

I am at risk of losing my foot or leg unless I have surgery: What type of surgery should I choose?

#### 1. Get The Facts

- Many patients have wounds or infections in part of their foot or leg from illness or injury. Some wounds or infections in the foot and lower leg are so severe that they can damage the foot or leg enough that it is no longer usable. Some can even be life-threatening. If that happens, patients need surgery.
- Some patients want to do anything possible to try to keep their foot or leg. Other patients choose to have an amputation (a surgery to remove the foot or leg).
- This decision aid can help you learn more about your surgery choices so you and your care team can talk about which surgery choice might be right for you.

# There are two main surgery options if you have a severe wound or infection in your foot or leg:

- Amputation surgery
- Limb preservation surgery.

# Why might a surgeon recommend an amputation or a limb preservation surgery?

- A surgeon might recommend <u>amputation</u> when the cause of a severe wound cannot be fixed. If a patient's bones are pushing through the skin, or if the arteries are blocked and can't be repaired, then an amputation could be the only choice.
- A surgeon might recommend <u>limb preservation surgery</u> when they think they can fix the cause of the wound.
- When there are choices, a surgeon's job is to help patients choose the option that will lead to the best function and quality of life. Surgeons think about each patient's ability to walk or be as mobile as possible, including with an artificial leg or special shoe. Surgeons also think about whether they are able to fix the wound and how likely the wound is to come back.
- Surgeons want to support patients' ability to continue living their lives. They want to help patients avoid a constant battle wounds and infections. At the end of the day, each patient's needs and goals are the most important factors guiding the choice.

#### Overall, the success of each surgery depends on:

- How many other medical problems the patient has
- How severe the wound is
- Whether there are blocked arteries in the leg, and how badly they are blocked
- Whether there is infection in the bone, and how bad it is
- Whether the bones in the foot are normal or are out of position
- How skilled the surgeon is at this type of surgery
- How well you follow your post-op care plan
- How well you protect your foot from new wounds

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### **Common Patient Questions About This Choice:**

Patient Question	Amputation	Limb Preservation
1. What is the surgery?	Amputation means taking off part of the foot or leg, to remove the source of the problem.	Limb preservation surgery means surgery to heal the wound or infection, and save the leg or foot. This usually means using "flaps" or "grafts," which we will talk more about below.
2. What are the main things to know about each surgery?	<ul> <li>Removes the part of the body affected by the wound or infection</li> <li>Cannot be reversed</li> <li>Only requires one surgery</li> <li>Many patients can still walk after amputation by using an artificial leg or special shoe</li> <li>Sometimes amputation is the only way to save a person's life from the infection</li> </ul>	<ul> <li>Limb preservation surgery can mean a lot of different things and is specific to each patient         ⇒ Some patients need simple surgeries         ⇒ Some patients need very complex surgeries         ⇒ Most patients need more than one surgery     </li> <li>Some patients can walk just as well as before, but others have a harder time walking</li> <li>Recovery can be difficult and less clear compared to amputation, but it might avoid the need to remove part of the body</li> </ul>

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### **Common Patient Questions About This Choice:**

Patient Question	Amputation	Limb Preservation
3. How good is it at fixing wounds?	<ul> <li>Amputation is the clearest way to solve the wound or infection with the foot or leg</li> <li>It is possible to have problems after an amputation depending on how much of the limb is removed</li> <li>If the surgery goes higher up to remove more of the leg, wounds are a lot less likely to come back. But, it might be harder to walk and use the leg if more is removed.</li> </ul>	<ul> <li>Limb preservation surgeries allow patients to keep the leg/foot by covering up the wound with new skin</li> <li>Limb preservation can sometimes fix a wound completely, but it depends on each specific patient         <ul> <li>Many different things can cause a limb-threatening wound, so these wounds need to be treated in different ways</li> <li>Some wounds have caused so much damage, they can't be fixed – discuss with your doctor whether this is the case for you.</li> </ul> </li> <li>If limb preservation surgery works perfectly, there is a chance the foot or leg can go back nearly to normal         <ul> <li>The chance of success can vary greatly depending on specifics of your health</li> <li>Ask your doctor about your personal chance of success</li> </ul> </li> </ul>
4. How painful is it?	<ul> <li>Amputation is a major surgery that can be painful</li> <li>The care team helps with pain by treating the nerves of the leg with numbing medication before surgery.</li> <li>There are people at the hospital who help patients with pain after surgery</li> <li>There is no way to completely avoid pain after this surgery</li> </ul>	Limb preservation surgery can cause very little pain or a lot of pain depending on the patient and type of surgery      ⇒ Pain can usually be managed with pain medications      ⇒ There are people at the hospital who help patients with pain after surgery

