

PCP PREVENTION

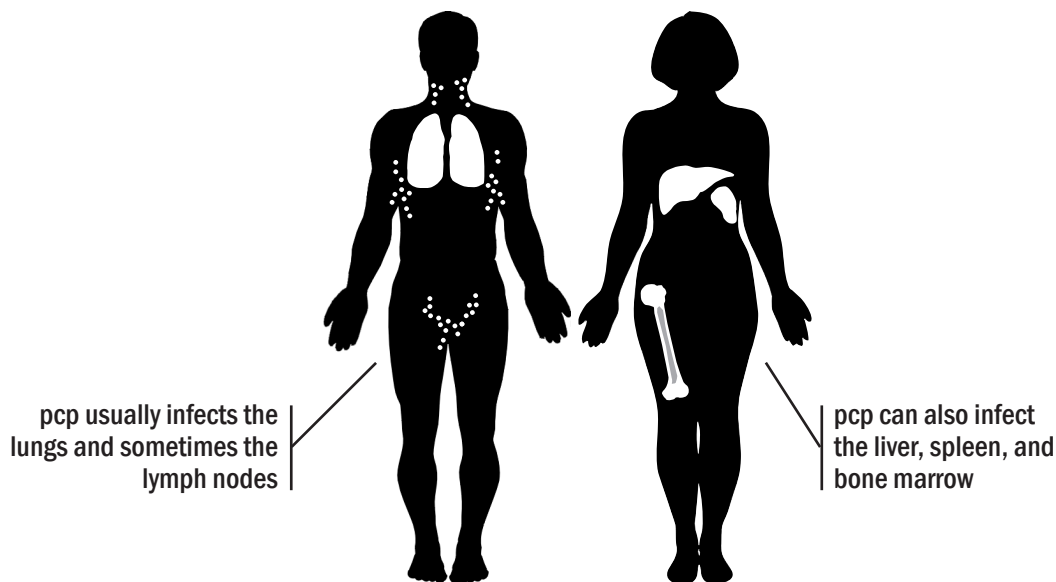


ways to prevent the common
infection called p.c.p.

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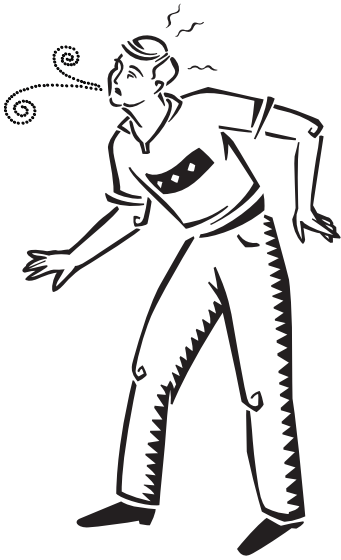


PCP has long been the most common severe illness among people living with HIV in the US. Though it is very preventable, it remains a leading cause of death among people with AIDS. PCP stands for Pneumocystis (NEW-moe-SISS-tiss) pneumonia. It is caused by a yeast-like fungus called *P. jiroveci*. People with healthy immune systems normally do not get PCP.

The main place that pneumocystis infection develops is in the lungs, where inflammation occurs and fluid builds up. This fluid buildup causes the pneumonia. Though it's rare, other parts of the body

can be affected, such as the lymph nodes, spleen, liver, bone marrow and skin. While it can be fatal, PCP can be prevented with regular therapy and several effective treatments are available for those who get the disease. PCP is an AIDS-defining illness, which means if you're HIV-positive and also have PCP then you will be diagnosed as living with AIDS.

This publication discusses ways to prevent PCP. For more information on how to diagnose and treat PCP, read Project Inform's publication, *PCP Treatment*, available at 1-800-822-7422 or www.projectinform.org.



How can I tell if I have PCP?

Most people have been exposed to the fungus that causes PCP. Most people's immune systems keep it in check, never allowing the fungus to take hold and cause disease. People are at higher risk for PCP when their immune systems are severely compromised, such as CD4 counts below 200–300.

