amputee coalition™

# Beginning Your New Journey

## Wrist Disarticulation

# WELCOME!

**The Amputee Coalition is a national non-profit organization dedicated to supporting individuals affected by limb loss and limb difference. Established with a mission to empower this community through education, support, and advocacy, the Amputee Coalition provides a comprehensive array of resources to enhance the quality of life for people who have limb loss and limb difference.**

The organization offers extensive peer support programs, educational materials, and a wealth of information on health and wellness. They actively engage in advocacy efforts to improve public policy and healthcare access for amputees. The Amputee Coalition also hosts events and initiatives aimed at fostering community, raising awareness, and promoting positive change.

Through their dedicated efforts, the Amputee Coalition strives to ensure that no amputee feels alone and that every individual has access to the tools and support they need to live life fully.

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It is not the intention of the Amputee Coalition to provide specific medical advice but rather to provide readers with information to understand better their health and healthcare issues. The Amputee Coalition does not endorse any specific treatment, technology, company, or device. Consumers are urged to consult with their healthcare providers for specific medical advice before making any purchasing decisions involving their care.

## After a wrist disarticulation amputation you will probably have a lot of questions.

**Remember, you are not alone on this journey. There are many people that can help guide you along the way. This booklet is just one of many Amputee Coalition resources designed to help provide you with information and support for your journey ahead.**

# INCIDENCE AND PREVALENCE

More than 5.6 million people in the United States live with limb loss or limb difference. Of these, about 2.3 million have lost a limb, and around 3.4 million were born with a limb difference.[1] Each year, about 9,000 people have a wrist disarticulation amputation. This type of amputation makes up just 2% of all amputations. [1]

Upper limb loss or difference can happen at many levels—from part of a finger to the whole arm. This guide focuses on people who are born with, living with, or preparing for an amputation through the wrist joint, called a **wrist disarticulation.**

In a wrist disarticulation, the two bones in the forearm (the ulna and radius) stay in place, but the bones of the hand and wrist are removed.[2] Unlike amputations that happen higher on the arm, people with a wrist disarticulation can usually still turn their forearm inward (pronation) and outward (supination), which is helpful for many tasks. Because of this, a wrist disarticulation may be chosen over higher-level amputations—if it is the right fit for the situation.

This type of amputation is most often caused by serious injury, but it can also result from infection, cancer, or conditions present at birth.[3]

The Amputee Coalition created this guide to help people with wrist disarticulations. Losing an upper limb can be more challenging than losing a lower limb because hands are used for many detailed and precise movements.[4] This guide is meant to go along with the advice of your doctor, prosthetist, and other healthcare providers. Always follow their guidance, especially if it differs from the information in this booklet.

# THE JOURNEY BEGINS WITH YOU

Whether you are living with limb loss or limb difference yourself—or you are a parent, friend, or family member of someone with a wrist disarticulation—this booklet is here to help. It can answer important questions as you begin this new journey.

The most important thing to remember is that everyone's journey is different. No two people will have the exact same experience. But with a wrist disarticulation, you can still live a full, happy, and successful life—at home, at school, at work, and in your community. Losing a hand does not define who you are.

Adjusting to life with upper limb loss can be hard at times. It takes time and patience to get used to the changes. Children who are born with a wrist disarticulation will keep learning and adapting as they grow. For those who lost a limb from illness or an accident, healing can take months, and full recovery may take even longer.

Support from family, friends, doctors, and others with similar experiences can make a big difference. Everyone moves forward in their own way and in their own time—there's no one "right" path.

**Be your own advocate.**

## BEGINNING YOUR NEW JOURNEY

It's important to take an active role in your care. That means talking with your healthcare team, asking questions, and helping make decisions about your treatment. You are the most important part of your healthcare team, and your voice matters.

If you have questions or worries, don't be afraid to speak up. Talk with your doctors and therapists about your goals and how they can help you reach them. Only you truly know how you feel and what you need, so make sure to share those thoughts with your team.

No question is too small—ask anything you need to feel comfortable and confident. Your healthcare team is here to support you.

# MEMBERS OF YOUR HEALTHCARE TEAM

When you or your child is going through limb loss or limb difference, you may work with many different healthcare providers. **Comprehensive care means that these providers work together as a team to help you reach your goals.** It's important that they stay in contact and share information to give you the best care possible. If your surgery is planned, try to meet with your care team before it happens.

Depending on where you live, your healthcare team may look different. Here are the most common providers and what they do:

## Physiatrist/Surgeon/ Physician

Your physiatrist, surgeon, or primary care physician will serve as the lead member of your care team. They will dictate and oversee your care plan after surgery. They will also serve as your main referral source for other services such as pain management, mental healthcare, therapy, prosthetic care, job training and social services.

## Occupational Therapist

Your occupational therapist (OT) will help you learn how to do everyday activities like bathing, dressing, cooking, or cleaning. They will teach you ways to stay independent. If you choose to use a prosthesis (artificial limb), your OT will work closely with your prosthetist to support you before and after it is fitted. It is best to start OT before getting a prosthesis, if possible.

## Physical Therapist

A PT helps you stay strong, flexible, and balanced. They can also teach you safe exercises to do at home to avoid injuries. PTs who understand upper limb loss can be especially helpful. For kids born with a limb difference, PTs and OTs work together to help them learn new skills and reach important growth milestones.

