

A life with limited energy

Reflection booklet for people with
energy-limiting chronic illnesses



Information about the project

This booklet is aimed at people with a chronic condition that limits their energy levels. (These include, for example, ME/CFS, EDS, fibromyalgia, MS, post-COVID, etc.) Please feel free to adapt the questions so that they apply to you. Share whatever you feel comfortable sharing with me. You don't have to answer everything.

Your answers can be brief, in the form of drawings or photos; there are no right or wrong contributions.

I would like to gather personal insights into your daily life, your needs and your tried-and-tested strategies.

The aim is to use the experiences gathered to develop a practical toolbox offering concrete help, everyday tips and ideas to make life with a chronic energy-limiting condition easier.

Thank you so much for sharing your time and experiences with me — both are incredibly valuable.



Questions / Suggestions to:
stella.waldvogel@zhdk.ch

Data processing

The scans/photos of the pages will be included in my written Master's thesis in an anonymised form. By sending me the pages, you agree to this. You may withdraw your consent to the use of the data you have provided at any time up until November 2026. (This is only possible if you send me an email.)

Please feel free to send me an email: stella.waldvogel@zhdk.ch

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Overview

How old are you? (in years, e.g. 35)

Gender

F

☐

D

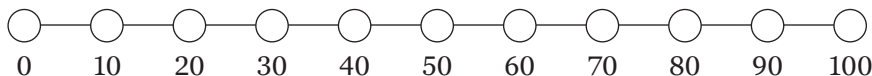
☐

M

☐

What diagnosis(es) have you been given?:

How high is your energy level normally? (Bell scale)

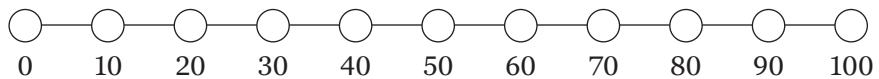


Bad day

What does a bad day look like for you?

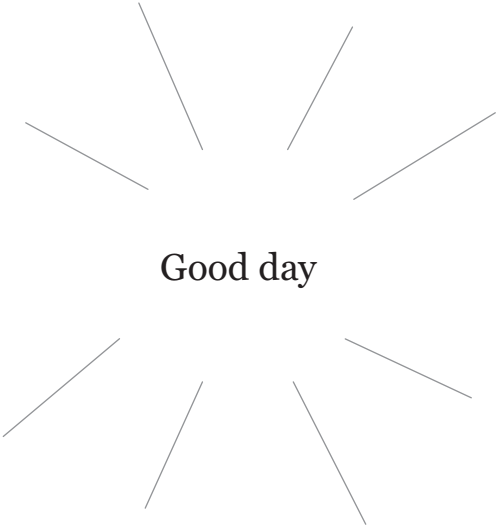
Bad day

How high is your energy level on a bad day? (Bell scale)



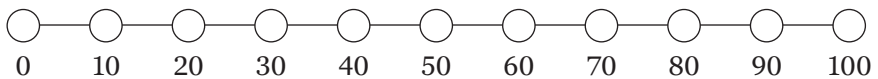
Good day

What does a good day look like for you?



Good day

How high is your energy level on a good day? (Bell scale)



Masking

Do you ever find yourself hiding your illness or playing it down? In what situations does this happen?

[draw/paint/write]





Energy draining things

What drains your energy? Rate how much energy the activity takes out of you. 1 = takes very little energy, 10 = takes all your energy. E.g. conversations, working, showering, cooking, sensory stimuli, going shopping, being out and about, etc.

1-10 Noise

[illegible]

Energy boosters ~~~~~

What gives you energy? Is there anything that helps? Rate how much energy the activity gives you. 1 = little, 10 = a lot

E.g. lying down, eating, being on your own, painting, having a bath, etc.

1-10 Lie down

[illegible]

Limitations

In what ways does your illness make you feel restricted?

