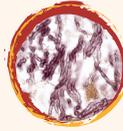




My IFI Journey Navigator

A helpful resource to guide your transitions of care



*my*IFI
UNDERSTANDING
invasive fungal infection

Dear patients and caregivers:

The My IFI Journey Navigator is an easy-to-use resource highlighting information that may be helpful to know as a patient or caregiver. 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 help you 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 caring for you or a loved one.

A note to health care professionals:

If your patient or their 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 transitions of care.



Douglas Brust, MD, PhD
Infectious Diseases Specialist
Fort Myers, FL



Nancy Skinner, RN-BC,
CCM, ACM-RN, CMCN
Principal Consultant
Riverside HealthCare Consulting
Whitwell, TN

My name: _____

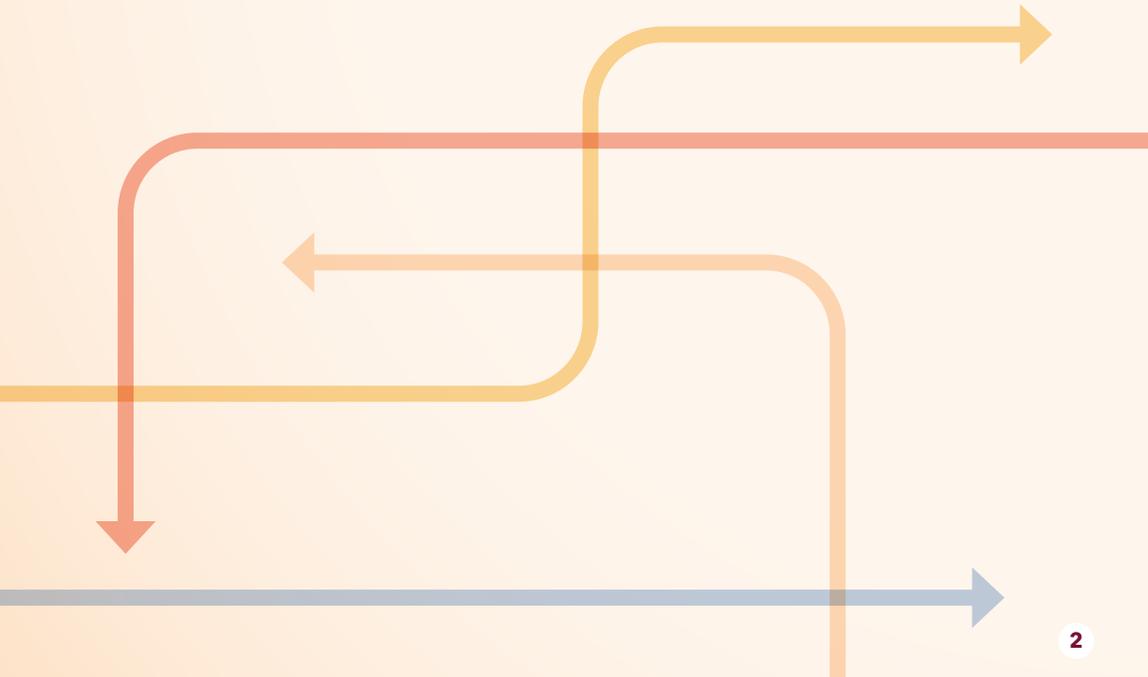
My emergency contact(s): _____



My IFI Journey Navigator

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Invasive fungal infection (IFI): The basics

Before you start on your journey, it's important to consider the conditions that led you here today. Once you have a handle on your immediate environment, you can be better prepared for the road ahead. For example, if you are about to drive through snow, you will take certain precautions and safety measures, right? Think of understanding your IFI as another environmental factor to consider.

What is IFI?

- IFI is a type of infection where a fungus spreads inside the blood or to body organs, causing potentially serious illness. Although IFI is rare, some people may be at high risk.
- IFI is more likely to affect people who are already sick or have a weak immune system.
- Many types of fungi can infect the body. Two of the most common are *Aspergillus* (mold) and *Candida* (yeast).

Why does IFI happen?

