PERSONA-SET INTRODUCTION

ABOUT THIS PERSONA-SET

A persona-set is a collection of research-based profiles presenting different kinds of people, their needs, and their everyday lives. They are built from data reflecting real people's experiences, with the intention to help others imagine how different individuals experience everyday life, challenges, and opportunities.

This persona-set captures the stories of children recovering from stroke and their families. This set was developed within BUILD CARE, a multidisciplinary research project exploring how the spaces where these children live, learn, and receive care influence their recovery and quality of life. The research included families in three European countries (Austria, Belgium, and Germany). It gathered insights into experiences of both informal environments, such as homes, neighbourhoods, and schools, and formal care spaces, such as hospitals, clinics, and rehabilitation centres.

To support different ways of using the persona-set, we have prepared two printable formats: an A4 version that is easy to print at home, and an A3 version well-suited for workshops and group discussions. Both are ready for you to download and use.

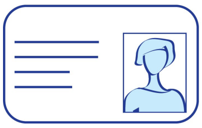
WHO IS THIS PERSONA-SET FOR?

Architects, designers, healthcare professionals – the personas can help you better understand the everyday lives of children affected by stroke, including those who make a full recovery and those living with lasting disabilities. They highlight both the challenges children and their families face in the built environment and the creative strategies they adopt to cope. The personas capture not just the physical needs, but also the cognitive and emotional aspects of life after stroke. By sharing these insights, the personas can inspire creating more inclusive, supportive, and enabling environments.

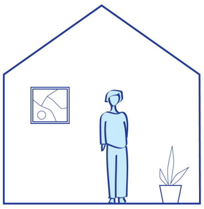
Families affected by childhood stroke – the personas may be just as valuable to you. Many of you will recognise pieces of your own story in these personas, which may help to feel seen and understood. They may also open up conversations about what kinds of spaces and features in the built environment really make a difference in everyday life. As you shape care environments in everyday ways and through formal decisions during the design process, this resource can help you imagine possibilities beyond your own personal experiences.

In this way, the personas become a shared reference point connecting families, practitioners, and researchers in building a common understanding of what it can mean to live with the lasting effects of childhood stroke.

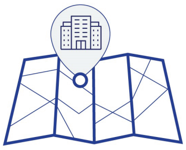
WHAT THE PERSONAS OFFER



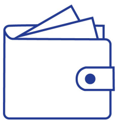
Each persona begins with **background information** about the child and their caregivers, including when the stroke happened and how it has affected them.



The personas are brought to life through **scenarios** showing how a child and their families use, experience and modify everyday spaces. The scenarios illustrate how they experience different environments, highlighting barriers, opportunities, and moments where thoughtful design could make a difference. A simple gradient, shown as different lines under the relevant text, helps readers quickly understand how each environment or activity affects the child's experience and whether a situation is impossible to overcome, only possible with help, possible with the help of tactics, supports their independence or is experienced as enabling.



Every persona includes a **care map** – a spatial overview of important places in the child's life. It also shows the distances between these places, helping to illustrate the journeys that shape their daily routines. These distances and frequencies are illustrative and will differ by home location and care needs, resulting in a map unique to each family.



Each persona includes examples of additional **stroke-related costs** that families may encounter, such as one-time expenses (for example, a grab bar or adaptive kitchen tools), and indicates what expenses were reimbursed by health insurance.

Household incomes shown in the personas are illustrative gross amounts. Travel-related costs, such as fuel, bus or train tickets and taxis, and the purchase or adaptation of a vehicle, were not included in this study.

Data sources shaping the personas – The persona development was based on interviews with 30 families affected by childhood stroke, cognitive data from standardised neuropsychological testing with 15 children, and findings from an online survey exploring the well-being and socio-economic impacts on these families completed by over 100 families across the three participating countries.

Foregrounding children's voices – A core value of the project was to involve children as active participants, not just as subjects of observation. The research team developed creative and age-appropriate ways to hear children's voices, including participatory methods that allowed them to draw, play or take photographs, which made it easier for them to share their experiences. Some children, however, were very young or had impairments that made direct communication difficult. In these cases, their perspectives were investigated through parents or other caregivers, which shaped the kinds of insights that could be gathered.

Diversity of participants' stroke-related impairments – The families who participated in research reflected a broad variety of impairments, which is characteristic of the diversity seen after childhood stroke. This variety is represented in the persona-set and helps illustrate many different needs and abilities. That said, the group did not include children with the most severe physical disabilities, such as those with extremely limited mobility or requiring intensive daily care, or those with profound communication impairments. While the personas focus on how stroke interacts with the built environment, co-occurring conditions such as autism can be just as influential in everyday life as stroke-related impairments. Because recruitment across countries was stroke-oriented, this resource remains primarily stroke-focused, and readers may wish to consult condition-specific research for further guidance. As a result, some spatial, care-related, or communication challenges may not be fully represented.

