infections.
- If your child has an IFI or is at risk for one, an ID specialist may help guide the treatment.





## What are *transitions of care*?

Transitions of care are defined as the movement of patients between health care locations, providers, or different levels of care within the same location as their conditions and care needs change.

Navigating from one care setting to another can feel confusing, but you and your child aren't alone. By connecting with your child's health care team, you can secure a copilot (or copilots) who can help you navigate through the transitions of care: from hospital to home, from home to outpatient center, and everything in between.



## Potential members of the health care team

The primary members of the health care team are *you and your child*! Of course, it is also important to know each health care provider's role, and how that role can change over time. Ideally, you will find support (aside from that of other family members) with a *physician champion*—your child's health care copilot. The role of the physician champion is not only advocacy but also maintaining clear pathways for communication among the many health care providers who assist you and your child on the health care journey.

*"You, your child, and other caregivers are all members of the health care team. All members should work together to achieve your family's goals."*

— Dr Danziger-Isakov

Team Member and Role	My Child's Health Care Team
<b>Physician Champion:</b> The main physician who directs your child's care.	<p><b>This is also my child's _____</b> <b>(e.g., pediatrician, infectious disease specialist, oncologist)</b></p> <p>Contact information (for inpatient and/or outpatient settings):</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>Notes: _____</p> <p>_____</p> <p>_____</p>
<b>Infectious Disease Provider:</b> Diagnoses and treats infections, such as your child's fungal infection. Frequently involved with prescribing antifungal medicine both in the hospital and at discharge. This provider should be able to answer your questions about fungal infection and antifungal medicine.	<p>Contact information (for inpatient and/or outpatient settings):</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>Notes: _____</p> <p>_____</p> <p>_____</p>
<b>Specialist Physician (e.g., Transplant, Oncology):</b> Treats specific medical conditions your child is living with, both short- and long-term. The type of specialists your child sees will depend on their health history. These specialists should be made aware of changes in your child's health and medicines, such as their IFI.	<p>Contact information (for inpatient and/or outpatient settings):</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>Notes: _____</p> <p>_____</p> <p>_____</p>
<b>Specialist Physician (e.g., Transplant, Oncology):</b> Treats specific medical conditions your child is living with, both short- and long-term. The type of specialists your child sees will depend on their health history. These specialists should be made aware of changes in your child's health and medicines, such as their IFI.	<p>Contact information (for inpatient and/or outpatient settings):</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>Notes: _____</p> <p>_____</p> <p>_____</p>

**Note:** Your child's care team may not include all of the members listed in this section.



Team Member and Role	My Child's Health Care Team
<p><b>Case Manager:</b> This person may help to coordinate care in the hospital and at discharge. Consider talking to this person about your child's health history as well as any social or financial challenges you are facing so they can help tailor care to your situation. Your child's case manager may arrange for care after hospital discharge, help with access to medicines, and arrange postdischarge follow-up.</p>	<p>Contact information (for inpatient and/or outpatient settings):</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>Notes: _____</p> <p>_____</p> <p>_____</p>
<p><b>Nurse:</b> While your child is in the hospital, a nurse may help to educate you on the disease, medicines, and the care your child will need after discharge.</p>	<p>Contact information (for inpatient and/or outpatient settings):</p> <p>_____</p> <p>_____</p> <p>Notes: _____</p> <p>_____</p>
<p><b>Pharmacist:</b> You and your child may see a pharmacist during the hospital stay or at discharge. The pharmacist will likely review the medicines your child is taking to make sure nothing has been missed and that the medicines can be safely taken together. The pharmacist can also provide education on how to give the medicines and what side effects your child might experience. Make sure the pharmacist knows all of your child's health conditions and medicines they are taking. This includes medicines they took before the hospitalization, prescriptions that were given at discharge, and any over-the-counter or holistic medicines they are taking. The pharmacist may also help make sure you have access to your child's medicines when you leave the hospital.</p>	<p>Contact information (for inpatient and/or outpatient settings):</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>Notes: _____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p> <p>_____</p>