- Although fungi are all around you, most people do not get sick from them. This is because of the immune system.
- The immune system stops the fungi from causing illness. People who are already sick or taking certain medicines can have weak immune systems. When this happens, the body has a harder time fighting the fungi.
- The fungi may enter the body through cuts in the skin. You may breathe fungi into your lungs. Or fungi may enter your bloodstream.
- People who are at greater risk of IFI include those:
 - With certain blood cancers, such as leukemia, lymphoma, or myeloma
 - With human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS)
 - Who have had a stem cell transplant
 - Who have had an organ transplant
 - Who are taking some kinds of medicines, such as certain cancer medicines or steroid medicines
 - Who have an existing viral infection
- Having diabetes or extensive burns also can put you at risk for some types of IFI.

How might IFI affect me?

- If you are already sick, having an IFI can make it harder to fight your other illness. And if your immune system is weak, this fight can be even harder. Your doctors may treat both illnesses at the same time. Sometimes when a person gets an IFI, doctors may stop treatments that affect the immune system.
- IFI can be very dangerous. But with the right treatment, many people can recover.
- If a family member is helping you with your care, they can help you deal with IFI. If you are out of the hospital and taking medicine, be sure to take it as prescribed. Your family may be able to help you do this.
- Your IFI is not likely to spread to others. Some fungi can live on the skin and might spread to other people and possibly cause an infection if they are at high risk.

How is IFI diagnosed?

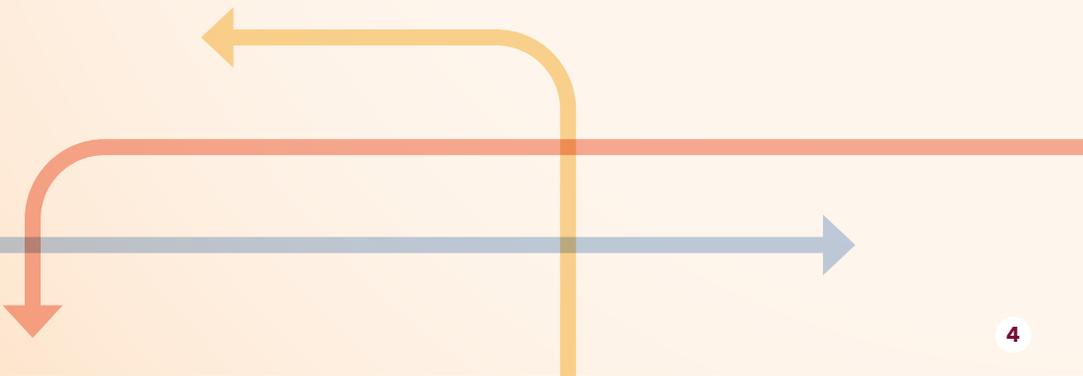
- The first signs of IFI are often fever and changes in your blood work. But these signs also could be due to a bacterial or viral infection.
- Your health care team may take a sample of blood, other body fluid, or tissue. These samples go to a lab, where testing is done.
- The team also may look at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

How is IFI treated?

- You 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 their IFI.
- Your immune system may be weak. If so, your doctor may give you medicine to help make it stronger. The goal is to help your body fight off IFI.

Who will treat my IFI?

- You may already have a few doctors caring for you. One of these doctors may focus on infections. This doctor is called an infectious diseases physician or an ID physician for short. They may lead your health care team to treat the IFI.





What are *transitions of care*?

