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?

I'm Maya. I'm 13 and I'm in eighth grade. I live in south Texas with my mom and my little sister. She's nine.

I'm on the cross-country team at school. I love to run - it's my favorite way to exercise and to clear my head. My friends are on the team too.

I also love to cook with my mom. We've been cooking together since I was little. The first thing I remember making with her is chocolate chip cookies. Now I make them all the time and she says mine are better than hers!

I play the guitar. I mean, I used to play the guitar. I really want to again. I've never had lessons or anything, but I know some chords. Enough to play most of the songs I like. It's so fun to see my sister's face or my friends' faces light up when I start playing one of their favorite songs.

My mom is a PA - a physician's assistant. I used to think that I wanted to do something like that as a job - maybe a doctor or a nurse. I guess I don't know if that's still an option for me. I wanna do something in the medical field, I think. We live in our bodies and with our bodies every day. When something's not working right, it affects everything else. I've learned that, for sure!

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Pause, retell, and compare

Pause here.

Imagine you're **retelling** this story as if you're introducing Maya to someone else. Without looking back at what you've read, what details of her story do you remember? What have you learned about her 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?

So, I lost my left hand a year ago. A month before that I was at a bonfire on the beach with a bunch of families - my mom's friends. I was trying to walk around to the other side of the fire and I lost my balance. I fell and burned my hand really bad. Like, black blisters and stuff. At first we were just worried about the damage to my hand and nerves from the burn. But then the wounds got infected. They had to amputate.

It's a wrist disarticulation. So, I still have all my bones and muscles in my forearm. The damage from the burns and infection was all in my hand, so everything that's left is pretty much fine. So, since I have so much muscle and nerves still in my arm, I can use a myoelectric prosthesis. It takes some time to learn how to use it. But now I'm getting better at knowing which muscle to move to make the fingers and thumb of my prosthesis move. My doctors say it'll feel more and more natural as I get more experience. I am not there yet!

Oh, can I tell you about phantom pain? I had no idea what it was going to be like. Sometimes it's like a zing, like a shock, and it shoots up my arm. It's so embarrassing when that happens at school. Sometimes it's this intense itch - and what do you do if there's no hand there to scratch?! It used to wake me up in the night and I'd be scared to go back to sleep. I've got some meds that help. If it doesn't go away, they say there's some surgeries that can reattach my nerve endings to muscles. They say it helps a lot.

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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 second paragraph, what does a "wrist disarticulation" mean?

Also 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.

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

So, I start my day by getting ready. Taking a shower and washing my hair was hard for a really long time. Then doing my hair, makeup, getting dressed. All of those, I had to relearn how to do. I wake up an hour earlier than I used to to make sure I have enough time to get ready for school. I still haven't figured out tying shoelaces, and I don't want to give up my favorite high-tops, so my mom and my friends help me.

I'm right-handed, which helps. I can eat one-handed most of the time, and when I need to cut food, I hold my fork in my prosthetic hand. It still falls out of my hand if I don't get the grip just right. I can also write with a pen or pencil. But working with my cell phone is not easy. I can't text with my thumbs, like my friends do - I've gotta either hold the phone in my sound hand and use one thumb or hold it in my prosthetic and type things out with my right hand.

I'm learning how to cook again. I have to think before I do things: Okay, is this something only my right hand can do? Is it something that might just be easier to do just using my residual limb? And my myoelectric hand can't get wet, so it's not even an option for some tasks.

I miss how I used to play the guitar. My uncle re-strung my guitar so I can play chords with my right hand and strum with my left. It doesn't feel very natural yet.

Whenever I meet new people, I'm always bracing for the question about my hand. My mom came up with some funny ways to answer, like "They really mean it when they say keep your hands and feet inside the ride!" or "Darn! It fell off again!" But in the moment, I always just tell what happened.

What really bugs me is when I tell about my hand and people say something like "Oh, but you have a prosthetic arm! That's great!" Like having a prosthesis means that everything's okay and back to normal. It's not and it never will be.

Some people say I should be on the news because they think I'm so inspiring. The news doesn't show all of my struggles. Besides, I feel like it would just be another way of people staring at me.