## Prosthetist

A prosthetist is the specialist who designs and fits your prosthetic limb. They'll make sure it is comfortable and works well for your needs. It is important to find a prosthetist who has experience working with people who have upper limb loss or limb differences because it is less common than lower limb loss.

## Psychologist/ Mental Health Therapist

Losing a limb or having a limb difference can be hard emotionally. If you are feeling sad, stressed, or overwhelmed, a mental health therapist can help. They will give you tools to cope and support your emotional well-being.

## Case Manager

Your hospital or insurance company might assign you a case manager. They help plan your hospital discharge, organize your care plan, and may work with your insurance company. Case managers make sure you get the services you need and keep everyone on your team connected. There are also nonprofit organizations that provide case management services, if needed.

## CHOOSING YOUR HEALTHCARE TEAM

Choosing the right people to be on your healthcare team is a very important decision. The relationships you build with your doctors, therapists, and other providers can have a big impact on your health and recovery. When you feel comfortable with your team, it is easier to talk about your needs, ask questions, and make good decisions about your care.

Many people do not realize that **they have a say** in who is on their healthcare team. In an emergency, you may not have a choice. But if your surgery is planned—or as you continue with therapy and follow-up care—you can and should choose providers who are the right fit for you.

Here are some things to think about when picking your healthcare team:

**Experience** – Do they have experience working with people who have upper limb loss or limb difference?

**Communication** – Do they listen to you, answer your questions clearly, and respect your opinions? Do you feel safe, supported, and understood when you talk to them?

**Teamwork** – Are they willing to work with the other members of your care team?

**Reputation** – What do other patients and healthcare professionals say about their work?

**Location** – Are their offices easy for you to get to? If not, it may be difficult for you to keep your appointments, which can negatively impact your health outcomes.

**Affordability** – Can you afford their services? Do they accept your insurance plan or offer payment options? Are they up front with you about any potential out-of-pocket expenses?

Your healthcare team should support your goals and respect your choices. If someone doesn't feel like the right fit, it's okay to ask questions, get a second opinion, or look for another provider. **Remember, you are in control of your care**—and you deserve a team that helps you be your best self.

# STAGES OF THE LIMB LOSS JOURNEY

## Before Surgery

The anticipation before your amputation can feel overwhelming but taking a few steps before surgery can help you feel more in control and support a better recovery. First, make a list of any questions you have and bring them to your doctor visits—ask about the surgery, pain management, recovery time, and what to expect afterward. Your doctor may suggest meeting with a physical or occupational therapist to start exercises that help strengthen your other hand and arm. This can make daily tasks easier after surgery. You might also talk with your care team about your home setup—like moving things you use often to easier-to-reach places. Some people find it helpful to practice doing things with one hand before surgery. Your doctor may also give you medications, like antibiotics, to take before the operation. Most of all, be kind to yourself. This is a big change and it's completely okay to have strong feelings like nervousness, sadness, or fear. Learning what to expect and taking steps to prepare can help you feel more ready and make the whole process a little easier to handle.

## During Surgery

Like with most upper limb amputations, one of the main goals of a wrist disarticulation is to keep as much functional length in the arm as possible. When it's an option, this type of surgery is often chosen over higher-level amputations because it can help preserve the ability to rotate the forearm.[3] During the procedure, the surgeon will make a cut just below the wrist joint and remove the bones in the wrist and hand. They will carefully close off blood vessels and nerve endings, then close the surgical site. Sometimes, antibiotics are used on the wound to help prevent infection.[5] Your surgeon might also place a small drainage tube in your arm temporarily to help with the healing process. Every surgeon has their own way of doing this, so the steps might be a little different from what is described here. If you want to know exactly how your surgery will go, it is best to discuss this with your surgeon. Some people feel more comfortable knowing all the details ahead of time, while others may prefer not to. Either way is okay. Going over your surgical plan, including the type of anesthesia and any medications you will receive, can help lower the chance of problems and help you feel more prepared.

## After Surgery

Recovering after surgery involves both physical and emotional healing. Your first phase of rehabilitation will include pain management, and how to care for your residual limb. Proper care of your residual limb will help to prevent complications and aid in healing. The next phase of your recovery should focus on learning how to perform daily tasks with one hand at first, and with the help of your residual limb when tolerable. While your health care providers will take care of you during your hospital stay, they should also educate you and your caregivers on how to continue your care at home after you are discharged. This section outlines what recovery may look like, from the early days after surgery through prosthetic training and beyond.

## 1-4 Weeks Post-Surgery

In the first few weeks after surgery, it is normal to experience swelling, sensitivity, and mild to moderate pain. Early physical therapy usually begins during this stage, focusing on maintaining the range of motion in your shoulder and elbow and building upper body strength. You may also begin occupational therapy, which can help you with everyday activities like dressing, hygiene, and basic self-care. These early steps set the foundation for a successful long-term recovery.

- **Pain Management** - You can expect to have some pain after surgery, this is normal. Your care team will help you manage it. It is important to identify the cause of your pain because the different kinds of pain may require different treatments. Nerve pain feels different than wound or bone pain. Generally speaking, most of the pain you experience will decrease over your time in the hospital. It is important to stay ahead of the pain and take your medications as recommended by your physicians.
- **Swelling** - Swelling is part of healing and will decrease over time. Using compression, like special bandages or shrinkers, can help reduce swelling, and shape your limb for a prosthesis. Your care team will show you how and when to use them.