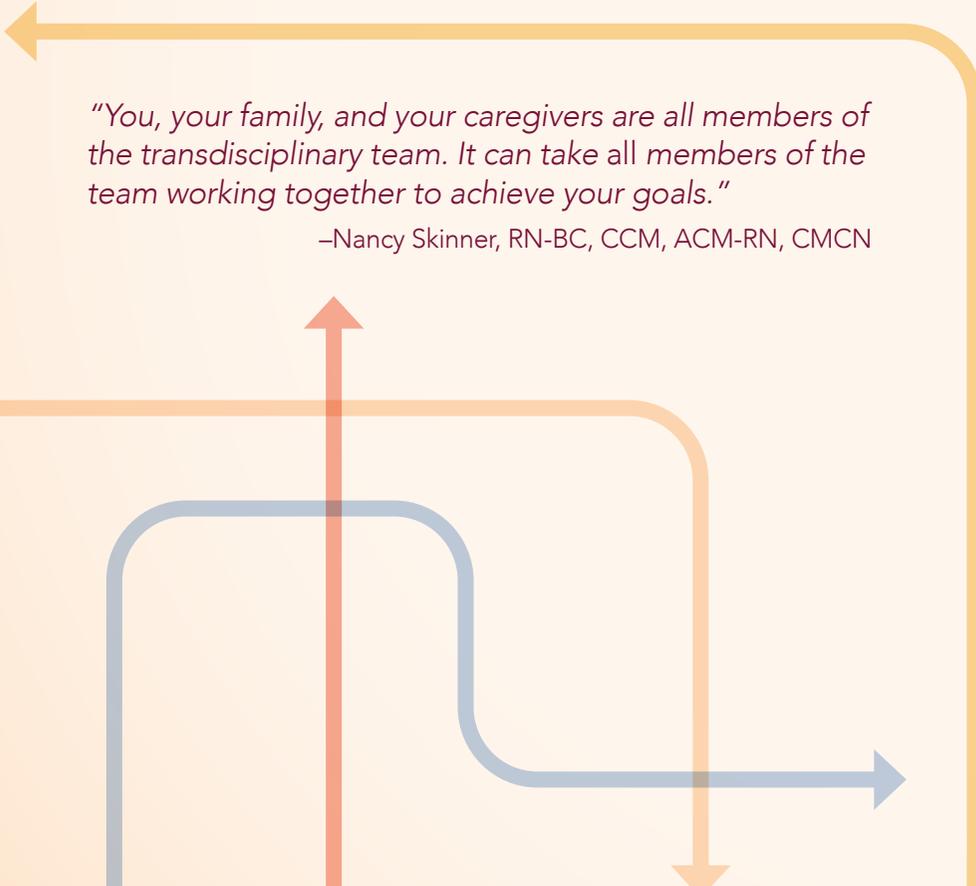
Transitions of care are defined as the movement of patients between health care locations, providers, or different levels of care within the same location as their conditions and care needs change.

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



Potential members of my health care team

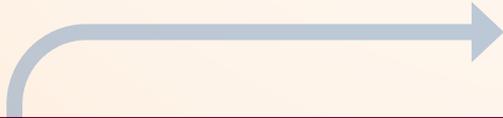
The primary member of the care team is *you*! Of course, it is also important to know each health care provider's role, and how that role can change over time. Ideally, you will find support (aside from that of your caregiver[s] and family members) with a **physician champion**—your health care copilot. 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 on your health care journey.



"You, your family, and your caregivers are all members of the transdisciplinary team. It can take all members of the team working together to achieve your goals."

—Nancy Skinner, RN-BC, CCM, ACM-RN, CMCN

Team Member and Role	My Health Care Team
<p>Physician Champion: The main physician who directs your care.</p>	<p>This is also my _____ physician (e.g., primary care physician, infectious diseases physician, oncologist)</p> <p>Contact information (for inpatient and/or outpatient settings):</p> <p>_____</p> <p>_____</p> <p>Notes: _____</p> <p>_____</p> <p>_____</p>
<p>Infectious Diseases Physician: Diagnoses and treats infections, such as your fungal infection. Frequently involved with prescribing your antifungal medication both in the hospital and at discharge. This doctor should be able to answer your questions about your fungal infection and antifungal medication.</p>	<p>Contact information (for inpatient and/or outpatient settings):</p> <p>_____</p> <p>_____</p> <p>Notes: _____</p> <p>_____</p> <p>_____</p>
<p>Specialist Physician (e.g., Transplant, Oncology): Treats specific medical conditions you are living with, both short and long term. The type of specialists you see will depend on your health history. These specialists should be made aware of changes in your health and medications, such as your IFI.</p>	<p>Contact information (for inpatient and/or outpatient settings):</p> <p>_____</p> <p>_____</p> <p>Notes: _____</p> <p>_____</p> <p>_____</p>
<p>Specialist Physician (e.g., Transplant, Oncology): Treats specific medical conditions you are living with, both short and long term. The type of specialists you see will depend on your health history. These specialists should be made aware of changes in your health and medications, such as your IFI.</p>	<p>Contact information (for inpatient and/or outpatient settings):</p> <p>_____</p> <p>_____</p> <p>Notes: _____</p> <p>_____</p> <p>_____</p>