[draw/paint/write]

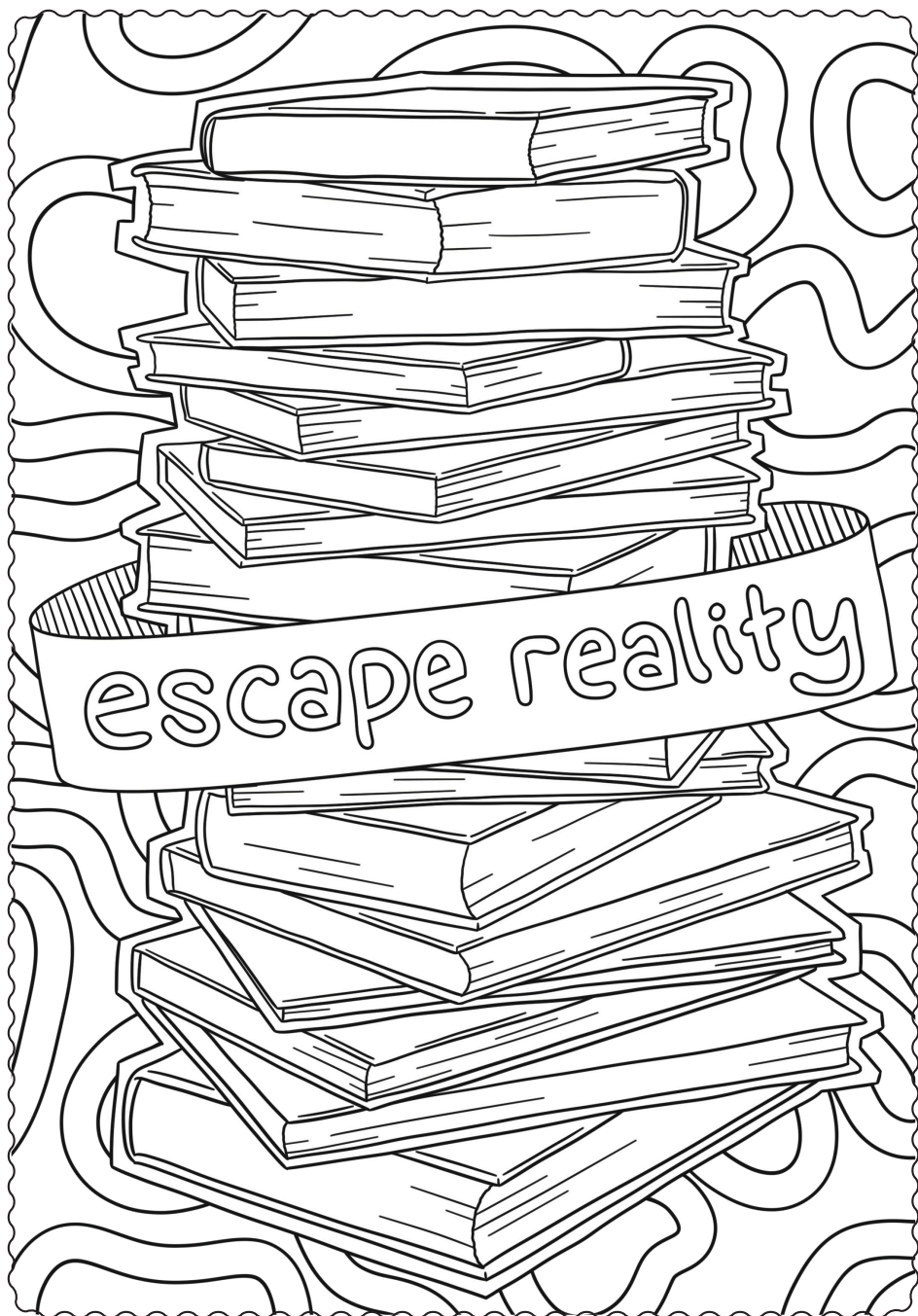


Impact on cognitive processes

Have you noticed any changes in your thinking, concentration, memory, imagination, perception, problem solving etc.? Can you describe how that feels to you? Are there things that help you with this?