## 2-3 Months Post-Surgery

As you continue to heal, swelling typically decreases and stitches are removed. The surface of your residual limb will look healed, but deeper healing is still taking place.

During this time, you'll continue physical and occupational therapy to support strength, mobility, and independence with daily tasks. Around 6 to 8 weeks after surgery, you'll likely meet with a physiatrist (rehabilitation doctor) and a prosthetist to begin discussing prosthetic options. If a prosthesis is right for you, your team will start the process of designing and fitting it. This can take 4 to 6 weeks, depending on your healing progress and the type of prosthesis selected.

Wound Healing. It's important to follow your doctor's instructions closely to keep it clean and avoid infection. 5 Once the wound has closed, keep washing it gently with mild soap and warm water. Rinse thoroughly then pat it gently to dry with a clean towel—don't rub it. It takes several months for the tissue beneath the skin to heal completely, even after the wound appears to be closed.

## 3+ Months After Surgery and Beyond

Around three to four months after surgery, you may receive your first prosthetic device. At this point, training becomes an important part of your rehab journey. Learning to use a prosthesis takes time and patience, and your rehab team will guide you through this process. You'll learn how to put on and take off your device, use it for functional tasks, and care for your residual limb. Physical and occupational therapy will continue, focusing on keeping your body strong, maintaining joint flexibility, and preventing overuse of your non-affected limb.

- **Emotional Healing.** Losing a limb can bring up many emotions, some of which are negative. These feelings are normal and part of the healing process. If your circumstances didn't allow you the time to prepare for this change, it can feel even more difficult. It's important to be honest when you talk about your feelings with your care team. With time, if given the necessary support, these feelings may resolve on their own. However, if the negative feelings persist, they can impede your recovery. Working with a mental health professional may be recommended by your care team to help you cope.

Rehabilitation doesn't stop once you receive a prosthesis. It's a lifelong process of adapting, adjusting, and growing. As your goals and needs change, so will your care plan. Some people continue with prosthetic use, while others may choose not to use one—and both paths are completely valid. What matters most is finding what works for you and staying connected to a support system that helps you thrive.

For additional ways to find support, including programs for peer counseling and support groups, check out the section on Living Well with Wrist Disarticulation.

## Stages of the Limb Difference Journey from birth

Growing up with any limb difference involves moving through the same general developmental stages as any child—but with a few unique experiences and challenges along the way. Here's an overview of the stages of development and how limb difference may play a role:

### Infancy (0-1 year)

In the first year of life, babies begin learning to roll, sit, crawl, and explore their world. A child born with a limb difference will often find creative ways to interact with their environment, using their other hand or feet. Encouraging play and movement is key to early development. Some families also find that occupational therapy during this stage helps with motor skills and early adaptations.

### Toddlerhood & Preschool Years (1-5 years)

During the toddler and preschool years, children work hard to become more independent. They begin to feed themselves, dress, and engage in imaginative play. At this age, your child may become more aware of their limb difference, and others may begin to ask questions too. These years are a great time to use positive language and reinforce your child's strengths and creativity. Occupational therapy can support skill-building, and some medical providers encourage the exploration of early prosthetic options. With the right encouragement and support, children typically find their own way to do everyday tasks with confidence.

### Elementary School Years (6-12 years)

In elementary school, children's awareness of their physical differences may increase as they begin comparing themselves to peers. They often want to try new sports, hobbies, and classroom activities, and they may need to adapt how they do certain tasks. This is a good time to support emotional development, build confidence, and encourage participation in social and physical activities. Connecting your child with mentors or peer groups who have similar experiences can also be very beneficial.

### Adolescence (13-18 years)

Adolescence is a time of self-discovery and growing independence. Teens may begin thinking more deeply about their identity, body image, dating, and long-term goals. It's also common for them to form strong opinions about whether or not to use a prosthesis. During this stage, open and honest conversations are essential. Support from family, access to counseling or peer mentors, and encouragement to pursue personal interests can all make a big difference. Helping teens feel empowered to make their own decisions supports their journey toward adulthood.

### Adulthood (18-65 years)

As adults, individuals with limb differences may face new challenges in the workplace, in relationships, and as parents. But by now, most have developed their own strategies for navigating daily life. Some may choose to use a prosthesis, while others may not, depending on lifestyle and personal needs. Access to workplace accommodations, adaptive tools, and supportive communities can be especially helpful during this stage.

## Older Adulthood (65+ years)

In older adulthood, physical changes such as arthritis or reduced mobility may affect how tasks are performed. Some people may find that techniques or tools they used earlier in life need to be adjusted. Regular check-ups with healthcare providers can help ensure continued comfort and safety. Updating prosthetics or assistive devices and making small changes at home—such as grab bars or easier-to-use tools—can support independence. Staying socially active and emotionally supported during this life stage is just as important for someone born with a limb difference as any other person.

**Personal Story:**

“Early on I was given the opportunity to participate in programming specifically for kids with physical disabilities. Each year, I eagerly awaited camp. I rode horses, rock climbed, did karate, learned yoga, sailed, and water skied. I cherished annual scuba trips to the Florida Keys, summer camps in Pennsylvania with high ropes courses, a week kayaking and camping along the Colorado River, and snowboarding. I joined the Paralympic Academy twice and was humbled by the Olympic Training Center. In 2008, I beamed with pride watching the Paralympic Games in-person. These experiences gave me exciting stories to share with my able-bodied friends, proving that people with disabilities can do extraordinary things. While the activities were fun, there were dedicated times to discuss our disabilities and build our confidence. I was encouraged to approach adversity with curiosity instead of shame. I was taught to question “how” I could do something rather than worry if I could. It felt so good to exist in a group where I felt normal and have a community that I felt fiercely proud to be a part of.