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



Team Member and Role	My Health Care Team
<p>Hospitalist: You may be assigned a hospitalist during your stay. This physician provides general medical care and may coordinate specialist care while you are in the hospital.</p>	<p>Contact information (<i>for inpatient and/or outpatient settings</i>):</p> <p>_____</p> <p>_____</p> <p>Notes: _____</p> <p>_____</p>
<p>Community Providers (e.g., MD/PA/NP): These are the doctors, physician assistants, and nurses that provide your medical care when you are at home. You will want to make sure these providers know about your hospitalization and any medication changes you had at discharge.</p>	<p>Contact information (<i>for inpatient and/or outpatient settings</i>):</p> <p>_____</p> <p>_____</p> <p>Notes: _____</p> <p>_____</p>
<p>Other Providers: There may be other members of your 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.</p>	<p>Contact information (<i>for inpatient and/or outpatient settings</i>):</p> <p>_____</p> <p>_____</p> <p>Notes: _____</p> <p>_____</p>
<p>Other Providers: There may be other members of your 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.</p>	<p>Contact information (<i>for inpatient and/or outpatient settings</i>):</p> <p>_____</p> <p>_____</p> <p>Notes: _____</p> <p>_____</p>
<p>Other Providers: There may be other members of your 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.</p>	<p>Contact information (<i>for inpatient and/or outpatient settings</i>):</p> <p>_____</p> <p>_____</p> <p>Notes: _____</p> <p>_____</p>



Possible transitions of care roadmap

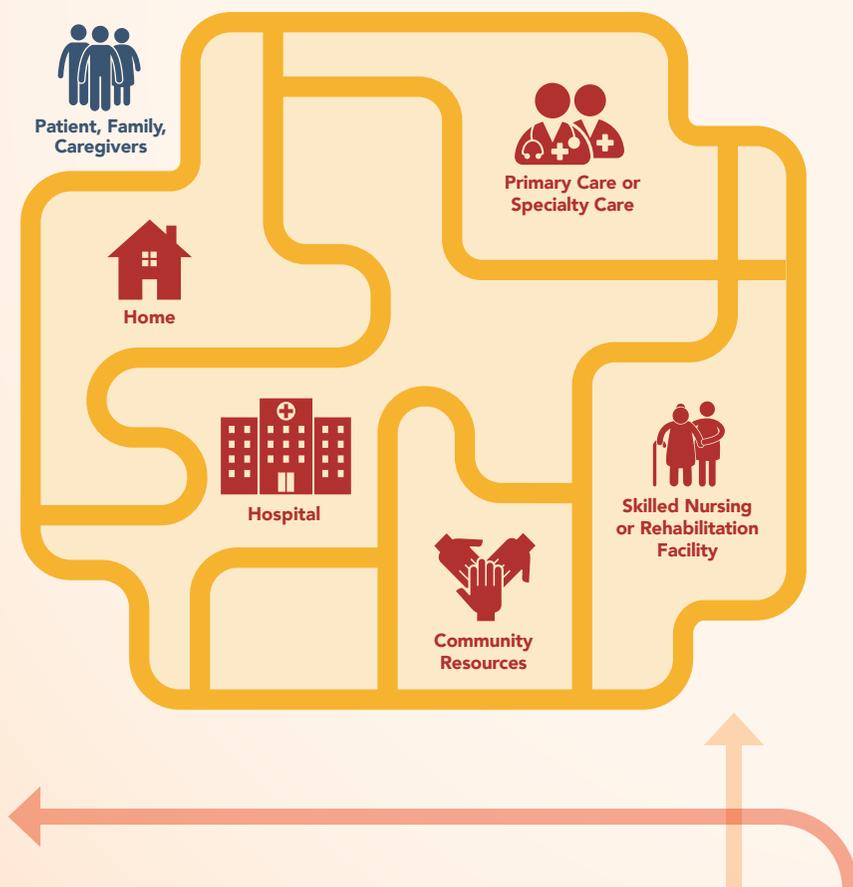
“The hardest transition of care is traditionally from the hospital to the first subspecialist visit because someone needs to own the coordination of care.”