**Note:** Your child's care team may not include all of the members listed in this section.

Team Member and Role	My Child's Health Care Team
<b>Hospitalist or APN:</b> Your child may be assigned a hospitalist or advanced practice nurse during their stay. This team member provides general medical care and may coordinate specialist care while your child is in the hospital.	Contact information (for inpatient and/or outpatient settings): _____ _____ Notes: _____ _____
<b>Community Providers (e.g., MD/DO/PA/NP):</b> These are the doctors, physician assistants, and nurses that provide medical care when your child is at home. You will want to make sure these providers know about the hospitalization and any medicine changes made at discharge.	Contact information (for inpatient and/or outpatient settings): _____ _____ Notes: _____ _____
<b>Other Providers:</b> There may be other members of your child's health care team, including a case manager from your insurance provider, your community or specialty pharmacist, a visiting nurse, a home health care service, or various therapists. List these providers here.	Contact information (for inpatient and/or outpatient settings): _____ _____ Notes: _____ _____
<b>Other Providers:</b> There may be other members of your child's health care team, including a case manager from your insurance provider, your community or specialty pharmacist, a visiting nurse, or various therapists. List these providers here.	Contact information (for inpatient and/or outpatient settings): _____ _____ Notes: _____ _____
<b>Other Providers:</b> There may be other members of your child's health care team, including a case manager from your insurance provider, your community or specialty pharmacist, a visiting nurse, or various therapists. List these providers here.	Contact information (for inpatient and/or outpatient settings): _____ _____ Notes: _____ _____

**Note:** Your child's care team may not include all of the members listed in this section.





## Possible transitions of care roadmap

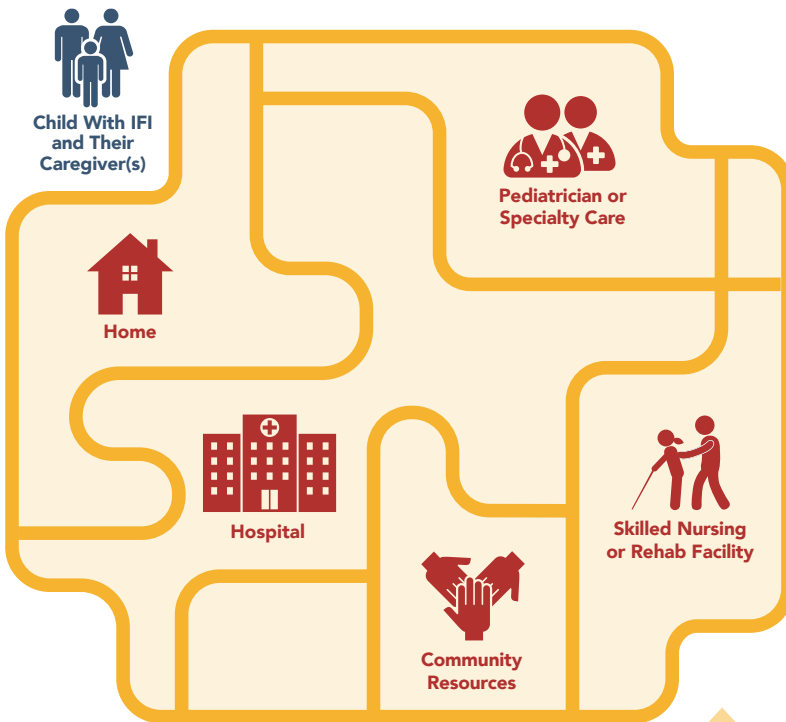
*"During your child's transitions of care, it is important to ask who to call with questions, so you understand who can address concerns between visits."*

— Dr Danziger-Isakov

As the caregiver of a child with an IFI, you may explore many routes on your child's health care journey. From one destination to the next, your child will experience a transition of care. At each transition, it is important that you have all the information you need to continue the health care journey. It is also important to communicate openly and effectively with the health care team and to keep all appointments—even virtually—as needed.

Before your child leaves the hospital, it is helpful to know which physicians you need to follow up with. Try to make those appointments before leaving the hospital. It is also important to make sure you have access to all your child's medicines as soon as they make a transition, whether that be to your home or another facility. The case manager should be able to help.

Here's what a transitions of care roadmap might look like.





## Key questions to consider posing to health care team members

It's important not only to consider what questions to ask, but which health care provider you should be asking at each transition of care.

