

Engelsk

## INTRODUCTION

Facing amputation is a profoundly challenging experience, but with time, you'll discover that it becomes more manageable. For those of you who are family members or close friends, there are unique challenges to navigate as well.

Initially, it may feel like everything is in disarray and almost surreal. During this phase, emotions like helplessness, emptiness, anger, and a myriad of negative feelings may overwhelm you. Please know that these reactions are entirely normal. The goal of rehabilitation is to help both amputees and their loved ones regain a sense of wholeness, safety, and happiness. Achieving this demands effort, but you are not alone; there are people here to support you. Be open to advice and assistance from those closest to you, various professionals, and individuals who've walked a similar path.

This brochure has been collaboratively crafted by prosthesis users and their loved ones, with the guidance of healthcare professionals. Our aim is to share insights, guidance, and personal experiences that will benefit you. We hope this brochure provides you with the ability to look forward to a better everyday life, as that brighter future will indeed come.

As experienced prosthetic users and their close ones, we stand ready to offer support through visits and conversations. There's an abundance of inspiration to be found in sharing experiences.

## PAIN, PHANTOM PAIN, AND DISCOMFORT

Losing a limb alters the signals your brain receives from your body, leading to a sensation of pain and discomfort from the missing body part. Phantom pains are very normal, and the experience varies from person to person. Sometimes, the pain gradually subsides, but not always.

Some individuals may experience minimal or no discomfort, while others might endure chronic, severe pain or episodic pain with intense peaks. The occurrence and intensity of phantom pain are not set in stone, and there's no one-size-fits-all solution for avoiding or alleviating it.

In planned hospital amputations, there is a greater chance of preventing or minimizing phantom pain. Preoperative measures, such as epidural and peripheral anesthesia, can provide a pain-free period of 3-4 days before the procedure, reducing the likelihood of phantom pain.

There is no universal treatment for phantom pain. What brings relief to one person may not work for another. Some find relief from phantom pain through medications when wearing a prosthesis or by using specially designed stump socks when not using a prosthesis. Others may require prescription pain relievers from a doctor or pain clinic.

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You may also experience a dull pain or nerve pain, which often diminishes over time, especially after you start using a prosthesis. However, there's no one-size-fits-all answer to how pain is experienced or relieved.

Some individuals find physiotherapy soothing, while others benefit from treatments like TNS (transcutaneous nerve stimulation), acupuncture, relaxation techniques, hypnosis, medications, healing practices, or simply listening to music through headphones as a way to redirect their brain's focus away from the pain. The key is that there are individual variations, and it's vital to consult with a healthcare professional for a tailored assessment and recommendations. Talk to your physiotherapist or general practitioner and inquire about a referral to a pain clinic.

## Swelling

Stump swelling is a result of fluid accumulation from the amputation surgery. This swelling will naturally subside over time, but you can expedite the process by using a compression bandage or a silicone- or gel-based liner that rolls onto the stump for relief.

Prosthetic fitting usually begins before the swelling has completely subsided, and using a prosthesis may help reduce the swelling. Be prepared for occasional adjustments or replacements of the prosthetic sleeve, and don't hesitate to reach out to your orthopedic engineer if you have any questions.

For leg amputees, avoid letting the stump hang down while sitting; use a stool or footstool to elevate your leg. Be mindful when selecting new shoes, opting for those that fit well, offer comfort, stability, and preferably have a secure heel cap and wide soles. The prosthesis is designed to work best with shoes that match the heel height. Avoid using worn-out shoes unless your prosthesis can adjust to different heel heights. Consult your orthopedic engineer if you wish to modify the heel height or wear high-heeled shoes.

## HYGIENE AND WOUND TREATMENT

Maintaining proper hygiene for the stump is crucial, especially since it may be enclosed in the prosthetic sleeve for extended periods. Cleanliness is essential for keeping the skin healthy, soft, and free from chafing and blisters. Wash the stump thoroughly every day, preferably in the evening, using mild, unscented soap with a low or neutral pH value, which won't strip the skin's natural oils. Rinse thoroughly and pat dry with a soft towel. A mirror can be useful for inspecting the stump for signs of blisters, cracks, or sores. If you spot red marks or ulcers, contact your orthopedic engineer and limit prosthetic use until the issue is resolved.

You can apply mild, unscented ointment or cream to the stump, allowing it to dry overnight. Avoid excessive sun exposure to prevent sunburn on the stump. For wounds or blisters, a medicinal soap bath may assist in cleansing and healing. Special blister

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bandages and other aids are also available. The prosthetic sleeve, which is in direct contact with your skin, should be cleaned daily with a damp cloth or disinfecting wipes. If you sweat significantly, consider removing the prosthesis during the day to clean and dry the inner part that touches your skin. Some people find relief by using antiperspirant. Ensure the sleeve remains empty at night to allow for ventilation. Seek advice from your orthopedic engineer or nurse – regarding suitable care products.

