Living With Limb Loss

Bioengineers use the engineering process to help make living things work better. User-centered design makes a product as usable as possible. Engineers and designers think about what a user needs. They think about how the product can be used easily and naturally.

To find out what users need, engineers need to talk to the users! Sometimes the users will tell engineers directly what they want. Sometimes they need to "read between the lines" to understand unspoken needs.

When designing prosthetics, user-centered design is critical. If a prosthesis can't help perform a desired function or doesn't fit properly, users may choose not to wear it. It might be inconvenient or, worse, might cause harm to the user.

In this activity, you're stepping into the role of a prosthetic engineer. You're reviewing interviews with people with limb loss or limb difference. In these interviews, users will talk about their lived experiences, preferences, and needs. Your task is to understand what the user needs in a new prosthetic design.

Read through this transcript. Prompts along the way will check that you're understanding what you're reading.

Note: This transcript is fictional. It's based on the experiences of people with limb loss and was developed in partnership with the Amputee Coalition.

1. Can you tell us a little bit about yourself?

Hi, I'm Steve. I'm 52 years old, and I live just north of Seattle. That's where I grew up and it's where I'm raising my kids. We have three kids, two boys and a girl. My oldest is in high school and my other son and daughter are in middle school. I really like playing basketball with all three of them. We have a hoop in our driveway and the time we've spent together out there is really special.

Many Saturdays you'll find me fishing! Sometimes on my own, sometimes with my buddies.

I've always loved to fix things - on my car, around the house. I do what I can now. I still have a few jobs that I haven't yet figured out how to do using my left hand and my prosthetic hook.

My wife and I like to eat at restaurants. Once a week, we go out to eat. I usually get a steak. We also like to go on walks in the forest.

I work as a civil engineer for the City of Seattle. I love to design things that really work for people. So I get why you're here talking to me about my prosthesis. I know what it's like to design something that makes people's lives better and think "I was a part of that!"

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Pause, retell, and compare
Pause here. Imagine you're **retelling** this story as if you're introducing Steve to someone else. Without looking back at what you've read, what details of his story do you remember? What have you learned about his personality? Now **compare** your retold introduction to what's written on the previous page. Did you get the details right? What else is here that you want to be sure you remember? Write out the details here or circle or highlight them in the text.

2. Would you be willing to tell us about your limb loss?

Oh, I can't count how many times someone's asked me that. I have what's called a transradial amputation of my right arm, and yes, I used to be right-handed. I'm missing my hand and about half of my forearm. The amputation happened after a car accident 12 years ago, when I was 40.

I have about four inches of residual limb left, from the inside of my elbow to the end of my forearm. There was a lot of nerve damage from my accident, so I've never been able to use a myoelectric prosthesis. There's just not enough electrical signal in my nerves for the electrodes to pick up.

For the first couple of years, I had a lot of phantom pain. Like, I'd wake up in the middle of the night feeling like my hand was on fire - but there was nothing there. Or I'd get that pins and needles feeling, like when your foot falls asleep. Except I'd want to wiggle my fingers to get it to go away, but it was like my right hand was clenched into a fist and I didn't know how to get it to relax.

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Context clues

Were there words in this section that you didn't understand? Often a community, like the limb loss community, will use words that they all understand but that might not be familiar, or might not mean the same thing to people outside the community.

Let's use **context clues** to guess at some definitions.

Using context clues in the first paragraph, what does a "transradial amputation" mean?

In the second paragraph, what would you guess a "myoelectric prosthesis" is? How do you think it works?

In the third paragraph, what clues help you know what "phantom pain" means? Highlight or circle the clues, then write what you think the definition is.

Once you've made your guess, go ahead and look up these terms. Were you right?