That encouragement was critical to my sense of self-worth. In a job interview I would be told my life goal could be to be a “cart pusher”; in school it’d be suggested I’m too disabled to graduate; and a teacher would begin a lecture judging a photo of “deformed children.” The self-worth I developed as a child protected me from accepting such demeaning treatment and taught me to dream much, much bigger.”

- Sara Koehnke

# ADAPTIVE TOOLS FOR DAILY LIVING

Learning to live without one or both hands can take time, creativity, and patience—but you don’t have to figure it out alone. There are many assistive tools designed to make everyday tasks easier and more comfortable. From getting dressed and preparing meals, adaptive devices can help you maintain your independence and make doing the things you enjoy a little easier.

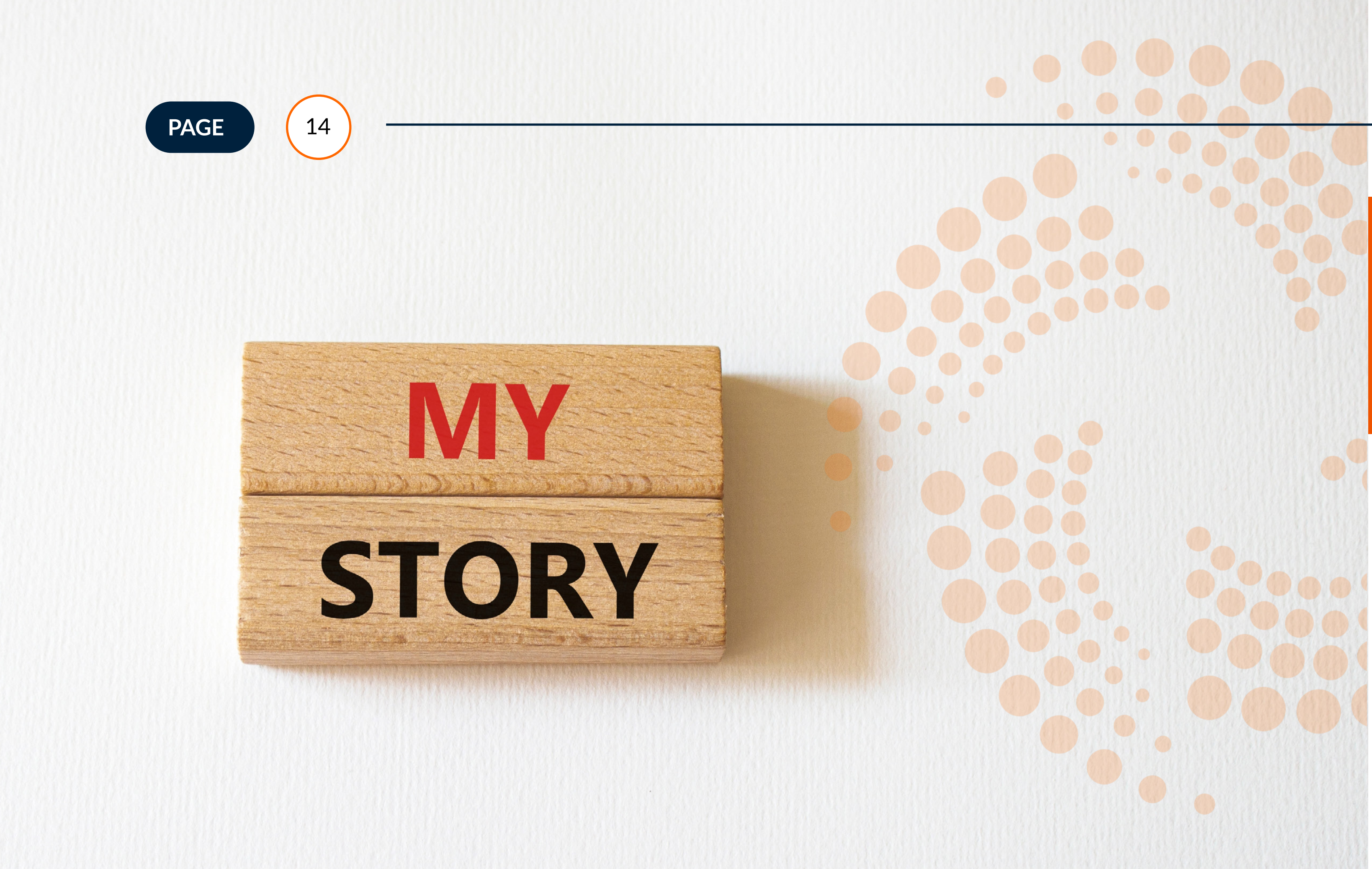
Some helpful tools include button hooks for fastening shirts or pants, and automated gadgets like toothpaste dispensers. In the kitchen, you might benefit from single-handed cutting boards, jar openers, or silicone stabilizers. There are also utensils with larger grips or universal cuffs that help hold a spoon, fork, or toothbrush. For driving, spinner knobs can help with steering, and for work or communication, single-handed keyboards or Bluetooth devices can make typing and calling easier.

