# COLOURING BOOK

European Reference Network
VASCERN

European Patient Advocacy Group

# Introduction

This colouring book offers a fun and interactive way for children to learn about managing lymphoedema. The activities in the book are tailored to educate children on the importance of proper skin care to prevent infections and keep their skin healthy.

Children will also learn about the role of compression garments and bandaging in reducing oedema and improving lymph circulation. By engaging with these activities, children can better understand why these practices are important and how they can help manage their condition.

Our goal is to empower children and their families with the knowledge and tools they need to confidently manage lymphoedema. We believe that by making learning interactive and enjoyable, we can foster a positive attitude toward managing the condition.

We hope that this colouring book will be a valuable addition to your child's learning journey. It provides a comprehensive and child-friendly approach to lymphoedema care, ensuring your child can lead a happy, active, and healthy life despite the condition. Enjoy the activities and let the learning adventure begin!

This colouring book was adapted from our Do's and Don'ts on Skin Care and Do's and Don'ts on Compression for Children, and inspired by the infographic.

# Skin Care

A person with lymphedema is more prone to develop an infection in the affected limb or area due to a localised reduction in lymph fluid drainage capacity and, consequently, to impaired immune function. This is why meticulous skin care is important. The purpose of skin care is to reduce the risk of skin breakdown, fungal infections, or cellulitis/erysipelas. These problems can worsen lymphedema and make the edema harder to manage. Daily management and monitoring keeps the skin supple, soft, and more resilient.

## ✓ WHAT IS RECOMMENDED

- Wash your skin daily (if possible) with warm water and, if the skin is very dry or fragile, use a soap-free cleanser
- Carefully dry your skin, especially in between skin folds, toes and fingers, in order to avoid fungal infections or tissue maceration.
- Moisturise daily with a lotion or cream suitable to your skin type making sure it is completely absorbed before applying compression garments (especially when you have compression garments produced with natural rubber). Use a towel to wipe away any excess moisturiser. Consider moisturising at night-time.
- Protect your skin from the sun by wearing your compression garments and applying UV protection cream where skin is exposed.

# Paediatric and Primary Lmphoedema

- Protect your skin from bites, scratches, cuts, burns and abrasions. Wear your compression garments and take care around pets. For those with upper limb lymphedema, use garden gloves, oven mitts, and dishwashing gloves, as necessary. For those with lower limb lymphedema, use correctly fitted shoes and socks to avoid friction and blisters. Consider using protective shoes at the beach to avoid walking barefooted.
- To avoid burns, be careful when exposing your skin to high temperature surfaces or water (e.g. saunas, spas, or bath water).
- Use insect repellent when necessary
- Pay attention with nail care, obtain a medical pedicure, or see a podiatrist for toenail problems.
- Check your skin daily for any changes such as breaks in the skin, leakage of lymph fluid, pressure points from compression garments or changes in colour.

## WHAT YOU SHOULD NOT DO

- Do not ignore signs of infections such as redness, rash, warmth, or tenderness/pain. Seek medical attention immediately if there is a suspicion of infection.
- Do not ignore leakage of lymph fluid. Keep skin clean and dry while still applying your compression garments or bandages and seek medical attention if needed.
- Do not ignore wounds on your affected limb. Clean and disinfect the wound. Seek professional advice in case of worsening or a slow healing process.

## Paediatric and Primary Lmphoedema

- Do not ignore pain, signs of pressure or friction from your garments, silicone band or bandages. It might mean that they should be refitted, or the bandage reapplied.
- Do not use a hair removal method on your affected limb that may upset the skin integrity or create skin breaks.

# Children’s Compression

Children with lymphoedema will need to wear different types of compression garments throughout their life. It is therefore important that parents/carers pave the way to independence based on well-founded specialist knowledge and personal body awareness. Compression should be something positive, not a daily fight!

Depending on the competence of the child, these are some tips to encourage the child to wear their garments or have bandages applied.

## ✓ WHAT IS RECOMMENDED

- Explain lymphoedema and the need for compression in a child-friendly manner.
- Create a routine to make the treatment part of their normal life.
- Make it a team effort between the carer(s) and the child to manage the lymphoedema.
- Give the child a sense of ownership of their self-management such as rolling up bandages.
- Make bandaging fun by helping them bandage their favourite cuddly toy or doll – or another family member.