## PROSTHESIS ADJUSTMENT

Once the stump swelling has subsided, new measurements will be taken for the prosthesis, which may involve a plaster cast, a direct socket, or scanning of the stump. A trial sleeve is typically crafted to assess how well it fits, and a trial prosthesis is made and adjusted for maximum comfort and functionality. Trying on this new trial prosthesis may occur at an orthopedic workshop, a training institution, or even at home.

Prostheses come in various types, tailored to individual needs. Whether you seek a simple functional prosthesis, a cosmetic one, or an advanced functional prosthesis, or have specific preferences regarding appearance, you can discuss your requirements with your orthopedic engineer. The main concern is minimizing any discomfort while using the prosthesis. While complete pain relief may not always be achievable, be sure to communicate any discomfort to your orthopedic engineer.

For mental well-being, you can request a prosthesis in a color you like, opt for a cosmetic prosthesis that matches your skin tone for a more discreet appearance, or even personalize it with a print of someone dear to you. The possibilities are diverse, and your orthopedic engineer will guide you in exploring them.

## EXERCISE AND PROSTHETIC FUNCTION

Rehabilitation usually begins shortly after amputation, starting with fundamental exercises to maintain movement and strength in the remaining muscles and joints. Regular training is vital to preserve strength and mobility and counteract muscle imbalances that can result in unwanted stump positioning and prosthesis fitting difficulties.

Continuing with exercise even after rehabilitation is essential. Engage in daily exercises and be as active as your overall health allows. The pace at which you adapt to your prosthesis varies from person to person and depends on factors like the severity of amputation, the stump's length and condition, your health, and motivation. Some may adapt within a month, while others may take several months.

Balanced and consistent training is advised, neither too much nor too little. Striking the right balance is crucial. Physical activity enhances strength and mental well-being, so consult your physiotherapist during your rehabilitation.

If you were physically fit before amputation, you may find post-rehabilitation training more manageable. Many individuals draw motivation from exercises that allow them to resume activities they enjoy, albeit with some adjustments. Your orthopedic engineer can assist you in finding the best solutions.

## RIGHTS

Amputation may impact your and your family's finances, but there are often support options available based on your specific needs. Some benefits are provided by government agencies like the Norwegian Labour and Welfare Administration (NAV), while others are means-tested.

Costs related to standard prostheses, spare prostheses, and shower prostheses are covered by National Insurance. Special prostheses tailored for specific gripping or activity needs can also be applied for. You have the freedom to choose any orthopedic workshop, and expenses for travel and accommodation to the nearest workshop are reimbursed, with exceptions based on individual circumstances. Typically, travel within the health region is covered, but there can be exceptions to ensure you can access the workshop that suits you best.

Your general practitioner can request physiotherapy treatment with full reimbursement. Basic allowances are available to cover extra expenses for transportation and clothing, but these are means-tested. You must demonstrate that you've had additional costs in the last three months before applying.

You can apply for rehabilitation, disability benefits, housing and car benefits, depending on your needs. These benefits vary in rates, depending on your specific needs and how well-founded your application is. During your rehabilitation stay, consult with an occupational therapist and/or social worker to identify and apply for the coverage you require. If you're at home, seek advice from your local municipality's occupational therapist, social worker, GP, or the social security office. Alternatively, you can contact Momentum for assistance.

In cases involving hospital errors or accidents, you may be entitled to compensation beyond what the public sector provides. In such instances, consulting with a lawyer is advisable. Momentum can guide you to lawyers with relevant experience who can assist.

## EQUAL HELPS EQUAL: SHARING EXPERIENCES

Questions will inevitably arise, whether they pertain to prosthetic information, pain management, rehabilitation, or practical solutions for daily life. Connecting with someone who has faced similar challenges can offer invaluable help and inspiration, whether you're recently amputated or have been using a prosthesis for a while. We're here to assist and inspire.

Equal peers are individuals who have experienced amputation or were born without limbs, and they've navigated their unique journeys. These experienced volunteers have undergone training and taken an oath of confidentiality. While they're not medical professionals, they can share their experiences and guide you to the right resources. They understand that feelings and reactions evolve over time, and they're available across Norway, willing to meet you at home, in a hospital, or a rehabilitation center.

Reach out to us, and our peer coordinators will strive to connect you with a peer who suits your specific needs.

### NEXT OF KIN: A LISTENING EAR

Next of kin refers to individuals with a familial connection to the amputee. As a next of kin, you are also deeply affected by the amputee's situation, yet you might sometimes feel overshadowed by the focus on the amputee. You may have as many questions as the amputee and experience various emotions.

As a next of kin, Momentum's volunteers can be a source of support during challenging times. They offer a listening ear and guidance, drawing from their own experiences as next of kin to prosthesis users. They can help you navigate feelings of guilt or uncertainty and assist you in finding solutions to the unique challenges you face.

There is no one-size-fits-all response to the myriad of emotions that next of kin experience, and it's entirely natural. By sharing their experiences, our volunteers can help you identify opportunities, solutions and explore your path forward together.