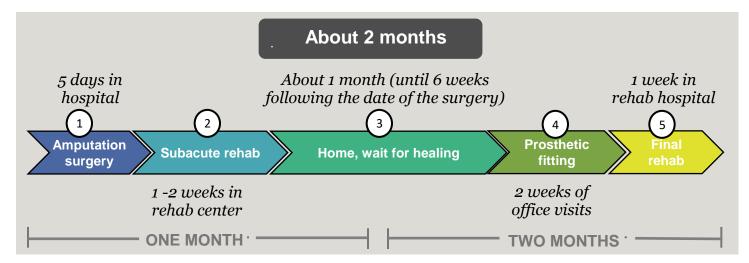


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### What is the process like after each surgery?

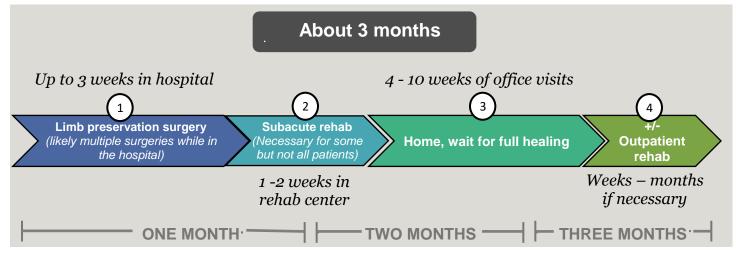
#### **Amputation Timeline**

In the best-case scenario, amputation is about a 2-month process to get back to walking. Stitches are removed in 3 weeks. The surgery site is healed at 6 weeks and ready to be fit for an artificial limb (prosthetic). Fitting takes about 2 weeks, and then you start to practice walking. The timeline below is the ideal timeline. However, for many patients the timeline is closer to 3 months. If the amputation has difficult healing (a common risk of surgery), the timeline may be longer.



#### <u>Limb Preservation Surgery Timeline</u>

Limb preservation surgery is highly specific to each patient. *Patients who are otherwise healthy may be completely recovered in 6 weeks*. However, patients who have medical conditions such as diabetes, peripheral vascular disease, and kidney disease often have a longer time to heal and need rehabilitation to recover their strength. Patients with medical conditions like these can expect about a 3-month total healing period before getting back to full use of the leg. Because limb preservation surgery is so unique to each patient, you will need to talk to your doctor to get an estimate of your personal timeline.





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### What do the numbers tell us about each surgery?

• Keep in mind that different sources give different statistics, and these may change over time. Not all statistics will exactly match your case, because people in the studies we quote may have different diseases than you. Below are the numbers we could find that agree fairly closely with what we observe.

### Here are some numbers we do know about limb preservation:

Limb preservation surgery is highly specific to each patient. Numbers and statistics are difficult to state, but your surgeon can talk to you about your chance of success. If everything goes well, the number to think about is the chance of the wound coming back.