Not every device works for everyone, and some are especially useful for people with limb differences in both arms. Your occupational therapist is a great resource for learning about tools that fit your needs and lifestyle. Peer support groups, online communities, and forums are also excellent places to discover tips, product recommendations, and encouragement from others with similar experiences.

**Helpful Resource: Hands Free – A Beginner’s Guide for Adaptive Equipment & Helpful Gadgets**

Hands Free is a free, downloadable catalog created by Occupational Therapists and individuals living without both hands or all four limbs. It includes around 200 adaptive items, thoughtfully organized by categories related to Activities of Daily Living (ADLs)—like grooming, eating, dressing, and more. This guide is especially helpful if you’re looking for real-life-tested products and practical solutions recommended by both professionals and peers.

You can download the catalog for free and explore what tools might work best for your needs.



**Personal Story:**

"My journey began with what felt like the common cold, but didn't seem to improve after two weeks. At which point, I asked my mother to take me to urgent care. I was then rushed by ambulance to the nearest hospital where they discovered that my heart, liver, and kidneys were all failing. This came on so suddenly too, because I had been at work the day before. Due to my failing organs and sepsis, the doctors weren't sure if I would pull through. Thankfully, after a series of lifesaving measures my condition had stabilized. But the skin on my hands and feet were left necrotic, which led to the loss of my toes and hands. Recovery has been difficult at times, but I have discovered new ways of doing things that make life easier. I use tools called universal cuffs that allow me to eat independently. I also wear prostheses that help me do even more. I believe having a prosthesis that you're comfortable with is so important. I encourage others to explore their options and make sure that the prostheses they choose feel like the best fit for them. You can't afford to settle for less."

- Marianne Groven

# PROSTHESES FOR WRIST DISARTICULATION

Choosing whether to use a prosthesis is a personal decision. There is no right or wrong answer—only what works best for you and your lifestyle. Talking early with a prosthetist can help you better understand your options. For some people, a prosthesis becomes an important tool that helps with daily life. For others, it may not be necessary. What matters most is choosing what feels right for you. As you think about your decision, it may help to ask yourself a few questions:

- What do I want to be able to do with a prosthesis?
- What activities did I enjoy before my limb loss that I want to keep doing?
- Are there new things I would like to try in the future?
- Will I need a prosthesis to do these things safely or comfortably?
- How important is the look of the prosthetic hand or arm to me?

After you and your rehabilitation team decide which type of prosthesis or an assistive device may work for you, you can try different options. Prosthetists should allow you to trial a prosthesis before you settle on a final device (and before you pay for it) if you choose to use one.

If you decide to use a prosthesis, there are several important steps that you will complete as part of your prosthetic training. This phase may involve many appointments with your prosthetist and therapist. It is important that you do not feel rushed into a decision and that you voice any concerns you have about the device. Your prosthetist and therapists should provide ongoing education about how the prosthesis works, any risks involved in its use, as well as proper care and maintenance for the device.[6]

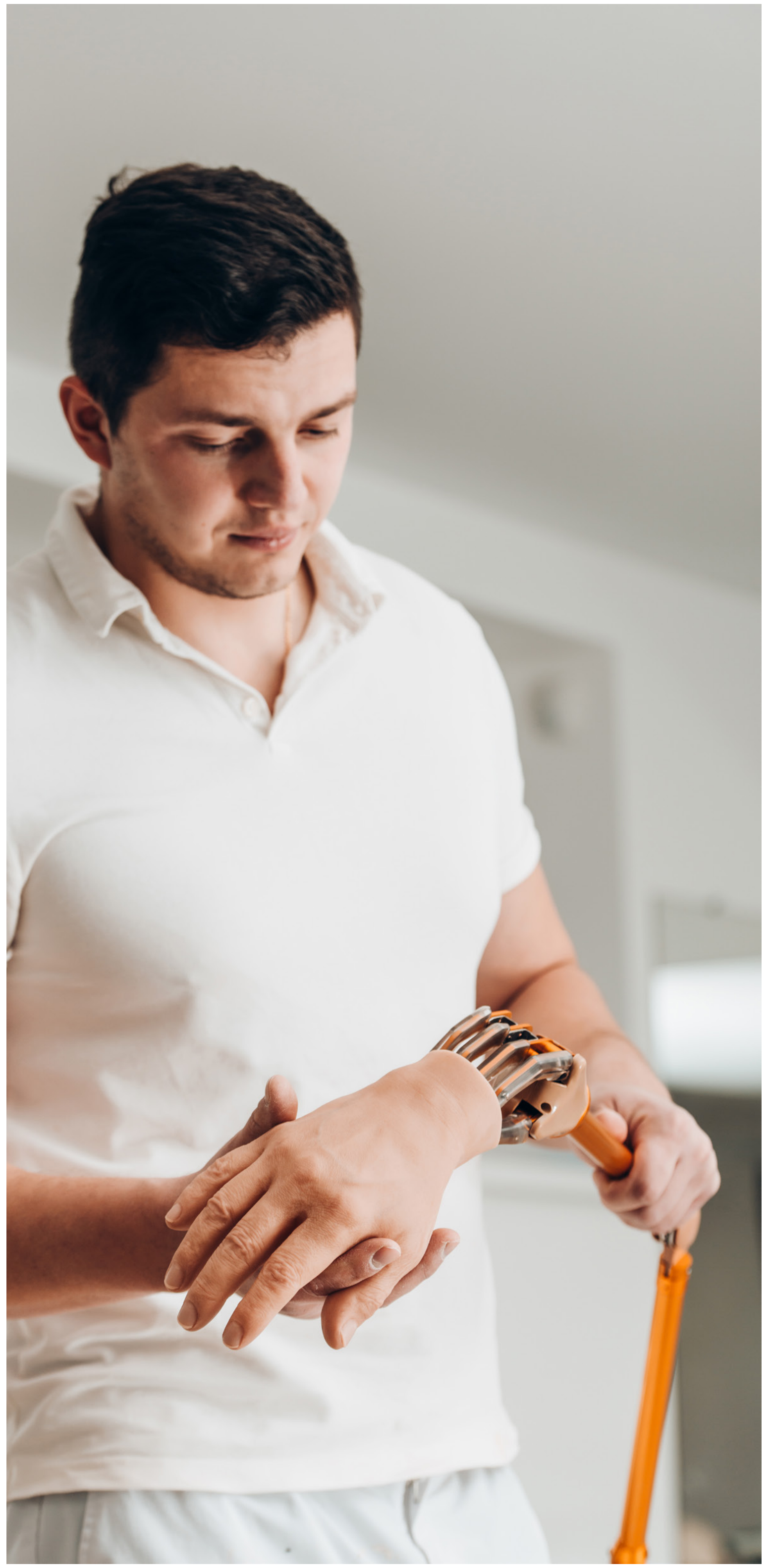
When choosing a prosthesis, your prosthetist should explain the different device options to you in detail. In general, they be categorized as follows:

**Passive-Functional:** These types of prostheses are usually made to look like your natural arm or hand. They do not move on their own, but they can hold different attachments to help with some tasks. You can move or position them using your other hand.

**Body-powered:** These types of prostheses use a harness and cable system that you control with your own body. By moving your shoulder or arm, you pull a cable that opens or closes the device at the end (called a terminal device). These prostheses are usually strong and reliable, and they work well for many daily activities as well as heavy-duty jobs.

**Externally powered (Myoelectric):** These prostheses are powered by a battery. They have sensors that detect small muscle contractions, which then control the device. Because they use electronics, they are not as tough as body-powered prostheses and many are not waterproof. Still, many active people use them successfully if certain precautions are taken.

**Activity-specific:** Some prostheses are made just for certain hobbies or sports. These are called activity-specific prostheses. For example, there are attachments for things like holding a fishing reel, swinging a golf club, or riding a bike. While insurance usually only covers one prosthesis, many terminal devices can be swapped out, making one prosthesis useful for multiple activities.



## Terminal Devices

The terminal device is found at the end of the prosthesis and can be used to grasp objects, provide aesthetic value, and perform other tasks. There are terminal devices available for body-powered, myoelectric, and hybrid prostheses.

**Hooks**

Allow you to hold and squeeze objects between two split hooks.

**Prehensors**

Consist of a thumb-like component and a finger component that may resemble a lobster claw, pliers or a bird's beak.

**Artificial Hands**

Designed to function more like a human hand. Most prosthetic hands make use of a pinching or squeezing function, using the thumb and first two fingers. Others have individual powered digits and adjustable grip control.

**Activity-Specific**

Are designed to help people perform specific activities and tasks often related to recreation or job duties, such as swimming, golfing, hunting, fishing, playing baseball, and weight-lifting – just to name a few.

| | |
|---|---|
| **Hooks** | |
| **Typical Advantages** | **Typical Disadvantages** |
| • Highly functional<br>• Easy to use<br>• Able to grasp small objects<br>• Durable<br>• Lighter weight<br>• Lower maintenance and repair costs<br>• Good visual feedback<br>• Able to tolerate high heat | • Mechanical look<br>• Tips of hooks are more prone to get caught on things<br>• Decreased grip strength |
| **Prehensors** | |
| **Typical Advantages** | **Typical Disadvantages** |
| • Highly functional<br>• Easy to use<br>• Durable<br>• Moderate visual feedback<br>• Do not look as threatening as a split hook<br>• Not as likley to scratch objects as a split hook<br>• Not as likely to get caught on things as a split hook | • Challenging to pick up small items<br>• Reduced visual feedback compared to split hook<br>• Not as good for typing |
| **Artificial Hands** | |
| **Typical Advantages** | **Typical Disadvantages** |
| • Look more like human hands<br>• Move like natural hands<br>• Specialized grip patterns<br>• Stronger grip force | • Less durable than hooks and prehensors<br>• Reduced visual feedback<br>• Higher cost<br>• Can be more expensive to maintain (depending on type)<br>• Glove covering hand can stain, get dirty |

## Nuances of the Wrist Disarticulation Prosthesis

For people with a wrist disarticulation, using a prosthesis can sometimes make their arm longer than it used to be. This extra length can make it harder to do daily tasks like bringing a spoon to their mouth or reaching the middle of their body. In the past, it was tough to find a prosthetic arm that worked well and was the right length for this type of limb difference.

But over the last ten years, prosthetic companies have made big improvements. Now, many prosthetic parts are designed to be shorter at the wrist, which helps keep the device closer to the natural arm length. This means people can choose parts based on how they want to use the prosthesis—whether it's for work, hobbies, or everyday tasks—without making the arm too long or uncomfortable.