[draw/paint/write]





Diagnosis

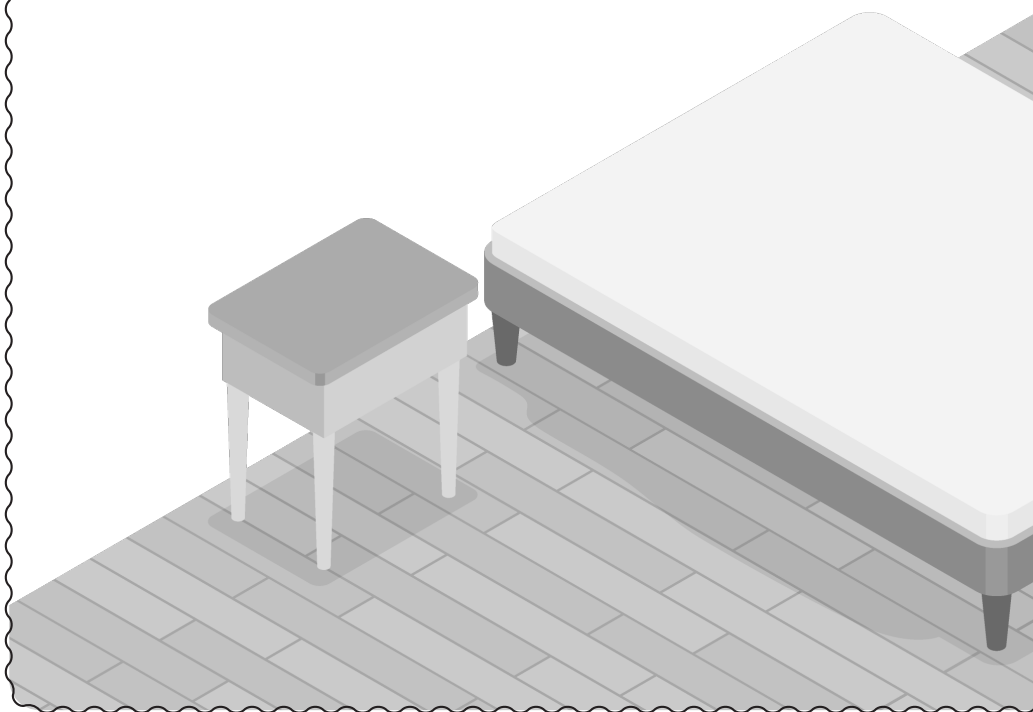
How did you receive your diagnosis? What would you have liked to have known or been given straight after?



Bedroom furnishing + décor

How should your room be arranged so that you can relax?

Lighting, cushions, drinks, windows, blankets, heating, cooling, music, eye mask, earplugs, white noise, etc. [add/draw/paint/label]





Don'ts

What have people around you said that was unwelcome?



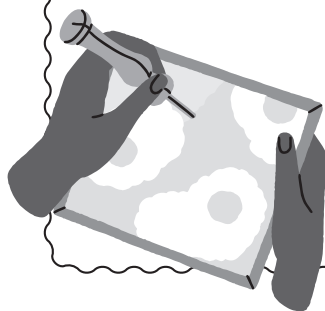
Do's

What have people around you said that has made you feel better?



Energy-friendly hobbies

Have you discovered any new hobbies that are low-impact?
Or have you adapted an old hobby so that you can still do it, or start
doing it again, despite your illness? If so, how?



Community

Do you talk to other people in a similar situation? If so, in what way?

E.g. online (in forums / on social media / at conferences), face-to-face, in self-help groups at events / conferences, etc.

How does talking to others help you?