# Paediatric and Primary Lmphoedema

- Make compression fun and fashionable. Examples include, allowing the child to choose their favourite colour of garment, applying stickers, and using colourful tape to secure the bandages.
- Connect with other families with children with lymphoedema for support and to create a sense of normality for the child.
- Consider involving social networks (i.e., school, recreational activity groups) and share information about lymphoedema and compression with them. Reach out to your patient association for support.

## WHAT YOU SHOULD NOT DO

- Don‘t put additional pressure on the child. Show understanding by saying: "I can understand that you don't feel like it today".
- Don’t allow the lymphoedema to progress by not wearing adequate compression.

make it a team effort

make it a routine

explain the need
for compression

make bandaging fun

take care
of wounds

don't limit yourself

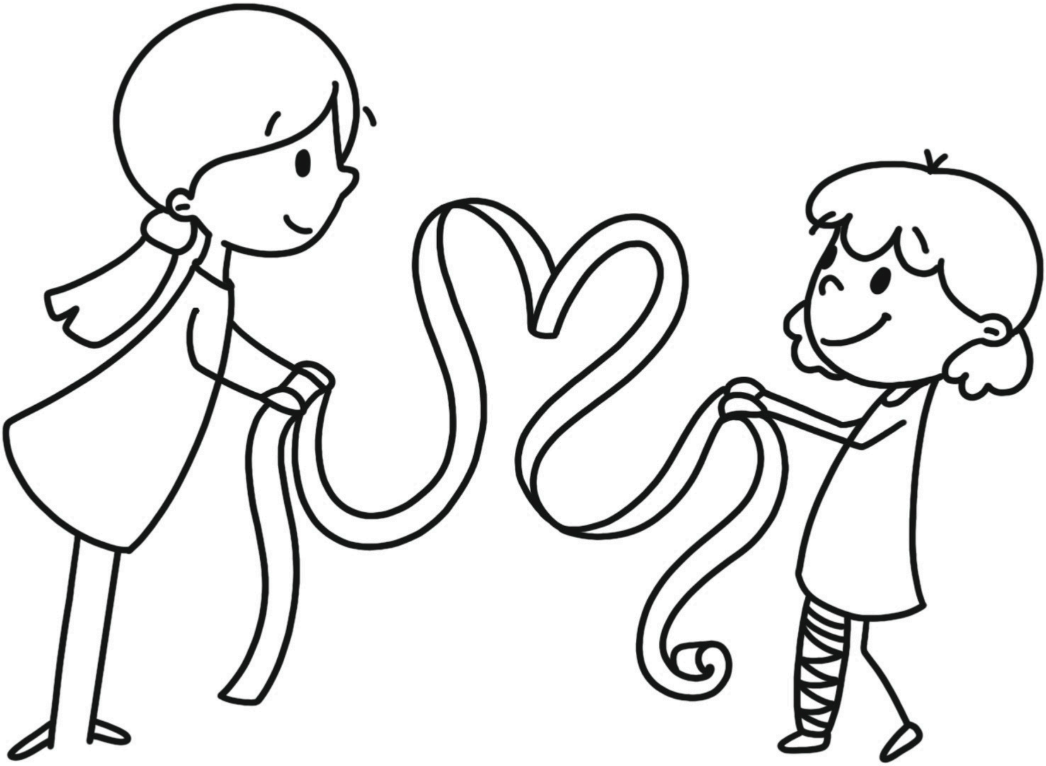
come as you are

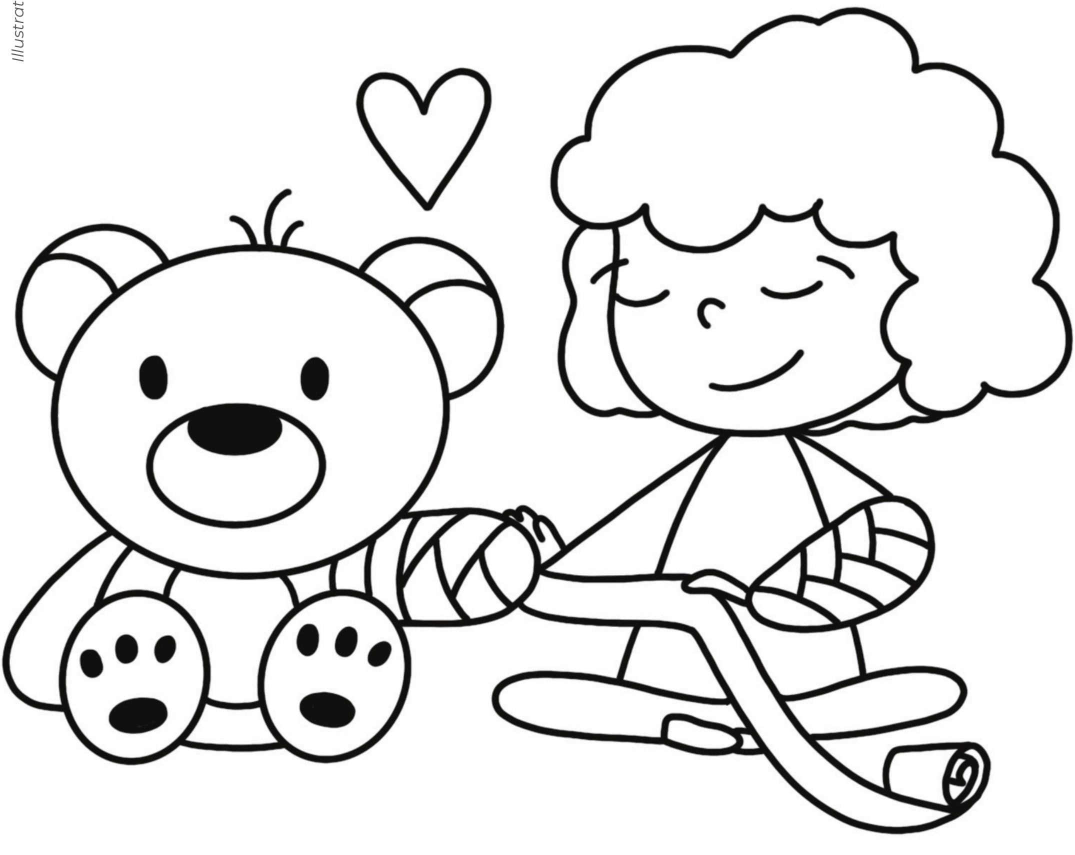
explain lymphoedema

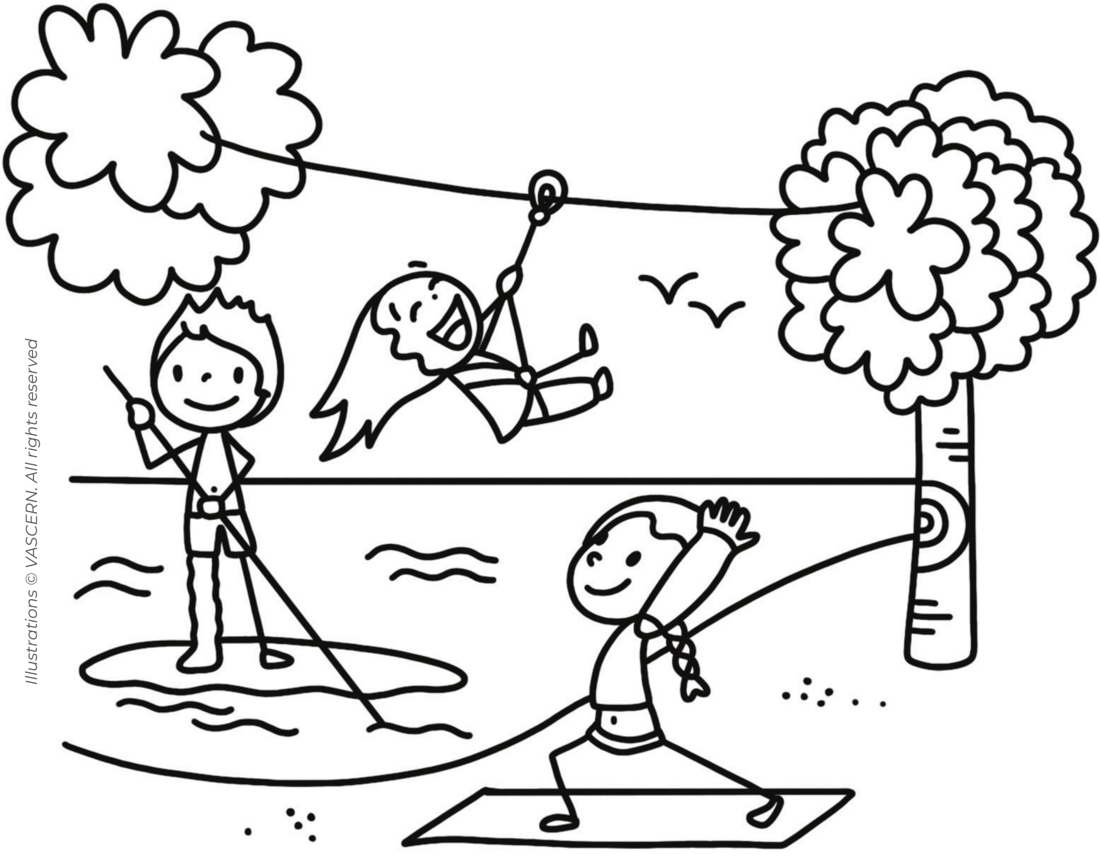
don't expose your body
too long to high temperatures