—Douglas Brust, MD, PhD

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

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

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

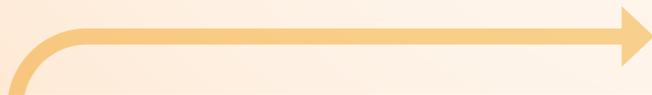




Key questions to consider posing to health care team members

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 am I going next?	Case manager, nurse, hospitalist	
What is my diagnosis?	Hospitalist, specialist	
Will my physician champion know about this diagnosis? Should I tell them?	Hospitalist, specialist	
Will my medicine change?	Infectious diseases physician, pharmacist	
Is my medication available today?	Case manager, pharmacist	
What if I need help at home?	Case manager	
Which doctor should I see after I go home?	Case manager, hospitalist, specialists	
When are my appointments scheduled?	Case manager, hospitalist, specialists	
What does my insurance cover?	Case manager, insurance provider	
What are my out-of-pocket costs?	Case manager, insurance provider	
What if I need help paying for my care?	Case manager	
Will a case manager or social worker be available to assist me after discharge? (i.e., financial challenges?)	Case manager	
How can I keep myself safe?	Case manager	



“You can’t be successful in your health care journey unless you know the specific steps that effectively address your illness. Knowing what you need to do to treat or prevent an IFI are essential elements of your path to wellness.”

– Nancy Skinner, RN-BC, CCM, ACM-RN, CMCN

General questions about your antifungal treatment	Which health care provider should you consider asking?	Notes/responses
How do I use it?	Infectious diseases physician, pharmacist	
How long do I use it for?	Infectious diseases physician, pharmacist	
What are the side effects?	Infectious diseases physician, pharmacist	
Are there any drug-drug interactions?	Infectious diseases physician, pharmacist	
Will it interact with any supplements I take?	Infectious diseases physician, pharmacist	
Will it interact with any food I eat?	Infectious diseases physician, pharmacist	
Will it interact with any over-the-counter medications?	Infectious diseases physician, pharmacist	
Will it interact with any holistic medicines I take? (e.g., CBD)	Infectious diseases physician, pharmacist	
What happens if I miss a dose?	Infectious diseases physician, pharmacist	

“IFI is a serious disease that can be managed with proper treatment. For successful therapy, it is vital that you understand your antifungal medication: How do I take it? For how long? Does it interact with any of my medications? What are the side effects?”

– Douglas Brust, MD, PhD



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 or case manager about this. You could also search the internet for the medicine or the drug company, along with the word “assistance” or “support.”



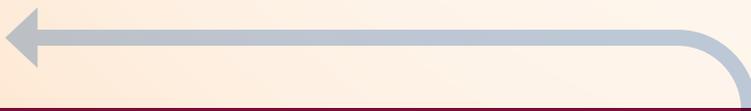
Commit to taking medicine as prescribed

Taking your medicine as prescribed by your health care provider—sometimes called treatment adherence—is an important part of your health care journey, and obstacles to taking your medicine may arise. Be honest with yourself as you describe any challenges to taking your medication correctly. Share this with anyone on your health care team—but especially your physician champion—so you can work on solutions together.

“I encourage patients to report any challenges (social, financial, geographic) that might prevent you from taking medications as prescribed.”

– Nancy Skinner, RN-BC, CCM, ACM-RN, CMCN

Challenges	Solutions
(example) Sometimes I forget to take my medications.	Set an alarm on my phone.