### Socket Interface for Upper Limb

A wrist disarticulation socket may appear a lot like other below-elbow (transradial) sockets. The socket is the part of your prosthesis that fits over your limb. It connects your body to the rest of the prosthesis. If the socket doesn't fit well, it can cause problems like blisters, skin irritation, and pain. When you first start using your prosthesis, ease into it gradually. Your prosthetist and occupational therapist will help you build up a wearing schedule. After each time you wear it, check your skin. If you see redness that doesn't go away after 15 minutes, tell your prosthetist so that they can adjust the fit.

# TIPS FOR STAYING HEALTHY & PREVENTING INJURY

Staying active and exercising regularly can help you live well with limb loss. Physical activity can improve your strength, energy, and overall health. Exercises like walking, swimming, lifting weights, or using resistance bands can help you build muscle and increase endurance. Over time, staying fit may also lower your risk of injuries. Your healthcare team can help create a safe and effective exercise plan that works for you.

It is important to know that people with limb loss or limb difference have a higher risk of overuse injuries. This means other parts of your body—like your elbows, shoulders, neck, or back—might be working harder to make up for the missing limb. This can happen with or without a prosthesis. For people with wrist disarticulation, these areas are especially at risk. In fact, about half of people with limb loss in one arm may experience overuse injuries at some point.

The good news is that these injuries can often be prevented with proper movement and training.[7] If you start to notice pain, tightness, or discomfort, tell your healthcare team right away. Catching these problems early can help prevent long-term pain, arthritis, or bone issues.

Your doctor may recommend different treatments, such as:

- Physical therapy
- Pain-relief medicines like ibuprofen or other NSAIDs
- Creams or ointments that reduce pain
- Cortisone shots (injections to reduce swelling)
- Surgery (only if other treatments don't work)
- Occupational therapy or job-related rehab to help prevent injury

Always talk to your doctor or therapist if something doesn't feel right. With the right care and support, you can stay active and healthy while protecting your body.

# LIVING WELL WITH WRIST DISARTICULATION

Ideally, your comprehensive care plan shouldn't end after surgery. Continuing to work closely with a team of healthcare professionals over time is important. Early on, you may need check-ins every three months, and then every six months as time goes on. These visits help make sure you are reaching your goals, staying healthy, and continuing to improve your functional skills and independence.

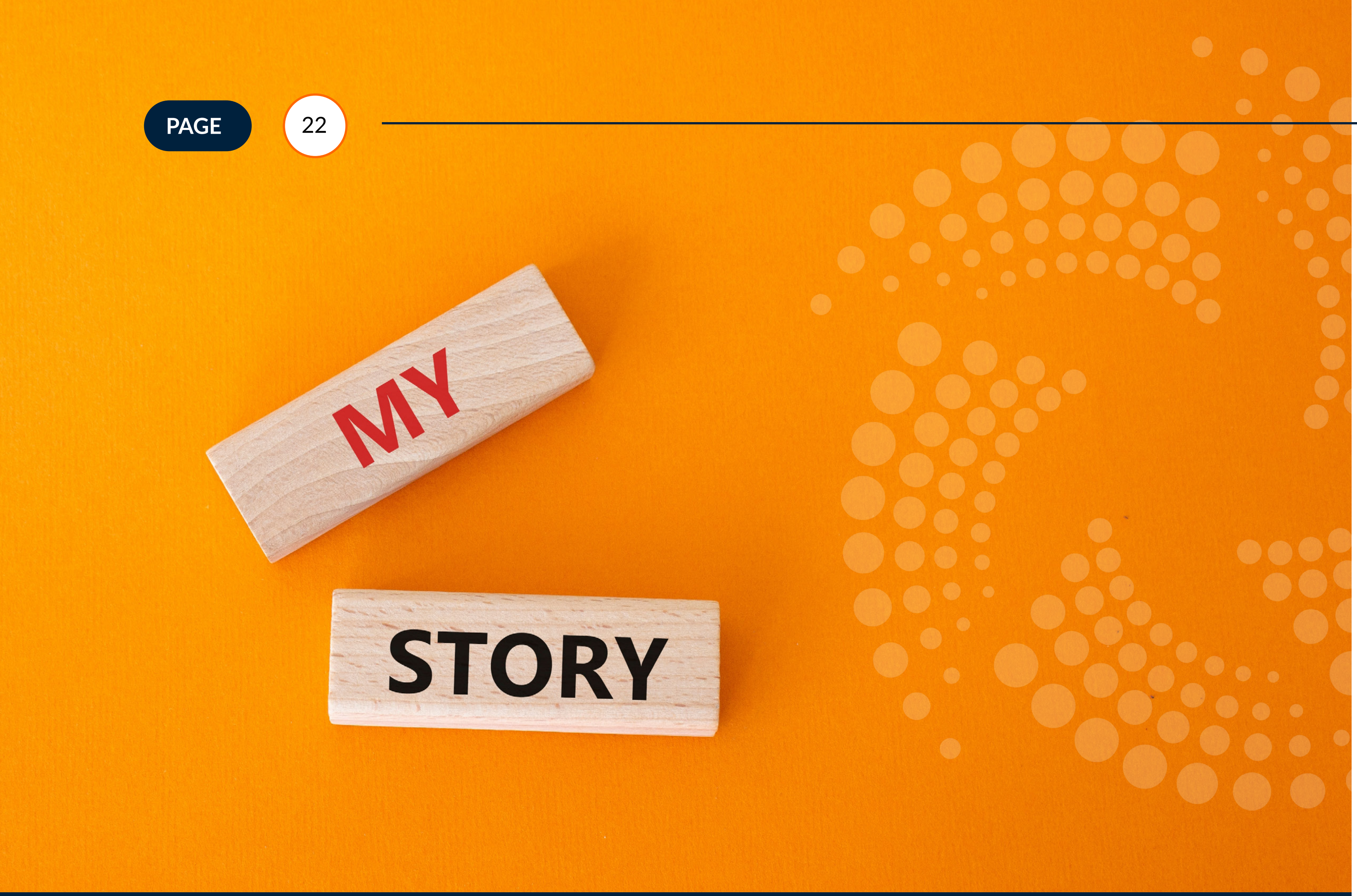
If you use a prosthesis, regular appointments with your prosthetist are important for making sure your device fits well and works the way it should. These check-ins are already included in the cost of your prosthesis, so do not hesitate to use them when you need help or have questions.