Questions to consider asking before leaving the hospital or treatment center	Which health care provider should you consider asking?	Notes/responses
Where is my child going next?	Case manager, nurse, hospitalist/advanced practice nurse	
What is their diagnosis?	Hospitalist/advanced practice nurse, specialist	
Will our physician champion know about this diagnosis? Should I tell them?	Hospitalist/advanced practice nurse, specialist	
Will my child's medicine change?	Hospitalist/advanced practice nurse, infectious disease provider, pharmacist	
Is my child's medicine available today?	Case manager, pharmacist	
What if we need help at home?	Case manager	
What doctor should my child see after they go home?	Case manager, hospitalist/advanced practice nurse, specialists	
When are my child's appointments scheduled?	Case manager, hospitalist/advanced practice nurse, specialists	
What does our insurance cover?	Case manager, insurance provider	
What are our out-of-pocket costs?	Case manager, insurance provider	
What if we need help paying for care?	Case manager	
Will a case manager or social worker be available to assist us after discharge? (i.e., financial challenges?)	Case manager	
How can I keep my child safe?	Case manager	

*"It is important to know the specific steps to address your child's illness. Knowing what you need to do to help treat or prevent an IFI is an essential part of your child's path to wellness."*

– Dr Danziger-Isakov

General questions about antifungal treatment	Which health care provider should you consider asking?	Notes/responses
How should the medicine be given?	Infectious disease provider, pharmacist	
For how long should I give the medicine?	Infectious disease provider, pharmacist	
What are the side effects?	Infectious disease provider, pharmacist	
Are there any drug-drug interactions?	Infectious disease provider, pharmacist	
Will it interact with any supplements my child takes?	Infectious disease provider, pharmacist	
Will it interact with any food?	Infectious disease provider, pharmacist	
Will it interact with any over-the-counter medicines?	Infectious disease provider, pharmacist	
Will it interact with any holistic medicines?	Infectious disease provider, pharmacist	
What happens if my child misses a dose?	Infectious disease provider, pharmacist	
Is any kind of testing needed while my child is taking this medicine?	Infectious disease provider, pharmacist	

*"For your child's IFI treatment to be successful, it is vital that you understand the antifungal medicine: How do you give it? For how long? Does it interact with any of their other medicines? What are the side effects?"*

– Dr Danziger-Isakov



## Paying for medicine

- The cost of antifungal medicine depends on the medicine prescribed. It also depends on the insurance you have. If you are worried about the cost, you may be able to get help.
- Many companies that make these medicines offer special programs to help people in need. Ask your health care team about this. You could also search the internet for the medicine or the drug company, along with the word *assistance* or *support*.



## Giving medicine as prescribed

Giving medicine as prescribed by your child's health care provider—sometimes called *treatment adherence*—is an important part of the health care journey. Obstacles to treatment adherence may arise. Describe any challenges to your child's physician champion or to anyone on the health care team, so you can work on solutions together.

*"I encourage caregivers of children with IFI to report any challenges (financial, geographic, social) that might prevent their child from getting and taking the antifungal medicine as prescribed, so that the health care team can try to help."*

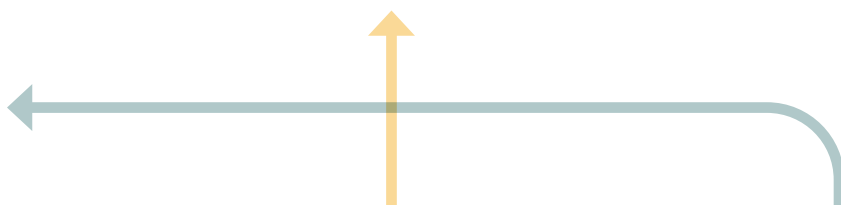
– Dr Danziger-Isakov

Challenges	Solutions
(example) Sometimes I forget to give my child their medicines.	Set an alarm on my phone.



Antifungal		
	Generic name Brand name	Generic name Brand name
Medicine		
Dose and Administration		
Prescriber		
Notes		

Other medicines		
	Generic name Brand name	Generic name Brand name
Medicine		
Dose and Administration		
Prescriber		
Notes		
Medicine		
Dose and Administration		
Prescriber		
Notes		





Other medicines (cont.)		
	Generic name Brand name	Generic name Brand name
Medicine		
Dose and Administration		
Prescriber		
Notes		
Medicine		
Dose and Administration		
Prescriber		
Notes		

Supplements or holistic medicines		
	Brand/type	Brand/type
Medicine		
Dose and Administration		
Prescriber		
Notes		





## What to do if symptoms change

Follow the instructions of the health care team if your child has any new symptoms or if symptoms have gotten worse, such as:

- ☐ Fever of 100.5°F (38°C) or higher
- ☐ Chills
- ☐ Cough or sore throat
- ☐ Diarrhea
- ☐ Ear pain, headache or sinus pain, or stiff or sore neck
- ☐ Skin rash
- ☐ Sores or a white coating in their mouth or on their tongue
- ☐ Swelling or redness, especially where a catheter enters their body
- ☐ Urine that is bloody or cloudy, or pain when they urinate
- ☐ Any other signs of infection



## Additional resources

### **myIFI Mobile App**

A mobile app with useful information on IFI for patients and caregivers. Available for download in the App Store® and Google Play™ store

<https://myifi.thehwpgroup.com/myifi.php>

### **More IFI Resources**

Educational resources to help you learn about IFI and its risk factors, as well as communication tips for the next doctor visit

<https://www.astellasresources.com>

## Helpful Websites

The following sources can give you more information about specific types of IFI:

### **American Academy of Pediatrics: Aspergillosis**

Provides information about pediatric infections with the mold *Aspergillus*

<https://www.healthychildren.org/English/health-issues/conditions/infections/Pages/Aspergillosis.aspx>

### **American Academy of Pediatrics: Fungal Diseases**

Reviews a variety of fungal infections that can occur in children, including mucormycosis (formerly zygomycosis)

<https://www.healthychildren.org/English/health-issues/conditions/infections/Pages/Fungal-Diseases.aspx>

### **Centers for Disease Control and Prevention: Fungal Infections: Protect Your Health**

Explains who may be at risk for a fungal infection, and why

<https://www.cdc.gov/fungal/features/fungal-infections.html>

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## Additional resources (cont'd)

### **Centers for Disease Control and Prevention: Types of Fungal Diseases**

Includes in-depth sections focusing on invasive candidiasis, aspergillosis, and mucormycosis

<https://www.cdc.gov/fungal/diseases/index.html>

### **National Library of Medicine: Fungal Infections**

Reviews a variety of topics relating to IFI, including diagnosis, prevention, and risk factors

<https://medlineplus.gov/fungalinfections.html>

### **National Organization for Rare Disorders: Aspergillosis**

Features information on the mold infection aspergillosis, including signs and symptoms, causes, diagnosis, and treatment

<https://rarediseases.org/rare-diseases/aspergillosis>

### **National Organization for Rare Disorders: Mucormycosis**

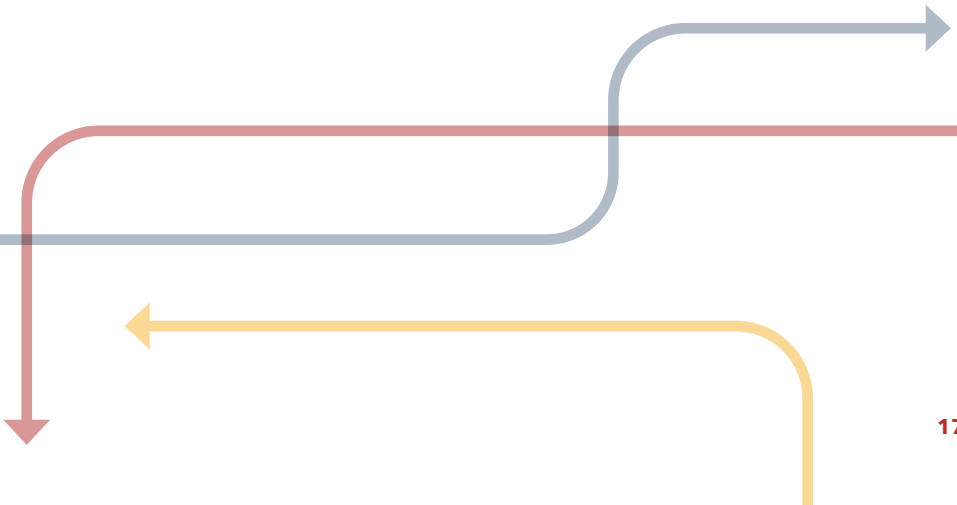
Features in-depth information on the rare mold infection mucormycosis, including signs and symptoms, causes, diagnosis, and treatment

<https://rarediseases.org/rare-diseases/mucormycosis>

### **National Organization for Rare Disorders: Systemic Candidiasis**

Features information on the yeast infection candidiasis, including signs and symptoms, causes, diagnosis, and treatment

<https://rarediseases.org/gard-rare-disease/systemic-candidiasis/>





## Terms to know

Here are some terms you might hear when discussing your care with your child's health care team. Refer to this list when you hear a word you're not familiar with or don't understand its meaning.