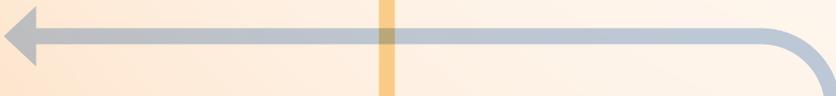




My medication tracker

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

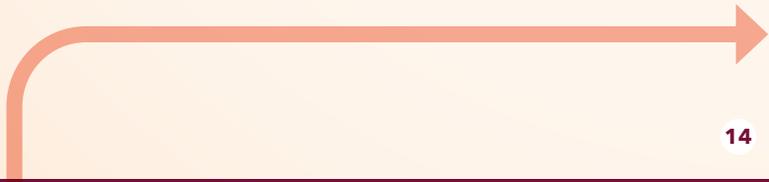
Other medications		
	Generic name Brand name	Generic name Brand name
Medication	(example) Generic statin STATIN® XX mg	
Dose and Administration	One tablet once daily with food	
Prescriber		
Notes	Pink oval pill	
Medication		
Dose and Administration		
Prescriber		
Notes		





Other medications (cont.)		
	Generic name Brand name	Generic name Brand name
Medication		
Dose and Administration		
Prescriber		
Notes		
Medication		
Dose and Administration		
Prescriber		
Notes		

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





When to call the doctor immediately

Call [insert name of health care provider] right away if you experience any of the following, as they may be signs of worsening infection:

- 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
- Sore or a white coating in your mouth or on your tongue
- Swelling or redness, especially where a catheter enters your body
- Urine that is bloody or cloudy, or pain when you urinate
- Any other signs of infection



Additional resources

Centers for Disease Control and Prevention: Fungal Diseases

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

<https://www.cdc.gov/fungal/>

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>

My IFI Website

Access to downloadable resources to support patients and their caregivers as they navigate invasive fungal infection

<http://www.myifiweb.com/>

My IFI Mobile App

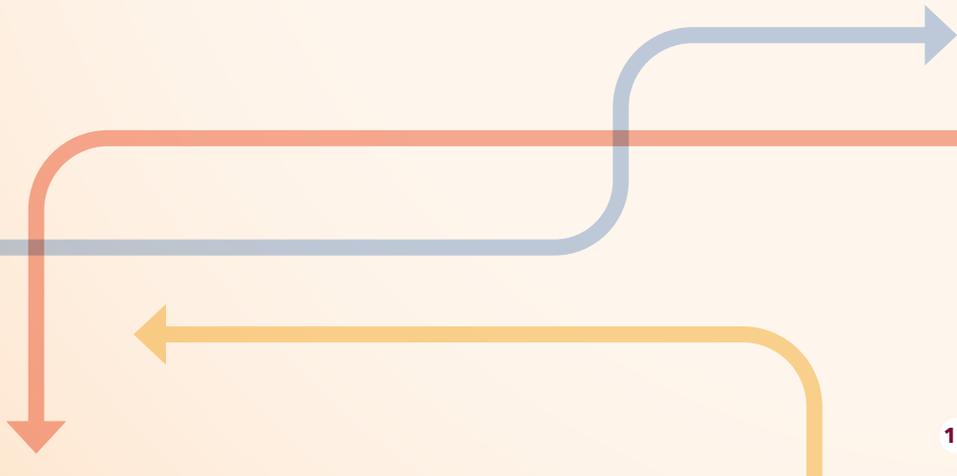
A mobile app with useful information on invasive fungal infection for patients and their caregivers

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

National Library of Medicine: Fungal Infections

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

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





Terms to know

Here are some terms you might hear when discussing your care with your 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 weak immune system. It is a common type of fungi that causes invasive fungal infections.

Candida

A yeast that can infect the bloodstream or body organs in people with a weak immune system. It is a common type of fungi that causes invasive fungal infections.

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.

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.



Terms to know (cont.)

Drug interactions

Negative or positive 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 weak 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 or to see if a treatment is working.

Infectious diseases (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*.

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.



Terms to know (cont.)

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 weak immune system.

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 tablet or capsule. Some people who need antifungal medicine are able to take it in pill 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.

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.