Diversity of families' characteristics – Most of the families presented in the personas have a higher socio-economic status, largely due to the recruitment methods and participation requirements. As a result, the experiences of families with fewer resources may not be fully represented. It is also important to note that the families who participated in this project were highly involved in supporting their child and willing to participate in research. Families who may be less engaged or face greater challenges in accessing support are not as well represented in this persona-set. However, information from an online survey was used to ensure the sample is representative of the broader population in terms of age, gender, family structure, and economic situation. This helps make the personas more accurate and realistic.

Including wider family perspectives – The project placed strong emphasis on the family as a whole, and where possible, included the voices of siblings, grandparents, and other relatives. These perspectives can be particularly insightful, as these family members often contribute meaningfully to care and daily routines. Nevertheless, their experiences are less prominent than those of primary caregivers, meaning some aspects of their support roles may be underrepresented.

Other factors shaping lived experience – While the project focused primarily on experiences related to childhood stroke, factors such as migration background, ethnicity, language barriers, or co existing disabilities can also shape how families interact with care environments and services. These aspects were not a central focus of the study, but they remain important for understanding the full range of lived experiences.

While no set of personas can capture every perspective, these personas provide a strong foundation to understand and support families better. Recognising where perspectives may be less included is an invitation to keep listening, learning, and expanding our view in future research efforts.

ACKNOWLEDGMENTS

We are deeply grateful to the children and families who shared their stories and experiences, making this persona-set possible.

The BUILD CARE team included Andrea Jelić, Ann Heylighen, Anna Franziska Kalhorn, Anna Hella Borsch, Anna-Theresa Renner, Anne-Sophie Schoss, Birgit Moser, Charlotte Rathjen, Els Ortibus, Gesine Marquardt, Johanna Baldassari, Lena Fuchs, Lisa Bartha-Doering, Maja Kevdžija (Project Coordinator), Magdalena Muszynska-Spielauer, Marion Göll, Mie-Jef Descheemaeker, Piet Tutenel, Pleuntje Jellema, Ruth Heying, Sophie Mandl, and Viktoria Kurstak. Each member made meaningful contributions to the project, bringing their expertise, dedication, and creativity to every stage of the work. We would like to express our special thanks to our colleagues: to Pleuntje Jellema for developing the care maps and the persona-set layout, and to Lena Fuchs for creating the drawings that illustrate the scenarios in the persona-set.

We also thank our collaborators SCHAKI e.V., Stiftung Deutsche Schlaganfall-Hilfe, and Rarity United, as well as the BUILD CARE advisory board: patient representatives, architects, healthcare professionals, interior designers, and other experts, for their valuable insights and guidance.

GLOSSARY OF TERMS

This glossary explains key words and concepts used throughout the persona-set. It is designed to help everyone, whether families, designers, or healthcare professionals, understand the language and ideas that shape these personas. This glossary does not cover every term but highlights selected medical, country-specific, and other key concepts (for example, formal and informal care environments) to help make the persona set clear and accessible for everyone, regardless of their background or familiarity with these concepts. By sharing clear definitions, we hope to make the personas easy to explore and use in supporting children affected by stroke and their families.

Attentional deficits: Difficulty focusing, sustaining attention, or filtering distractions.

Cognitive impairment: Difficulties with thinking, memory, attention, language, or problem-solving due to brain injury or other causes.

Dyspraxia: A condition affecting physical coordination, often making tasks like writing, dressing, or using tools more difficult.

Formal care environments: Institutional settings like hospitals, rehabilitation clinics, and outpatient clinics where professional medical or therapeutic care is delivered.

Hemiparesis: Weakness or partial paralysis on one side of the body often caused by stroke. It can be arm-dominant (more pronounced in the arm and hand), leg-dominant (more pronounced in the leg and foot), or affect both equally with varying severity.

Informal care environments: Everyday settings such as the home, school, and neighbourhood where care occurs outside the formal healthcare system.

Inclusive schooling: Educational settings that accommodate children with and without disabilities.

Motor skills: The ability to perform movements, including gross motor skills—large movements like walking or jumping, and fine motor skills—precise movements like using fingers or handling small objects.

Neuroplasticity: Brain's ability to change, adapt, and reorganize itself by forming new neural connections throughout life.