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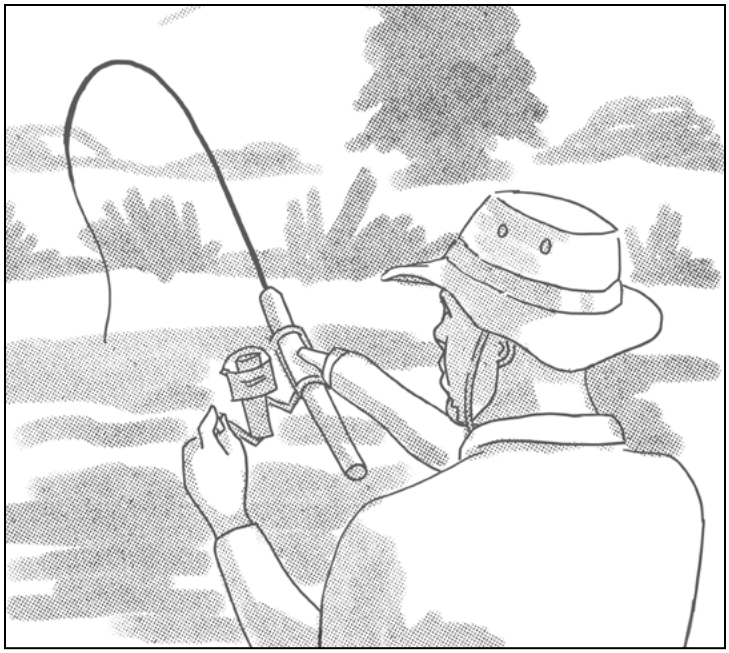
3. What have been some challenges that you've encountered as a result of your limb loss?

You know, there are a lot of things you do every day that you just do without having to think. Like eating with a knife and fork, getting dressed, tying shoelaces. Try buttoning a shirt using a pair of tongs as one of your hands, and you'll get an idea of what it's like for me.

Now, I can do all of those things. And after 12 years of practice I do many of them without thinking. But it takes longer and it's harder to do since my amputation. Most of my shoes don't have laces and most of my shirts don't have buttons. Those are just choices I made to make things easier for myself.

One of the things that my prosthesis can't replace is the ability to feel, to hold someone's hand, even to know if I am close to being able to pick something up. Having the sense of touch is important to know just how tightly I'm grasping onto something delicate like a styrofoam cup full of water. It can be difficult to hold on tight enough not to drop it, but not too tight or I'll crush it. So I have to pay extra close attention to everything I do.

It's been a process of learning and accepting that this is me, this is my body now. I took a lot of time looking in the mirror, with and without my prosthesis. For a long time, there was still that picture in my head of how I used to be. But it's taken time and it's taken work and now I've accepted how I look.



I get it that people will look when something is different. And I am used to people looking at me now when I'm out in public. But it hurts to see the looks on my wife's face and on my kids' faces when people stare, or when people come up out of the blue and ask what happened. I don't want to be the reason my family can't have a normal day out together. I'd love to just be able to do "normal" things like cutting a steak without everybody in the restaurant watching to see how I do it.

It's also hard when people tell me I'm so brave or tell me stories about other inspiring amputees they've known. I don't feel brave. And I'm not trying to inspire anyone. I'm just Steve.

Being in a minority, even among other amputees, has been difficult. Upper limb amputees are a small portion of the amputee community, so we don't always have things made for us. I've sometimes used small pediatric leg "socks" on my arm that just didn't really fit right.

And it's hard when someone tells me about some new robotic hand they saw on TV, and they talk

like it'll fix everything. They don't understand how those hands actually work and why they don't work for me. Don't even get me started on the struggle it'd be to get my insurance to pay for something like that!

It hasn't been all bad. I've had a lot of positive experiences too. My family knows what I've been through. They understand what I'm capable of and what I want and don't want. I'm lucky to have them. And many people out there are kind, helpful, and genuinely want to learn more about my amputation and my experiences.

Pause, retell, and compare

Pause here.

Without looking back at what you've read, answer these questions.

How has Steve's limb loss affected him **physically**?

How has it affected him **emotionally**?

How has it affected him **socially**?

Now **compare** what you've written with what you read. Are there details here that you forgot about, or didn't understand? Circle or highlight those details in the text, or write them out here.

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4. What is your experience with prostheses or other adaptations?