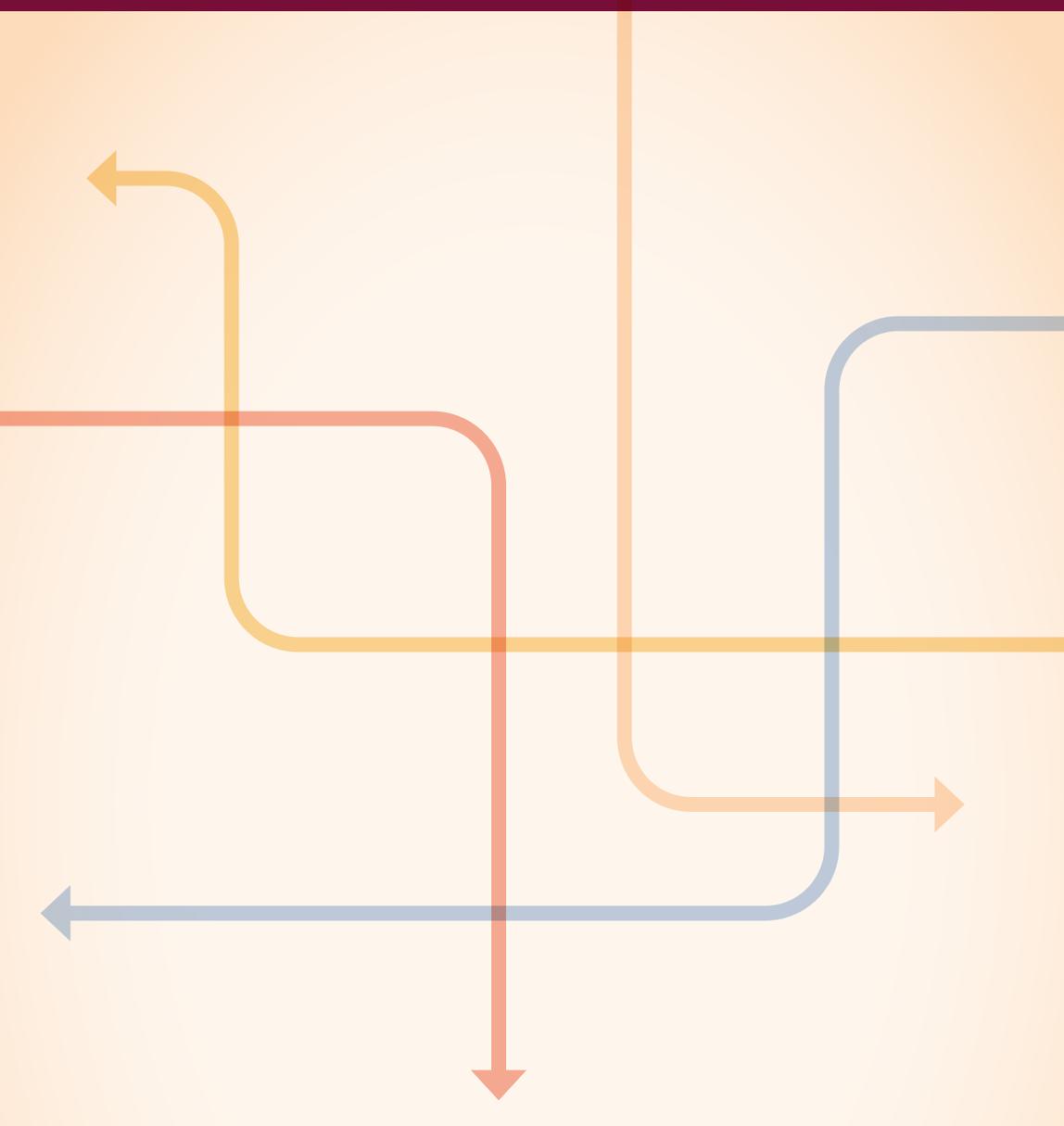
Spores

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 weak immune system.

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 weak immune system, the yeast *Candida* can cause a serious infection (IFI).





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.

This material was developed and sponsored by Astellas Pharma US, Inc.

Dr Douglas Brust and Nancy Skinner received a fee for their contributions to this material.

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