Orthosis: A device, such as a brace, that supports weakened muscles or joints, often worn on arms or legs to assist with walking or movement.

Paresis: Partial loss of voluntary movement or muscle strength.

Seizures / Epilepsy: Sudden bursts of abnormal brain activity that may cause convulsions, confusion, or sensory disturbances. Some children in the study took anti-epileptic medication.

Sensory-reduced space: A quiet, low-stimulation environment where children can retreat from noise or visual overload to recover focus and calmness.

Snoezel garden: A calming, multi-sensory outdoor space designed to help children relax, self-regulate, and engage their senses.

Social Paediatric Centre: A specialised outpatient clinic (in Germany) that provides interdisciplinary diagnosis, consultation, and therapy for children and adolescents with developmental delays, chronic conditions, or disabilities.

Visuoperceptive deficits: Challenges in processing and understanding visual information, affecting activities like reading or navigating space. The ability to perceive things like shapes, objects and faces may be affected; it may be hard to distinguish an object from what is in the background; also detecting and understanding motion, judging distances, navigating spaces and understanding spatial relationships may be experienced as difficult.

Visual memory deficits: Difficulties in remembering visual information, such as the location of objects (e.g., keys), routes, or faces.

BUILD
CARE

BUILDING SUPPORT FOR CHILDREN AND FAMILIES AFFECTED BY STROKE

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Project period: 2020 - 2025

www.buildcare-project.eu

PROJECT PARTNERS

TU WIEN TECHNISCHE UNIVERSITÄT WIEN

Technische Universität Dresden

KU LEUVEN

MEDIZINISCHE UNIVERSITÄT WIEN

Ben

PERSONAL

- 8-year-old boy
- Only child, likes to be the centre of attention
- Lives in a detached house
- Attends an inclusive school where he also receives therapy
- Finds maths challenging but proudly says he can count to infinity

Likes:
His favourite food is sushi (he eats and writes with his left hand)

Dislikes:
Tricky things that need small finger movements, such as buttons or using scissors

STROKE

Shortly after birth
In the left hemisphere of the brain

This continues to cause

- Right-side hemiparesis (affecting his right arm and leg); uses an orthosis to walk
- Seizures, managed with anti-epileptic medication
- Language, memory, visuoperceptive, attentional deficits; leading to difficulties with symbols; aligning buttons and zippers; some clumsiness in spatial judgement

CARE GIVERS

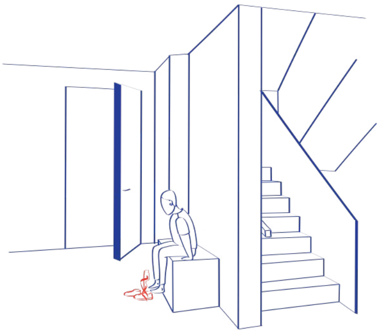
- Both parents are employed
- Father works full-time
- Mother works part-time