- The more you take care of your foot or leg, the less likely the wound is to come back
- Limb preservation does not fix the cause of the wound (like diabetes) it only fixes the wound
- A key factor for successful limb preservation usually comes down to how involved the patient is in caring for the limb after surgery.
- Although there is less research about limb preservation with flaps and grafts, several sources report that 92% have success with surgery and up to 84% are able to keep their limb.<sup>1</sup>
- However, up to 22% of patients who have limb preservation surgery still go on to have an amputation in the future. This risk is higher in patients with kidney failure, uncontrolled diabetes (hemoglobin A1C > 8.4%), with heal wounds, and with severe infections.<sup>2</sup>
- Keep in mind that the success of surgery and limb preservation can be lower in some patients depending on specifics of their health. Your doctor can tell you about your chance of success.
- Some experts report that up to 93% survive 2 years after surgery and up to 86% survive 5 years after surgery when limb preservation is successful.<sup>3</sup> Other authors report lower survival rates, but still show that more people survive after limb preservation compared to amputation.<sup>4</sup>
- In patients with peripheral vascular disease (disease of the arteries in the leg), surgery can still be successful, but there is a higher chance of complications, such as slower wound healing. It can take 2-3 months longer to recover if you have a complication.<sup>5</sup>
- Between 85 92% of patients who could walk before surgery were able to walk after healing from surgery.

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### Here are some numbers we do know about amputations:

With amputation, some patients do very well, but many have problems after surgery. Some of this is from the surgery itself, and some of this depends on the patient's health before surgery.

- More than 60% of major amputations are due to diabetes and peripheral vascular disease. 6
- Although it is impossible to know exact numbers, several sources state that if a patient has diabetes and has any level of amputation, approximately 86 % are alive at 1 year, and 40% are alive at 5 years after surgery.
- If a person with diabetes has a major amputation (removing the entire foot or higher up in the leg), between 50 90% are alive at one year and between 20 70% are alive within 5 years after surgery.<sup>8-10</sup>
- o If a patient is also on dialysis from kidney failure, 26% are alive 2 years after surgery.8
- If you keep more of your foot or limb, you have a higher chance of surviving.9
- 65-76% of patients will go to a rehab center, not right home, after the hospital stay. 11,12
- Amputation can take a long time to heal—even months.
  - $\circ$   $\;$  Up to 30% of patients who have below the knee amputation cannot walk after it.
  - $\circ$  Up to 64% of patients who have above knee amputation cannot walk after it.
  - Up to 87% of patients will not be able to walk if both legs undergo amputation.
- The ability to walk after surgery can depend on patients' health and how well they walked before surgery. It can also depend on the quality of the surgery. <sup>15</sup>
- The risk of needing a second amputation goes up a lot after having one.
- If you already had any type of amputation (including toes or partial foot), the risk of having a second amputation of any type is: 20% within 1 year, and around 40% within 5 years. <sup>7,16</sup>
- If you have had any type of amputation (including toes or partial foot), the risk of going on to have a major amputation (below the knee or above the knee) is: 9% at 1 year, 13% at 3 years, and 23% at 5 years. <sup>9,16</sup>
- If you have had a major amputation, the risk of having a second amputation on that limb is up to: 4.7% at 1 year, 12% at 3 years, and 13.3% at 5 years.<sup>17</sup>
- If you have had a major amputation, the risk of having a major amputation of the other leg is between : 6-12% at 1 year, and 12-53% at 5 years. 17,18
- People who have had an amputation say that they have a lower quality of life because of the physical and mental burden. This is especially true for those who are unable to walk, unemployed, in chronic pain, or have severe medical problems.<sup>19</sup>