As the infection develops, lung problems start to occur. Symptoms can worsen quickly or gradually over a period of weeks or months. Common symptoms are fever, cough, shortness of breath, weight loss or a general sense of illness. The cough usually does not produce mucus and for that reason it's called a dry cough. You may first notice some of these symptoms after exercise or other physical movement.

PCP is a serious illness. People with PCP may die if the infection is not treated promptly. Anyone who has these symptoms should report them to their doctors as soon as possible. Your doctor will diagnose for PCP based upon your symptoms and by using a chest x-ray, CT scan and blood oxygen tests or by taking a sample of fluid or tissue from the lungs.

Who is at risk of getting PCP?

You are at higher risk for getting PCP when your CD4 count goes below 200 or your CD4 percentage falls below 14%. If you have a slightly higher CD4 count (200–300) but have other symptoms of immune suppression, such as repeated fungal infections (thrush, yeast, candidiasis), you are also considered at high risk for PCP. Most cases of PCP occur when the CD4 count falls below 100, including those that “break through” preventive therapy.

If you experience fungal infections, have recurrent fevers, or have had your spleen removed, you are at higher risk for PCP regardless of your CD4 count. Pregnant women can experience drops in CD4 counts during their third trimester. So, HIV-positive pregnant women sometimes may need medicine to prevent PCP during that time.

People who have had PCP before are also at higher risk of getting PCP again. If you smoke, you may develop PCP more quickly than non-smokers. Other factors that may increase your risk include having a history of lung problems or other types of pneumonia or if you take drugs that affect your immune system, such as corticosteroids or other immune suppressive therapies, such as those used in people who have undergone organ transplants.

How do I prevent myself getting PCP?

The PCP fungus is very common, but it has been difficult for scientists to identify it in the environment. Since it is difficult to prevent yourself from being exposed to PCP, the best ways to prevent it are by maintaining a healthy immune system, taking preventive medicine if you are at higher risk for PCP, and getting proper medical care.

The best way to prevent PCP is by using effective HIV therapy and maintaining your immune health. Keeping your CD4 count above 200 helps keep your immune system healthy. This, in turn, helps keep PCP from becoming a problem. If your immune system shows signs of being compromised, taking PCP preventive therapy is critical while you're at risk. If you smoke, quitting smoking may help you prevent PCP, likely by improving the health of your lungs and thus your ability to fight lung infections. Smokers who haven't smoked in a year or more do as well on PCP medicines as others who never smoked.

Common flu vaccinations will not prevent PCP. There is no vaccine for PCP.

your cd4 counts

When people living with HIV get their routine blood work done, a common lab value that doctors look at is CD4 count. This count is an important measure of the health of your immune system. CD4 counts are considered in the “normal” range when they're above 500. When they fall around 350, people are often encouraged to consider HIV therapy to prevent more damage to the immune system by HIV. When CD4 counts fall to 200 or a little higher, people are encouraged to start preventive therapy for PCP. For more information on monitoring your immune health, see Project Inform's publications titled *Day One, Blood Work: Two Common Tests to Use*, and *Strategies for Improving Your Immune System*.

concerns for pregnant women and children



Pregnant women

Women who are pregnant or thinking of becoming pregnant should follow the standard guidelines for PCP prevention and use preventive therapy if they are at risk. However, there are some concerns that most PCP preventive therapies may harm the developing child during the first three months of pregnancy. Ask your doctor about the best treatment for you.

Children

Early diagnosis and treatment of HIV in pregnant women can help prevent HIV and PCP in their children. Newborn children of mothers with HIV should start Bactrim/Septra (B/S) at age 4–6 weeks. (Babies don't usually get PCP until they are about 8 weeks old.) If HIV tests later show that the baby does not have HIV, then the B/S can be stopped. If the baby does have HIV, B/S should be continued until he or she reaches 1 year of age. After one year, the decision to stay on PCP preventive therapy is based on the child's CD4 count.



When should I start preventive treatment?