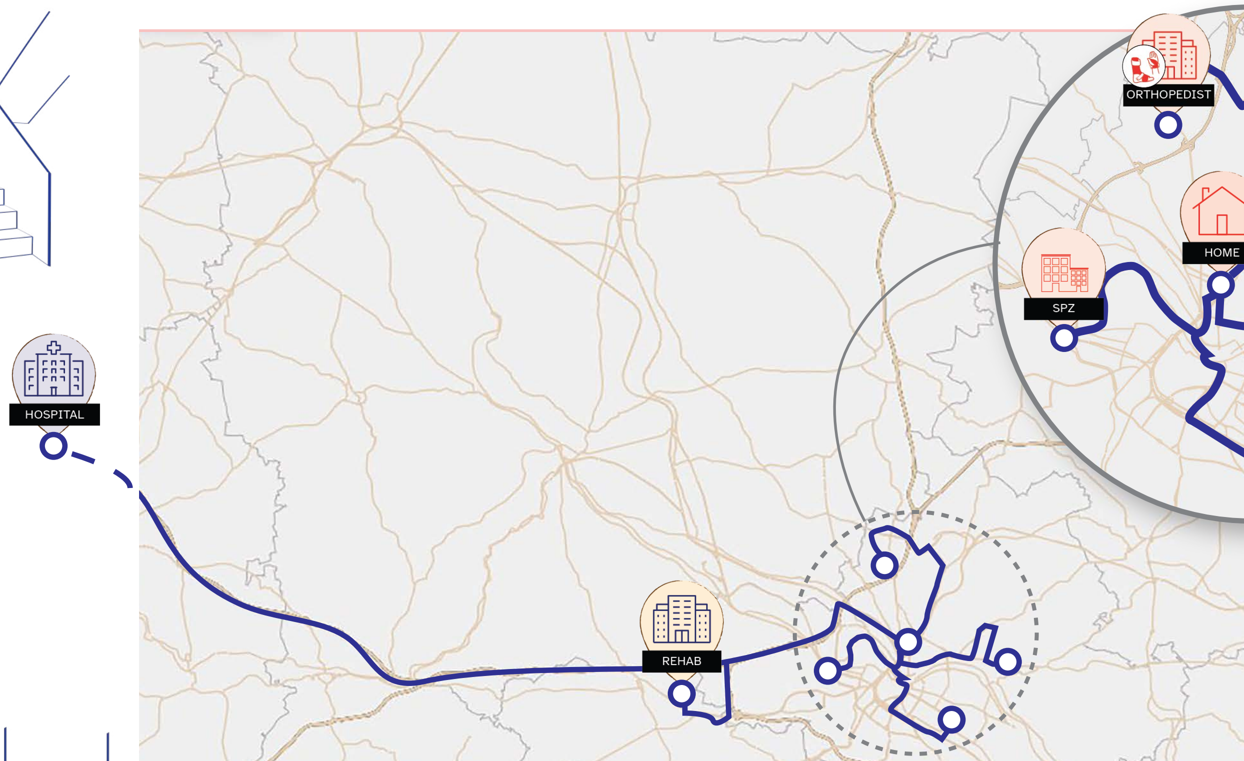
Ben's mother takes on most of Ben's care, from organising therapy and appointments to staying in touch with teachers and managing daily routines. His special care needs require about 40 additional hours per week, sometimes even more.
The family manages their daily living with a yearly income of around €65.000, although they had to pay for modifications and special gear to support Ben.
The family's total expenses on these needs were about €5.000, with almost €2.000 reimbursed by their health insurance. They're currently saving €2.000 to buy a therapy bike, which will help Ben gain more mobility in his everyday life.

LANDSCAPE OF CARE

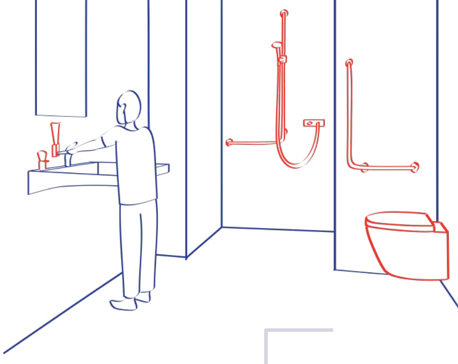
His Right Side Needs an Extra Invitation

When Ben comes into the house by himself, you can usually hear him before you see him. The rhythmic scrape of his foot orthosis on the tiles - clack, shff, clack - then a soft thud as he drops his rucksack. He sometimes calls his right leg his “favourite leg”. It’s the one that doesn’t always cooperate. His parents smile and say, “That leg just needs an extra invitation sometimes.” Ben is eight and had a stroke when he was very young, too young to understand it at the time. Now he explains it like this: “Something broke in my head. Like a water balloon popping. Since then, my right arm and leg feel kind of numb. I can’t feel them properly.” At home, there are helpful tools everywhere: a cutting board and an automatic soap dispenser designed for one-handed use, grab bars in the bathroom, and a second handrail on the stairs. Still, Ben stumbles more than other children. Balance is difficult, especially outside, like the playground down the road. That playground is tough for him: steps too high, climbing too wobbly, slides too steep.





home			
to hospital 1	🚗	4 km	10 min
to orthopedist	🚌	4 km	25 min or 🚗 10 min
to school	🚌	4 km	30 min
to social paediatric center (SPZ)	🚗	5 km	15 min
to rehabilitation center	🚗	20 km	40 min
to hospital 2	🚗	560 km	6 hrs