### **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 caused 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 can give more information than an x-ray.



## Terms to know (cont.)

### **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 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 the body. Doctors often use imaging tests to check for infection or to 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 usually refers to a type of fungal infection where a 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*.



## Terms to know (cont.)

### **Microbiologist**

A medical expert who looks at blood and tissue samples taken from patients to check for infection and figure out what is causing it. 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 tiles to damp basements to old bread. It is normally harmless to healthy people, but can cause serious infection (IFI) in people with a weakened immune system.

### **Mucorales**

A group of molds that are rare but can sometimes cause very serious infections (IFI).

### **Mucormycosis**

A rare type of invasive mold infection that is very serious and can be 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**

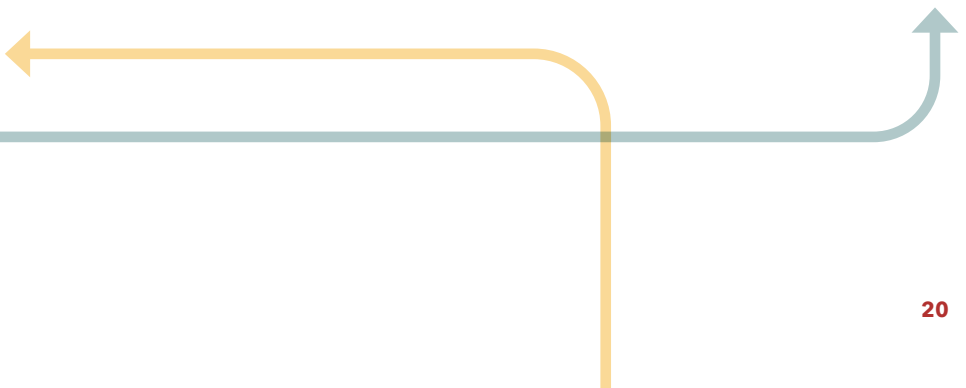
A medicine that is taken by mouth, such as by swallowing a pill or liquid. Some people who need antifungal medicine are able to take it in oral form.

### **Pathologist**

A medical expert who looks at blood and tissue samples taken from patients to identify disease.

### **Prophylaxis**

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





## Terms to know (cont.)

### **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.

### **Risk factor**

Something that makes it more likely a person will get a certain disease or infection.

### **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**

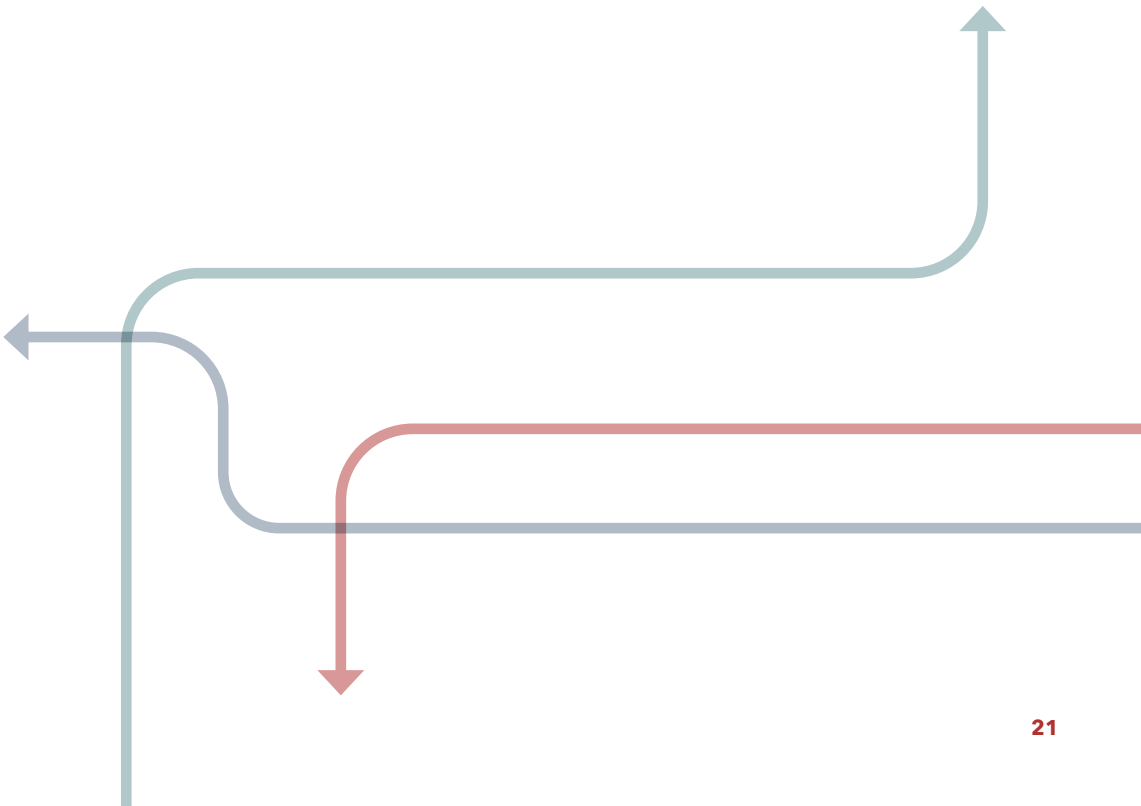
A usually harmless infection of the mouth caused by yeast.