You should have your blood tested regularly to check the health of your immune system. (For more information, see Project Inform's publication, *Blood Work: Two Common Tests to Use*.) It's generally recommended to start PCP preventive therapy if your CD4 count falls below 200. If you show certain symptoms, such as a temperature above 100°F that lasts for two weeks or longer or a fungal infection in the mouth or throat (*thrush*) despite having higher CD4 counts, PCP preventive therapy is recommended. Having a fungal infection in this case is believed to raise your risk for getting PCP. This may also be true for HIV-positive women who experience repeated vaginal yeast infections.

Can I ever stop preventive therapy?

Yes, stopping preventive therapy seems to be okay if your blood tests show a certain level of health and you remain free of worrisome symptoms (like fevers, fungal infections, etc.). If your CD4 count goes above 200 and stays there for three months, it may be safe to stop taking PCP medicine if you're otherwise free of symptoms. However, some researchers suggest that six months is a safer length of time or that a CD4 count above 300 is a safer level for when to stop. Discuss the pros and cons of stopping with your doctor and devise a plan for safely stopping therapy if you feel this might be right for you.

If a person develops PCP when his or her CD4 count is above 200, then it's recommended that PCP prevention be given for life. PCP prevention should be started whenever your CD4 count drops below 200, CD4 percentage drops below 14%, or there's evidence of persistent fungal infections and/or fever. If you have stopped using PCP prevention before, restarting is necessary if these conditions return. There are no guidelines in place to recommend if or when children can safely stop their PCP prevention therapy, but doctors will likely make recommendations based on a child's immune health.



what medicines are used to prevent PCP?

The most effective drug used to prevent PCP is the double antibiotic Bactrim/Septra (B/S, TMP/SMX, trimethoprim-sulfamethoxazole). Other drugs used include dapsone, Mepron (atovaquone), and NebuPent (aerosolized pentamidine).

When taking these medicines, it's important to take them as prescribed. Talk to your doctor first if you find it hard to stay on them as prescribed. Also, these drugs may interact with other medicines that you're taking. Make sure your doctor knows what other drugs you use when you start taking a new medicine. As with any medicine you take, reading its full prescription insert or talking to your doctor or pharmacist are good ways to know the possible drug interactions.

Bactrim/Septra (B/S)

B/S is an inexpensive and effective drug that prevents PCP and other types of pneumonia, bacterial infections and toxoplasmosis (toxo). Because Septra is a sulfa drug, about half of the people develop an allergic reaction to it. The main side effect is body rash. Other side effects can include, fever, nausea, vomiting, liver and kidney problems, high blood potassium level, sensitivity to sunlight (*photosensitivity*), low red blood cells (*anemia*), low white blood cells (*neutropenia*), or low platelets (*thrombocytopenia*).

In rare cases, rashes and other side effects may be the early warning signs of a life-threatening condition called *Stevens-Johnson Syndrome* (SJS). Symptoms can include severe blisters or splotching of the skin; blisters in the mouth, eyes, nose, and genital area; fever; and swelling of the eyelids. Although SJS is rare, people should alert their doctors at the first sign of these side effects.

Even if you have a mild reaction to B/S, your doctor may still want you to use it. This is because

it is such an effective drug for both preventing and treating PCP. For people who can be made to tolerate the therapy, they will have a very potent and important drug to use against their PCP. To do so, you will go through a process called desensitization. This involves taking B/S first at very small doses and then slowly increasing it until the proper dose is reached. Almost 70% of people who try this can use B/S without other major problems. Going through this process with an experienced doctor will help ensure its success.

B/S comes in a tablet and in a liquid form for younger children. The standard dose is a double-strength tablet of Bactrim 800mg/Septra 100mg given 1x/day. It may also be given three times a week, which causes fewer side effects. However, people who take it daily have lower rates of bacterial pneumonia and toxo and in general live longer.