# PEER SUPPORT & CAREGIVER SUPPORT

You do not have to go through this journey alone. Peer support can be a powerful resource, both during your recovery and in the years that follow. The Amputee Coalition can connect you with a Certified Peer Visitor—someone who also lives with wrist disarticulation or upper limb loss and understands what you are going through.

While some parents learn about their child's limb difference during pregnancy through routine screenings, while others find out a birth. No matter when you learn the news, it's normal to feel overwhelmed at first. The good news is that there are many ways to support your child so they can grow up confident and capable. Do not forget to take care of yourself, too. If you are feeling overwhelmed, reach out to friends, family, or healthcare providers. You can also connect with the Amputee Coalition for peer support from other parents who understand what you are going through.

Remember, you are not alone—there's support available no matter what role you play in someone's journey with limb loss or limb difference.



**Personal Story:**

"My journey began with a severe allergic reaction to a new medication, which resulted in my body becoming septic. At the time, the doctors told my family that I only had a 9% chance of survival. Fortunately, the doctors were able to save my life, but blood had to be redirected to my heart which left my extremities in bad shape. After a couple of opinions from different doctors, we were able to save more of my limbs than we originally thought, and I had bilateral amputations at my wrists. I had to go through many hours of rehab where I learned helpful techniques to desensitize my residual limbs, and methods for performing daily activities independently. This is also when I discovered my love for peer support. Helping to heal others has truly helped heal me as I have learned to live with my limb loss. This has brought me immense joy and helped me to focus on the good things while also pushing me to work hard for the things I really want."

- Kim Gilliam Steele

# ADDITIONAL RESOURCES

This booklet is just one of the resources the Amputee Coalition provides to help amputees live well with limb loss and limb difference. For more information, check out these additional resources on our Web site:

**Amputee Coalition**
Amputee-Coalition.org

**National Limb Loss Resource Center®**
Amputee-Coalition.org/service/find-support-services

**Certified Peer Visitor Programs**
Amputee-coalition.org/service/request-peer-support

**Support Group Network**
Amputee-coalition.org/service/find-a-support-group

**Educational Resources**
Amputee-coalition.org/service/national-limb-loss-resource-center

**Youth Engagement Program**
Amputee-coalition.org/empowering-the-next-generation

## COMMUNITY RESOURCES

**Community Connections | Limb Loss Resource Database – nllrc.amputee-coalition.org**
Whether you are looking for local services or a space to engage with others who share similar experiences, our Community Connections database provides valuable connections to help you navigate your journey. Search by zip code for support groups, adaptive sports programs, and other community services and partner organizations.

**Association of Children's Prosthetic-Orthotic Clinics, ACPOC – www.acpoc.org**
The Association of Children's Prosthetic-Orthotic Clinics (ACPOC) provides a comprehensive resource of treatment options provided by professionals who serve children, adolescents, and young adults with various musculoskeletal differences including upper and lower limb loss and deficiencies.

**Enhancing Skills for Life – www.enhancingskillsforlife.org**
Enhancing Skills for Life is a nonprofit organization that supports people living without both hands or all four limbs by providing education, resources, programs, events (with scholarship support) as well as peer connections.

**Lucky Fin Project – www.luckyfinproject.org**
The Lucky Fin Project enables children with upper-limb difference to attend specialized camps and obtain prosthetics, maintains a support network for parents, provides education on limb differences, and links parents to medical information and resources

## CONTRIBUTORS

The Amputee Coalition is grateful to the many organizational members and individuals that have contributed to this work. The Amputee Coalition Scientific and Medical Advisory Committee (SciMAC) conducts expert peer view for the Amputee Coalition commissioned patient education materials. SciMAC contributes clinical and scientific expertise in developing, implementing, and evaluating the Amputee Coalition program and policy initiatives.

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**About the Amputee Coalition**
The Amputee Coalition is a donor supported, voluntary health organization serving 5.6 million people with limb loss and limb difference and more than 28 million people at risk for amputation in the United States.

**For more information, please call 888/267-5669 or visit amputee-coalition.org.**

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# ABOUT THE AMPUTEE COALITION

The Amputee Coalition is a national donor-supported, nonprofit health organization serving the over 5.6 million people who have limb loss and limb difference in the United States.

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