I use a body-powered hook prosthesis. The way it works is that, this part is called the socket and that goes over my stump and then it has a harness that goes all the way over to my other shoulder - right here, you see? So, I open and close the hook by moving my other shoulder. This one I've had for a few years now. It just works for me. I haven't felt a need to get a new one. Putting it on and taking it off is kind of a process, though. And it's heavy, but I've gotten used to it. It puts a lot of strain on my sound arm, so I need to be careful with how I use it and take breaks when I need to.

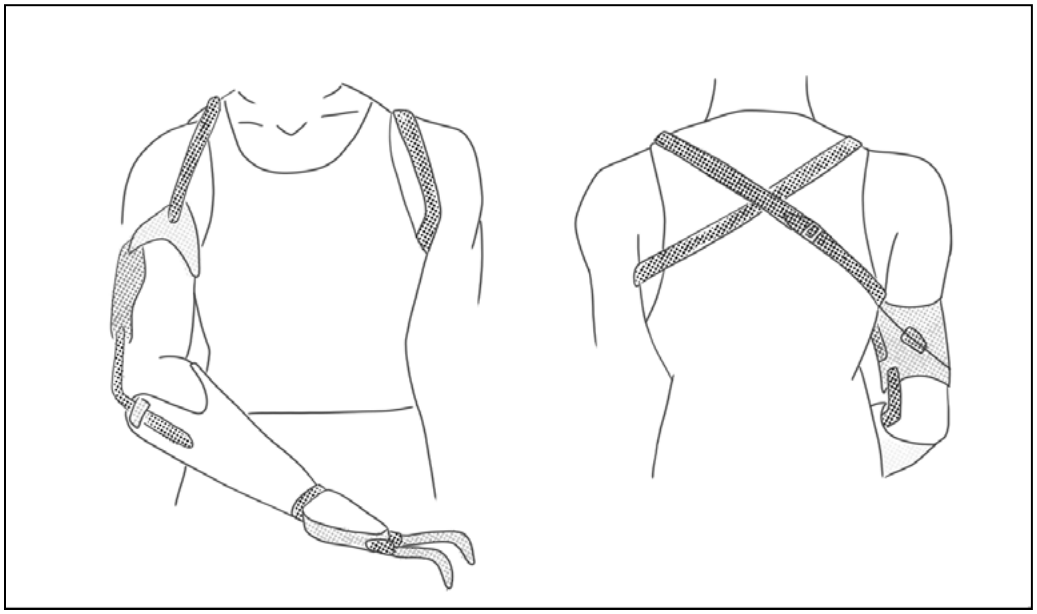
I have a knife that allows me to cut things with one hand, but then I have to figure out a way to clean it off before storing it again. My prosthetic hook is not great for helping me cut food.

At work I've gotten used to typing mostly with one hand, but I can still hunt and peck with my hook. Doing most things with my phone is awkward sometimes because my touchscreen doesn't respond to my hook. A lot of our life is connected to our phones!

A couple of years ago I got a terminal device that's just for holding a fishing pole. It attaches on to the end of my prosthesis. It does one job, and it does it well. It's great! It really made fishing a lot more doable for me again. I love having an attachment that's specially designed just for this purpose. I'm thinking about getting more.

I usually wear my prosthesis all day at work and when I'm out of the house. At home I mostly wear it only when I'm working on home repairs. I never wear it when I'm playing basketball with my kids. It would only get in the way. That is, unless I had an attachment just for holding a basketball.

I'd say probably about- I mean, most days, maybe – maybe half the time? Just at home, you know, about half the time I don't wear – I take off my prosthesis. And it's usually because it's hot, and I'm starting to get sweaty, or because it's heavy and my arm's getting tired- or sometimes I can do something better, when I need to feel what I'm working on or, or, you know, just-- when my residual limb will do the job better than my prosthesis.



NAME _____ DATE _____

Chunking

Was that last paragraph hard to follow? People talk differently than they write, so sometimes sentences in transcripts can be harder to understand.

When a sentence is confusing or hard to read you can break it into chunks to help your understanding. **Chunking** can also help when you're reading a long section of text or long sentences.

Here's an example. This might be found in an interview with a prosthetic designer:

"And so, um, just to give you some examples, uh, you know, we ask people who use prosthetics what they, what they want or, or need, and they'll, you know, they'll tell us functions or features– like touch feedback, wrist motion, um, noise, weight, and durab-, uh, reliability—as well as the daily, um, the, um, activities, like, you know, cutting with a knife, getting dressed, typing, that they want to be able to do, uh, uh, better."