B/S can interact with many drugs, including dapsone, diuretics, methotrexate, phenytoin, sulfonylureas, warfarin and HIV drugs.

dapsone

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Dapsone (with or without pyrimethamine) is another antibiotic pill. It isn't as effective as B/S, and it must be taken with pyrimethamine in order to prevent toxo. Its side effects include rash, nausea and sometimes hepatitis. Although dapsone may be a reasonable option for people who are allergic to B/S, about half may also be allergic to dapsone. The standard dose is prescribed as a 50mg pill 2x/day or a 100mg pill 1x/day.

Dapsone can interact with many drugs, including clofazimine, dideoxyinosine, folic acid antagonists, probenecid, rifampin, trimethoprim and HIV drugs. Many patients who take dapsone should be screened for a G6P enzyme (glucose-6-phosphate) deficiency.

Mepron (atovaquone)

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Mepron is as effective as dapsone in preventing PCP. It has fewer and different side effects than dapsone (mostly stomach problems), but it's more expensive. Mepron is probably active against toxo but not bacterial pneumonia. The standard dose is prescribed as an oral suspension of 1,500mg per day, taken with a fatty meal to help it get absorbed. Because of cost, it's usually only considered for people who cannot tolerate B/S and/or dapsone, or for those who are believed to not tolerate these other drugs well.

Mepron can interact with many drugs, including Bactrim/Septa, rifabutin, rifampin and HIV drugs.

NebuPent (aerosolized pentamidine)

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NebuPent is the least often used treatment. It involves breathing a fine mist of the drug into the lungs through a machine called a *nebulizer* on a monthly basis. Although it has not proven to be as effective as B/S, it's a reasonable option for people who cannot tolerate either B/S or dapsone.

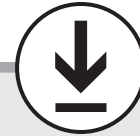
The main advantage of NebuPent is that it causes few side effects and does not have to be used daily. The main side effect, a metallic taste in the mouth, usually disappears soon afterwards. It can also cause dry throat, headache and coughing fits, especially for smokers. The main disadvantage is that people who take NebuPent get PCP more often than those who take antibiotics.

Because NebuPent is concentrated in the lungs, it's not effective in preventing PCP in other parts of the body. It is also not as effective as B/S in preventing other bacterial pneumonias or toxo. This, coupled with its inferiority in preventing PCP, are the main disadvantages of using it.

Most people taking NebuPent go into a clinic every 4 weeks for treatment. The standard dose is 300mg. A Respigard II™ nebulizer should be used for taking the dose because it increases how well the drug is absorbed. Pentamidine can interact with many drugs, including cidofovir, foscarnet, certain heart drugs and HIV drugs.

How do I get the medicines to prevent PCP?

The medicines used to prevent PCP disease are available by prescription through a health provider. Most states also cover these drugs through their AIDS Drug Assistance Programs (ADAP). To check to see if you're eligible for your state's ADAP and to find out if these therapies are covered by it, contact your state department of public health, your state Office of AIDS, or your state ADAP. Information is also available through the AIDS Treatment Data Network at 1-800-734-7104, or visit www.atdn.org and click on "Access Project". People who lack insurance, Medicaid, ADAP coverage and can't otherwise afford the drugs can sometimes gain access to them through the manufacturers' Patient Assistance Programs.



the bottom line on p.c.p. prevention

- › You can prevent getting PCP. The best way to prevent it is by keeping your CD4 count above 200.
- › If you develop the disease, you may not feel symptoms at first. Most people will feel dry cough, fever, trouble breathing, weight loss or a general sense of illness. Report these symptoms to your doctor immediately.
- › Your doctor will start you on preventive PCP medicine if your CD4 count falls below 200, your CD4 percentage falls below 14%, or if you have a fungal infection, recurrent fevers or have had your spleen removed.
- › Four drugs are used to prevent PCP: Bactrim/Septra, dapsone, Mepron, NebuPent. Your doctor can work with you about which drug is the best option for you, depending upon your tolerance for side effects, cost and other health issues.
- › Pregnant women and children may have special concerns when taking PCP medicines.
- › Medicines used to prevent PCP should be taken as long as you are at risk for PCP. If your CD4 count goes above 200 and stays there for three or more months and you are not having other symptoms of concern, you may be able to safely stop taking preventive PCP therapy.

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