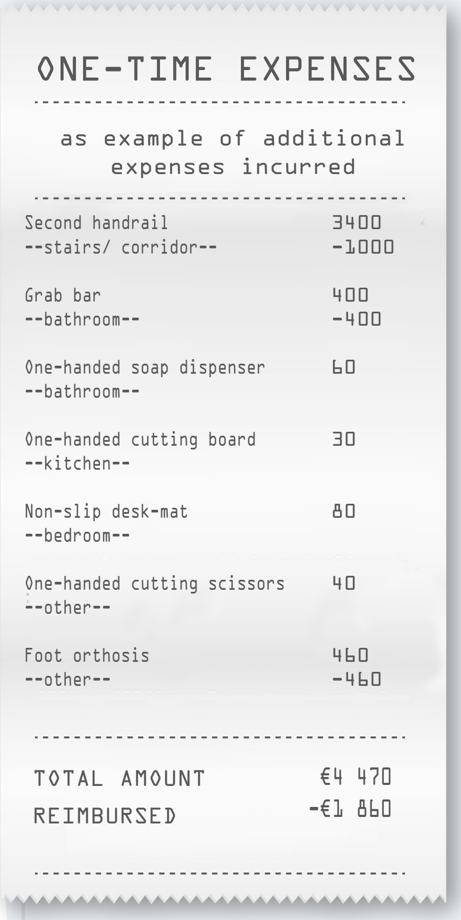


Lessons and Therapy Go Hand in Hand

Ben is in third grade at an inclusive school. Math isn’t his favourite: he likes the numbers but talking about them is difficult. Still, he’s proud he can count to infinity. And he does - often while at dinner, trying to grab sushi with his colourful chopsticks. “Ninety-three, ninety-four...” Rice sticks to his fingers. His mom just smiles and quietly wipes soy sauce off the floor. At Ben’s school, learning and therapy go hand in hand. Between German class (which he doesn’t really like) and physio (which he sometimes loves, sometimes hates), there’s often just one corridor. Ben has hemiparesis, a complicated word. His therapist explains it like this: “Imagine the brain talks to the body - like on the phone. It says, ‘Move your hand!’ or ‘Lift your foot!’ But Ben’s phone line to the right side is damaged. It crackles, cuts out, or goes silent. So the message don’t get through, or are delayed.” There are supports in place, but every day is still a balancing act - between focus, fatigue, therapy, and the simple desire to just be a kid.

Often, he just watches the other children. “I’ve got better things to do,” he says. But his mom knows that he feels left out and unhappy when they run and laugh without him.

> ***“Playgrounds are a real problem - even here in our own neighbourhood. He just doesn’t want to go any more.”*** *mother*



ONE-TIME EXPENSES

as example of additional expenses incurred

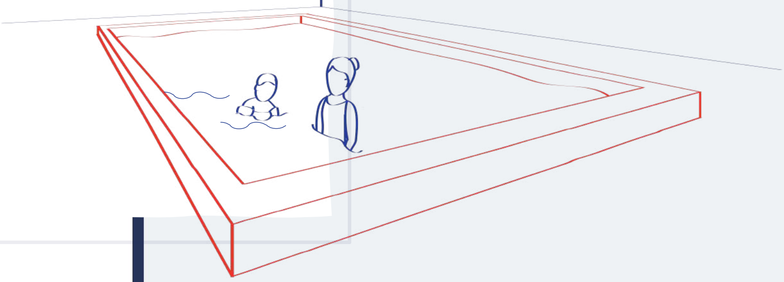
Second handrail --stairs/ corridor--	3400 -1000
Grab bar --bathroom--	400 -400
One-handed soap dispenser --bathroom--	60
One-handed cutting board --kitchen--	30
Non-slip desk-mat --bedroom--	80
One-handed cutting scissors --other--	40
Foot orthosis --other--	460 -460
TOTAL AMOUNT	€4 470
REIMBURSED	-€1 860

One Button at a Time

A year ago, Ben spent four weeks at a rehabilitation centre. Every day was full of therapy: physical, occupational, and speech. His favourite part? Swimming. “In the water, I feel light,” he says. That’s where he learned to use the right side of his body more actively.

Mother: “Up until last year, he only wore tracksuit bottoms because he just couldn’t do buttons. We practised that in rehab. For other kids, buttoning trousers is nothing – for him, it took several sessions of physio to get there.”

His doctor at the social paediatric centre, where Ben goes for check-ups every six months, explains: “The left side of the brain controls the right side of the body. In Ben’s case, that connection was damaged. But the brain can build new pathways. We call that neuroplasticity. It’s quite incredible.” Next week, his orthosis has to be refitted - Ben’s growing. He used to hate it. Now he calls it his “power shoe.” “It makes me a superhero,” he says. “My right side needs special powers.”



> ***“Even getting him to use his right hand at all - to bring it into play - that’s something we worked on a lot during rehab, too.”*** *mother*

LEGEND

Situations that for the child ...