Let's use chunking to make sense of this.

First, take a pen or pencil and cross out the words than aren't important - the *um*s, *uh*s, and the repeated words or false starts.

Next, draw brackets around parts of the sentence that make sense on their own. In the sentence above, you might start with [we ask people who use prosthetics what they want or need].

Keep going, breaking the sentence down into chunks that each make sense on their own.

Now, start linking the meaning of one chunk to another. In your own words, what is the meaning of the example sentence above?

Now use these strategies again to help make sense of that last paragraph in the text above. Why does Steve sometimes choose not to wear a prosthesis?

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5. What do you need from a prosthesis?

One thing I really need is something that's strong, you know, that I can put a lot of strength into. For when I'm fixing things around the house. I especially need something that has a strong grip – that is tough with any prosthesis. And I need it to have a surface that won't slip so I can use two hands and really work a screwdriver or a wrench. It's also gotta be durable because I put it through a lot when I'm working!

I really can't move my hook at all like a wrist. That would be really great and would open up a lot of possibilities for me, like being able to angle my toothbrush or a fork. You know, one thing I've thought about sometimes - "What if I could have a wrist that's just, you know, bendy enough that I could shoot a basket with my right hand?" But then I wonder - how would I end up controlling or powering it? It would be really nice though.

Another thing that would make life a lot easier is if I could feel things again. Right now, if I can't see where the end of my hook is, I don't know what's going on. I can't tighten a screw anywhere on my car that I can't see. I'd love to have some of that touch feedback again.

Pause, retell, and compare

Pause here.

Retell Steve's answer to a partner.

Together, **compare** your retelling of this response to what's written here. Did you get the main points right? Talk about what else is written here that you want to be sure you remember.

6. Is there anything else you think we need to know?

Yeah, I have some thoughts. I mean, I've been living with this for a while.

Don't start by asking "what are all the things we can make this device do," and instead start with "what things does the user need this device to do." There's this idea sometimes that if we can just invent the perfect device, that'll make everything go back to the way it was before my accident. Maybe a new device will make some things easier, but it'll never be all the way back. Now, I'm grateful for what you do, really. But I want to keep things grounded. The fine motor use of a hand and wrist are not possible to replicate. Try moving your fingers all together as one, opening and closing them with no wrist movement. That is what prosthetics usually can give.

My body-powered prosthesis is heavy but it's sturdy and I'm used to it--and it just really works for me. I know it's not the fanciest or most advanced model out there. It's still just a pincer hook. But sometimes the simplest answer is the one that works the best.

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The “right” prothesis for me isn’t the same all the time. It’s all about what I’m doing at the moment. Am I fishing? I’m gonna use the rod holder. It’s not going to work for other things but it works for that. Am I working on the car? Then I’m using the body-powered hook. So let me tell you what tasks I need to do and we’ll design something to work for that.

I could make a whole list for you of everything I want a prosthesis to do - but in the end it’s really gonna come down to if it makes things easier for me and if it’s comfortable - if it’s just gonna feel right. I don’t really know how to tell you exactly how to do that. But I’d love to help work on this with you. I’d rather try things out while you’re still working through the process than wait until it’s all done to see that something’s not sturdy, something’s not moving right. Yeah, I’ll be happy to help you out.

Make a claim and provide evidence

Your task is to understand what this user needs from a new prosthesis design. Based on the whole interview, **make a claim** about something Steve needs from what he said directly.

Now **provide evidence** for that claim - what facts in the text or statements support your claim? You can write your evidence here or circle it in the text above - but be sure to mark it differently than you did for other questions so you can keep track of evidence.

Make another claim about Steve’s needs from reading “between the lines” of his statements. What does he need or want that he didn’t state directly?

What evidence supports this claim? If you choose to mark evidence in the text, mark it differently than for other questions.

Compare your claims and evidence with a partner’s. Politely challenge each other’s claims if you feel like there’s not enough evidence.

After comparing with your partner, are there more questions you’d like to ask Steve?