Setting boundaries

What boundaries do you set in your daily life, and what helps you to set them? E.g. going home earlier, using noise-cancelling headphones on public transport, etc. [draw/paint/write]



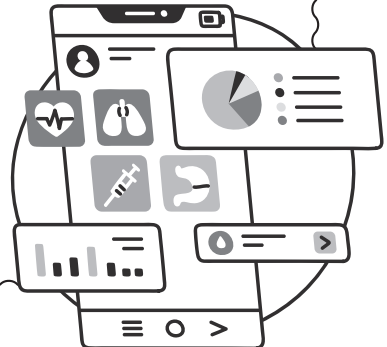
Symptoms

What symptoms are you experiencing?



Track symptoms

Do you keep track of your health or symptoms? How do you do it, and what motivates you? Do you use an app, a spreadsheet, a notebook, etc.? Do you do it for example, for doctors, your health insurance provider, credibility, or your own record-keeping, etc.



Flare-Up plans

Do you use flare-up plans to explain how you can be helped during a flare-up?

Symptom	Signs and questions that can help	Things that help
Headache	▪ Massage / rub the temples or the back of the neck ▪ Need a nap (?) ▪ Sensitivity to stimuli: light / noise / smells / stress ▪ “Is it a migraine?”	▪ Painkillers ▪ Move away from the trigger ▪ Drink something and lie down ▪ Cool your head (mask) ▪ Migraine medication

Goals & Self-image

Have your goals and self-image changed since your diagnosis? If so, how exactly? For example: what you thought you would do in the future, how you view your own body, the extent to which you identify with your hobbies, and so on.

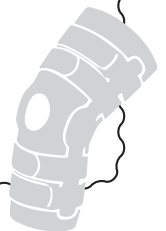
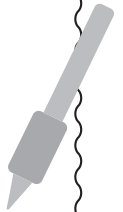
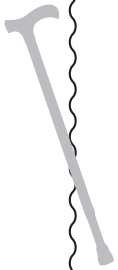
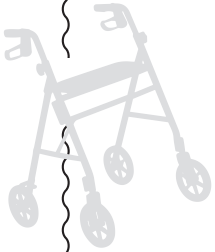


Assistive devices

Do you use any aids in your daily life? What do they look like?

How do they help you / what do they make easier for you?

[draw/paint/write]



Everyday life hacks

Do you have any tips that make housework easier? This is the place to share all your tips and tricks (including DIY and design ideas).

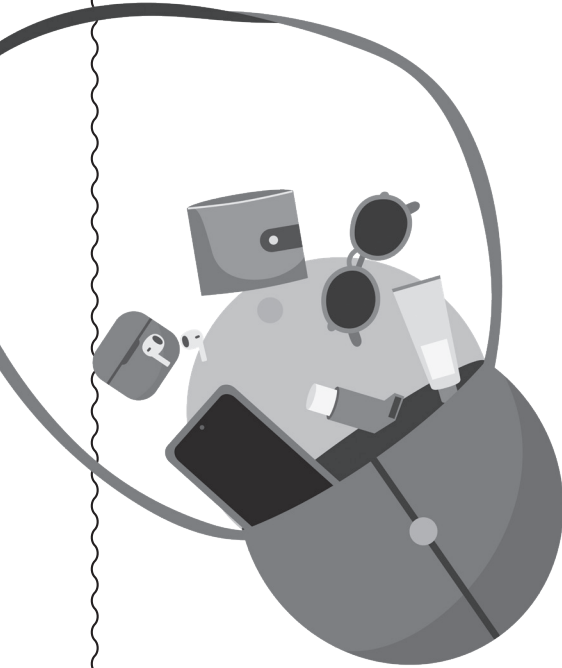
For example: not ironing laundry, using a stool when cooking, robot vacuum cleaners, etc.

**Dry the laundry in
the tumble dryer**



Always with you ~~~~~

What do you always carry with you? E.g. emergency medication, health insurance card, inhaler, snack, sunglasses, noise-cancelling headphones, electrolytes, mobile phone, etc. Write down keywords / draw and label



Information on submission

Please photograph or scan the pages and
send them by **August 10th 2026** to:
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Impressum

Image sources

Stella Waldvogel (Cat + Books), Adobe Stock:
Good Studio, Paper Trident, kharlamova_lv, Igor Zakowski

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