━━━ are impossible
┈┈┈ require help
- - - require tactics
∿∿∿ allow independence
═══ are enabling

Ella

PERSONAL

- 12-year-old girl
- Has a twin sister and four other siblings
- The family lives in a terraced house with good access to therapy and support services
- Attends a regular school
- A bit shy, has only a few close friends

Likes:
Listening to music alone in her room

Dislikes:
Crowded or noisy places

STROKE

At preschool age
In the right hemisphere of the brain

This continues to cause
- Left-sided hemiparesis, leg-dominant (uses a wheelchair for longer distances)
- Learning and attention problems

CARE GIVERS

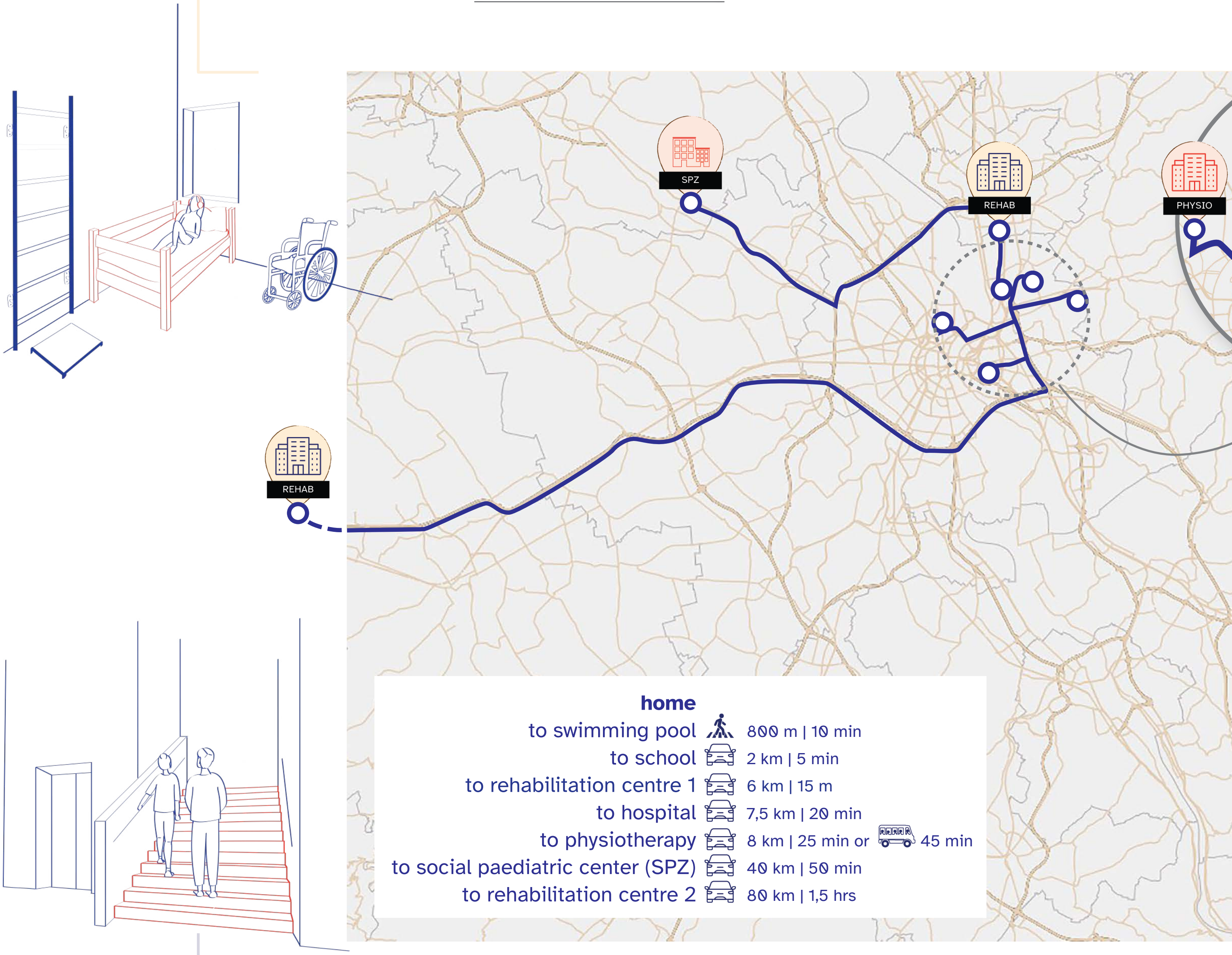
- Both parents try to balance work and caregiving
- Ella's mother works 30 hours a week
- Ella's father works full-time and sometimes works night shifts so he can take Ella and her siblings to school and be around during the day

Ella's parents are both employed, though her mother had to cut back her hours and now works 30 hours per week. She dedicates several hours every day caring for Ella's special needs, but with five other children it is sometimes hard to give her the attention she needs. She's the one who takes care of therapy sessions for Ella, hospital appointments, and school communications.
With a household income of €49.000 they are just able to manage daily expenses but with a family of eight it is sometimes hard to tend to everyone's needs, especially if they have to make adjustments at home or purchase specialized equipment for Ella.
In total, the family spent around €7.000 on these modifications and devices, with almost everything covered by health insurance. They are currently putting money aside — €2.000 — to install a second handrail on the staircase, so that Ella can move between floors more safely and gain more independence at home.