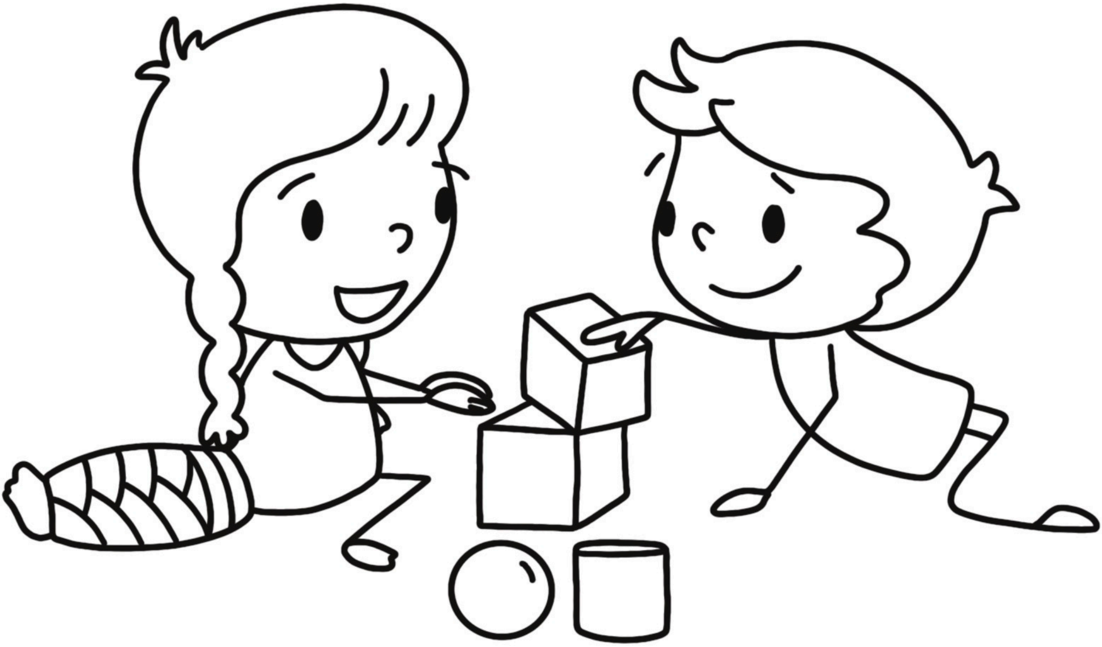
make your skin-check
a routine

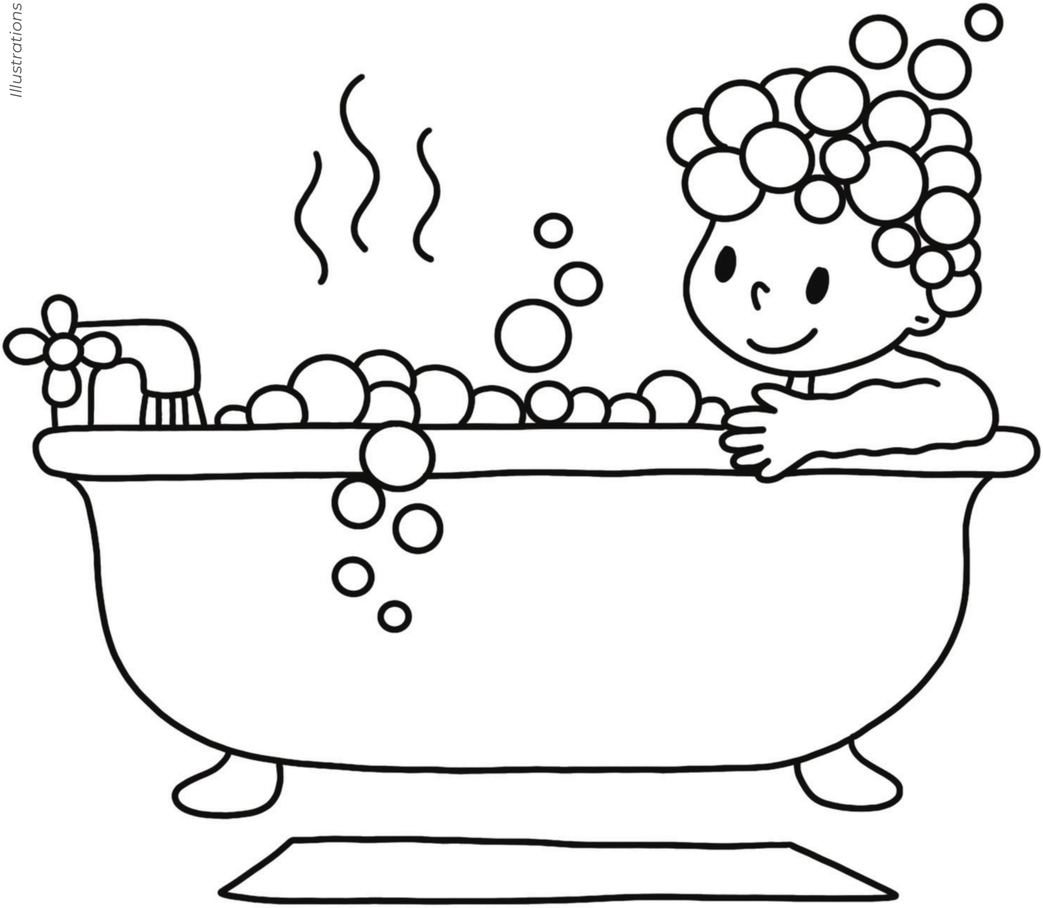
ask for help if needed,
don't be alone











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**HCP member before Brexit, January 1st, 2021*

***Cooperating guest*

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European
Reference
Network

VASCERN

Gathering the best expertise in Europe
to provide accessible cross-border healthcare
to patients with rare vascular diseases

VASCERN, the European Reference Network on Rare Multisystemic Vascular Diseases, is dedicated to gathering the best expertise in Europe in order to provide accessible cross-border healthcare to patients with rare vascular diseases (an estimated 1.3 million concerned). These include arterial diseases (affecting aorta to small arteries), arterio-venous anomalies, vascular malformations, and lymphatic diseases.

VASCERN currently gathers 48 expert teams from 39 highly specialized multidisciplinary HCPs, plus 6 additional Affiliated Partner centers, coming from 19 EU Member States, as well as various European Patient Organisations, and is coordinated in Paris, France.

Through our 6 Rare Disease Working Groups (RDWGs) as well as several thematic WGs and the ePAG – European Patient Advocacy Group, we aim to improve care, promote best practices and guidelines, reinforce research, empower patients, provide training for healthcare professionals and realise the full potential of European cooperation for specialised healthcare by exploiting the latest innovations in medical science and health technologies.

More information available at: www.vascern.eu

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