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### 2. Compare Your Options

Compare your options		
	Amputation Surgery	Limb Preservation Surgery
1. What happens during and after surgery?	<ul> <li>Part of your limb will be removed</li> <li>You will stay in the hospital for up to 5 days.</li> <li>You will go to rehab for 1-2 weeks after the hospital, to learn how to transfer yourself safely without falling</li> <li>You will not be able to put any weight or pressure on the limb for 6 weeks</li> <li>Stitches are removed at 3 weeks</li> <li>You will wear a "shrinker" sock on the limb to reduce swelling</li> <li>At 6 weeks after surgery, the limb is often healed enough to be fit for a prosthetic (artificial leg or foot)</li> <li>Once you get your prosthetic, you might or might not need more rehab.</li> </ul>	<ul> <li>You will have surgery to try to heal the wound and keep your limb</li> <li>You will likely have a flap or graft surgery (see graphic)</li> <li>You may have a simple outpatient surgery (go home the same day), or may be in the hospital for up to 3 weeks, depending on the type of surgery needed.</li> <li>You often need more than one surgery</li> <li>The limb is often healed between 6 weeks - 3 months after surgery.</li> <li>Your time to heal and outcome depend on how closely you follow your post-op care plan.</li> </ul>
2. What are the benefits?	<ul> <li>Amputation removes the body part that has the wound, so that the wound will not come back.</li> <li>If a foot or leg is "dragging you down" because of wounds or infections that keep coming back, or if blocked arteries mean there is no way to keep it alive, then amputation can improve your quality of life by removing the "problem foot."</li> <li>It is often just one surgery.</li> <li>The outcome of an amputation is "known" in many ways.</li> </ul>	<ul> <li>Limb preservation surgery means you get to keep as much of your foot or leg as possible.</li> <li>It keeps all future options open, even if the surgery does not work at first.</li> <li>It gets you back as close to "normal" as possible, if it works.</li> <li>You can avoid some of the potential long term problems from amputation</li> </ul>

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### 2. Compare Your Options (Cont'd.)

Compare your options				
Amputation Surgery	Limb Preservation Surgery			
<ul> <li>All surgery has the risks of bleeding, infection, and wound healing problem higher risk than most surgeries for se bleeding.</li> <li>Depending on your overall health, the may be a risk of other serious complications, like needing to be in the ICU, having a heart attack, or rarely, (3-4% of patients)</li> <li>Other risks include:  ⇒ Risk of amputation not healing leading to long-term wound of another surgery, or more amputation higher up</li> <li>⇒ Risk of chronic pain or phant pain</li> <li>⇒ Risk of not being able to walk the amputated leg or foot</li> <li>⇒ Risk of long-term problems ling pain or back pain</li> <li>⇒ Risk of loss of some independence of the pain or back pain</li> <li>⇒ Risk of loss of some independence of life</li> <li>⇒ Risk of depression or lower quot life</li> <li>⇒ Risk of depression or lower quot life</li> </ul>	<ul> <li>All surgery has the risks of bleeding, infection, and wound healing problems.</li> <li>Depending on your overall health, there may be a risk of serious complications, like needing to be in the ICU care, having a heart attack, or rarely, death.</li> <li>Other risks include:</li> <li>⇒ The surgery does not work - for example, "the graft doesn't take." In that case, you are back to where you started and would need to decide on surgery.</li> <li>⇒ You might have a "donor site" from somewhere else on your body where the flap or graft was taken from. Donor site problems are not that common, but can include bleeding, infection, pain, and wound healing trouble. Even if the flap or graft doesn't take, the donor site risk is still there.</li> <li>⇒ Even if surgery goes as planned, there may be unanticipated problems with healing that could require other surgeries to fix, or weeks to months of wound care.</li> <li>⇒ Even if the surgery works perfectly, the wound could come back.</li> <li>⇒ It can mean up to 3 months of not walking which could weaken</li> </ul>			

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#### 3. How Do You Feel?

### What matters most to you?

Your personal feelings are just as important as the medical facts. Think about what matters most to you in this decision, and tell us how you feel about these statements. You can draw an "X" on the questions below to show what is important to you.