LANDSCAPE OF CARE

Where She Didn't Feel "Different"

Mother: "During our stay at the rehabilitation centre, we realised how even the smallest door threshold can become an obstacle. Ella had great difficulty entering the treatment room in her wheelchair, especially in the older part of the building. Her hemiparesis affects the left side of her body, including her leg, making longer distances hard to manage without breaks. Our paediatrician had recommended the rehab to help her learn to walk more safely. For the first time, Ella didn't feel "different". There were other children facing similar challenges. In this environment, she could just be herself, without constantly having to explain her impairment. Still, it wasn't always easy. Her brothers and sisters visited at weekends, bringing some much-needed family joy into an otherwise clinical environment. The therapy sessions demanded a lot of energy and focus, and her attention difficulties made it hard for her to stay engaged. The area outside the therapy rooms was always chaotic - when all the children finished their sessions at the same time, it felt like a crowded train station. The dining hall was overwhelming too, with so many voices, so much

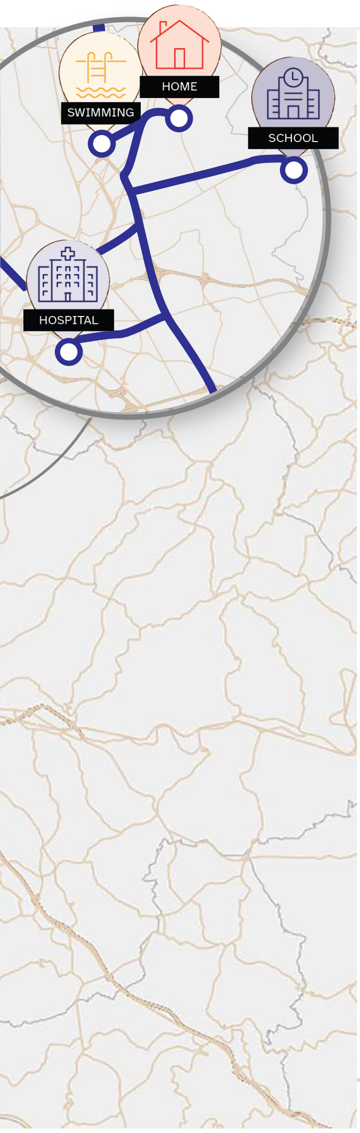


home		
to swimming pool	🚶	800 m | 10 min
to school	🚗	2 km | 5 min
to rehabilitation centre 1	🚗	6 km | 15 m
to hospital	🚗	7,5 km | 20 min
to physiotherapy	🚗	8 km | 25 min or 🚌 45 min
to social paediatric center (SPZ)	🚗	40 km | 50 min
to rehabilitation centre 2	🚗	80 km | 1,5 hrs

Already Exhausting Enough

Father: "I take Ella and her twin sister to school. We drive the same route through the city. They're twelve, but I don't want them taking the school bus - it's already exhausting enough for Ella. I don't want her to feel any pressure or stress. As we enter the building through the automated glass door, we see the teacher, greeting us warmly, joking around, setting a good mood. Ella always jokes that she doesn't want to go to school, but I know she likes it here - much more than at her previous school. The elevator is already waiting, but I encourage her to use the stairs, just like she did in rehab. Back then, she managed to reach the top floor without help – something we never thought possible shortly after the stroke. Other children rush past, careless, unaware. I can feel how much effort each step takes for Ella. I insist on accompanying her to the classroom. The thought of her falling is unbearable. I don't even want to imagine what could happen. She gets annoyed that I watch her so closely, but I just want to be there - just noise. She quickly became overstimulated. There were few places to retreat, and sharing a room with me meant she had little space of her own."