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Pause, retell, and compare

Pause here.

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

How has Maya's limb loss affected her **physically**?

How has it affected her **emotionally**?

How has it affected her **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 started using a temporary prosthesis a few weeks after my surgery, while the swelling was going down and the wounds were healing. My doctor told me that it was important for me to start using some kind of a prosthesis as soon as possible. Not gonna lie, I hated it! It just reminds me of how sad I was those first few months, and how much it hurt while my surgery healed.

Now I have a new permanent prosthesis that I like SO much better. It's a myoelectric hand. The fingers work separately. It can move the thumb, the pointer finger, and then the other three fingers all together. I can pick things up. I can grip and hold on to things, but it doesn't always have the tightest grip. Because I'm right-handed, I don't have to try to write with my myoelectric. But I can't type as fast as I can with my sound hand.

I just can't win. If I don't wear a prosthesis, people stare at my residual limb. If I wear my myoelectric, it looks like a cool robot hand, but it gets hot and it's noisy. Like, imagine how quiet it is when you're taking a test - I feel like everyone can hear every noise my hand makes.

When I'm with my best friends, or with my family, I know that they don't treat me any differently because of my limb loss. So I feel like I can take off my prosthesis around them - it's more comfortable that way.

My residual limb is still pretty useful too. It's almost the same length as my sound limb, so I can use it to hold things against my other arm, carry things that have a strap or a loop, stuff like that.

I remember when I started using my prosthetic to play jokes on my friends - like putting it on the end of a broom and tapping someone on the shoulder. It made me feel like I could be myself - my new self - with my friends, and that I didn't have to pretend I wasn't an amputee.

So if I - I mean, like – If it's getting - when I'm home and it's hot outside or something, not, like, every day but most days, I take off my prosthesis. I mean, after a few hours - more like after lunchtime, you know, and it's getting heavy or it's hot out and I'm starting to sweat- and it's just, I mean, it's not always the easiest way to do something, you know? -- I can do - I can do some things better with just my residual limb.

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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 Maya sometimes choose not to wear a prosthesis?

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5. What do you need from a prosthesis?

Right now, my pinky finger, ring finger and middle finger on my myoelectric hand all move together. I know it's not easy to do, but I would love to move each finger by itself. I wanna be able to do things that need fine movements, like helping my sister with beading.

Oh, if I could feel anything with my myoelectric, that would be amazing. It would make it feel a lot more like an actual hand and not just a tool. Right now I have to watch my prosthetic hand a lot to know how it's moving. If I'm at lunch with my friends, I eat with only my sound hand, since I don't have to watch it all the time.

I need a really good battery, just like in my phone. It's kinda awkward when the battery just dies and the hand stops working all of a sudden.

I live in a really hot place - south Texas. I need the hand to not make me too hot. And I get worried about when I start sweating, because I know I'm not supposed to get the myoelectric wet.

I need it to have a good grip, so that when I'm cooking I can pick up a glass bottle. Or hold something really steady while I'm cutting it with a knife.

I know that there are some prostheses that have attachments that are good for one specific task. I kind of like that idea. I mean, I can kind of strum a guitar with my myoelectric, but maybe an attachment that's built just for that would work better. Or an attachment that holds my hairbrush in place at the right angle. Yeah - I would be willing to switch out attachments if they each do one really good job.

Pause, retell, and compare

Pause here.

Retell Maya'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?

For kids like me especially, you need to have a prosthesis that you can make your own. I didn't like my first temporary prosthesis for a lot of reasons, but one of them was the color. Ugh. For my permanent prosthesis I was so excited when I heard I got to pick the color - that really helped me want to start wearing it.

You can learn more about what people who use prostheses need by getting on social media. Social media helped me find other people my age with upper limb amputations. We share hacks, we

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complain - they get me and I get them. Be honest with who you are and what you're working on. Be upfront with what you can and can't offer. We can help you design something that we'll actually want to wear.

I kind of have a list in my head of the things I want to be able to do that I haven't figured out yet. Can I give you that list? Maybe we can start crossing some things off of it.

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 Maya needs from what she 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 Maya's needs from reading "between the lines" of her statements. What does she need or want that she 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 Maya?