### **Ultrasound**

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

### **Yeast**

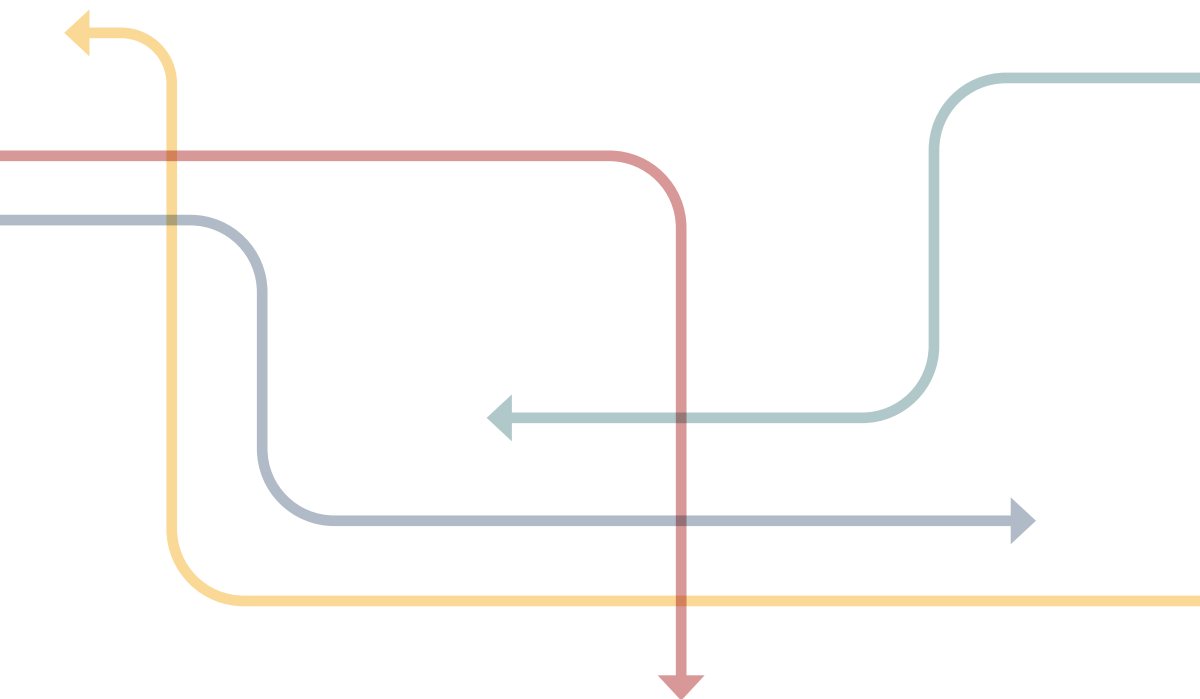
A common type of fungus. Yeast can be harmless and even helpful, like baker's yeast. But yeast can also cause infections. Some of these infections are not serious. But in people who are sick or have a weakened immune system, the yeast *Candida* can cause a serious infection (IFI).







## Notes (cont.)



The material provided herein is for informational purposes only and is not intended to diagnose, treat, or prevent any disease or condition. Nothing herein should be construed as medical, legal, or professional advice or opinion. This resource is intended to provide education on invasive fungal infections. This information is provided for educational purposes only and should not replace discussions with a healthcare professional or serve as a substitute for sound clinical judgment.

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