4	Reasons to choose amputation	Reasons to choose limb preservation
1	I want to get rid of my wound for good, with the smallest chance of getting a new wound	I can accept the risk of a wound coming back as long as I can fix the wound and keep my foot or leg
	+++	+ + ++
More 1	Important Equally Imp	portant More Important

	Reasons to choose amputation	Reasons to choose limb preservation
2	I can accept long term changes in how I walk and live if I can get rid of my wounds.	I would much rather live my life the way I have been with my foot or leg, even if it causes me some problems
-	+++	+ + ++
More 1	Important Equally Imp	portant More Important

	Reasons to choose amputation	Reasons to choose limb preservation
3	This foot is weighing me down and I am ready to get rid of it.	I am not ready to accept getting rid of my foot or leg, without at least trying to save my foot.
	+++	+
More 1	Important Equally Imp	portant More Important

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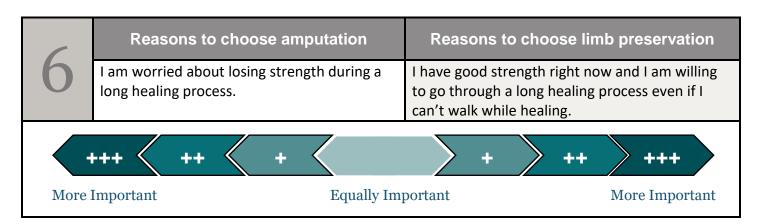
### 3. How Do You Feel? (Cont'd)

### What matters most to you?

Your personal feelings are just as important as the medical facts. Think about what matters most to you in this decision, and tell us how you feel about these statements. You can draw an "X" on the questions below to show what is important to you.

	Reasons to choose amputation	Reasons to choose limb preservation
4	I think I would be able to do more and walk better with an artificial leg than with my foot or leg that is causing me trouble right now.	Besides the wound, I function very well with my own foot or leg. I think amputation would make it much harder for me to get around.
•	+++	+ + + +++
More 1	Important Equally Imp	portant More Important

	Reasons to choose amputation	Reasons to choose limb preservation
5	I would rather have one surgery and "get it over with," even if it means a big adjustment for the rest of my life.	I am willing to have a hospital stay and more than one surgery if it means keeping my foot or leg.
•	+++	+ + ++
More l	Important Equally Imp	portant More Important



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### 3. How Do You Feel? (Cont'd)

### What matters most to you?

Your personal feelings are just as important as the medical facts. Think about what matters most to you in this decision, and tell us how you feel about these statements. You can draw an "X" on the questions below to show what is important to you.

	Reasons to choose amputation	Reasons to choose limb preservation
	I am not able to care for my foot enough to prevent future wounds	I can be careful to take care of my foot to prevent future wounds.
•	+++	+ + ++
More l	Important Equally Imp	portant More Important

	Reasons to choose amputation	Reasons to choose limb preservation
8	I am ready to deal with an artificial limb (prosthetic). I know I might need to adjust or replace my prosthetic for the rest of my life.	I am prepared to wear special shoes or braces if needed, and to potentially have regular care from a foot doctor for the rest of my life (especially if I have diabetes and the wound is on the foot)
	+++	+ +++
More	Important Equally Im	portant More Important

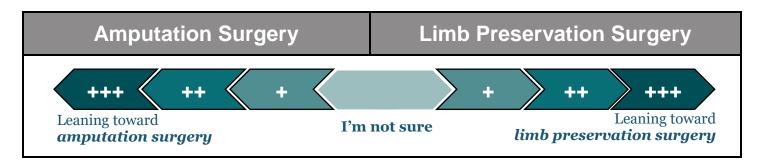


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### 4. What Do You Think About Your Options?

# Are you leaning toward one option now?

Now that you've thought about the facts and your feelings, you may have an idea of where you stand on this decision. Show which way you are leaning right now. You can draw an "X" on the scale below to show what is important to you.



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#### 5. Links To More Information, Support Groups, And Patient Stories

- The American Diabetes Association: Amputation Prevention Alliance:
  - o https://diabetes.org/get-involved/advocacy/amputation-prevention-alliance
- The Amputee Coalition:
  - https://www.amputee-coalition.org/resources/online-support-resources-for-people-with-diabetes/

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