> ***"This wasn't her first rehab - it's actually been her fourth time now. At the beginning, she really struggled to find her way around the large clinic."***
>
> *mother*

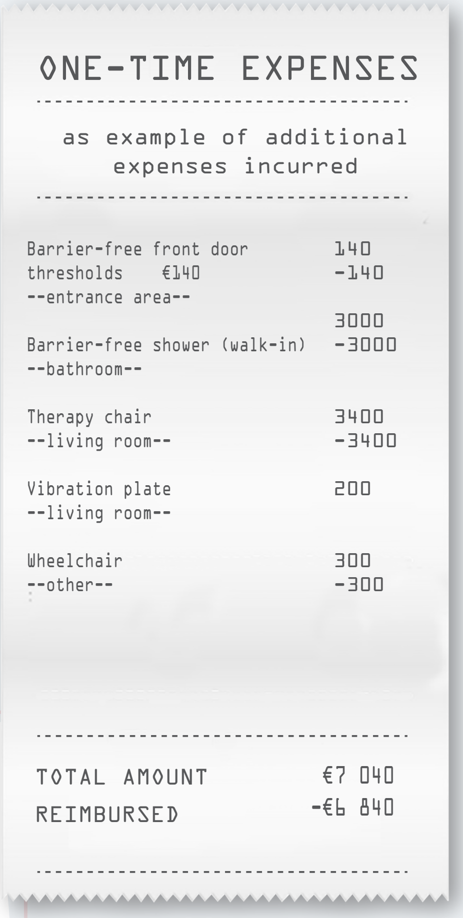


in case. Step by step, I help her position her foot correctly, exactly how the physiotherapist taught us. She said that taking the stairs would strengthen the muscles affected by the hemiparesis. And so we practise."

The Stroke Walks with Her

Mother: "As Ella's mum, I would say the stroke always plays a role in her life. For example, she can't simply go to therapy on her own like others her age might. Ella has physiotherapy twice a week, plus regular check-ups at the children's hospital or the social paediatric centre in a nearby town. Even something as basic as opening the heavy glass door to the therapy building is impossible without help. It becomes even more apparent in the city. There are barely any benches, no places where she can rest when walking becomes too exhausting. She tires quickly, and every step takes effort. Stairs, uneven pavements, long distances are a challenge for her. When I think about it, there's probably only one place where the stroke doesn't play a role: her own room, in her bed."

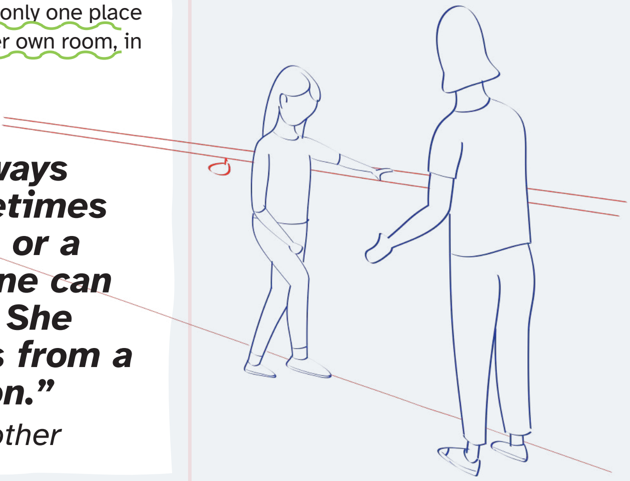
> ***"She doesn't always realise it, but sometimes even a small curb or a stupidly placed stone can cause her to fall. She sometimes stumbles from a standing position."***
>
> *mother*



ONE-TIME EXPENSES

as example of additional expenses incurred

Barrier-free front door thresholds €140 --entrance area--	140 -140
Barrier-free shower (walk-in) --bathroom--	3000 -3000
Therapy chair --living room--	3400 -3400
Vibration plate --living room--	200
Wheelchair --other--	300 -300
TOTAL AMOUNT	€7 040
REIMBURSED	-€6 840



LEGEND

Situations that for the child ...

- ━ are impossible
- ┈ require help
- - - - require tactics
- 〰 allow independence
- ═ are enabling

Lenny

PERSONAL

- 9-year-old non-binary (they/them)
- Has 1 brother (Tigo: 11), 1 rabbit, grandparents nearby
- Lives in a bungalow
- Attends an inclusive school
- Often joins their parents in bed at night
- Sometimes has difficulty finding their way around

Likes:
Swings, swimming, their rabbit

Dislikes:
Being alone, hospitals

STROKE

At 4 months, during heart surgery
In the right hemisphere of the brain

This continues to cause

- Hemiparesis of left arm
- Visual impairment (partial)
- Visual memory impairment; affects their ability to remember faces or remember a route (so-called 'landmarks' are important)
- The need to take anti-epileptic medication

CARE GIVERS

- Parents have their own business
- Father works (more than) full-time
- Mother works 60%; usually more but flexibly and often from home
- Grandparents

Both of Lenny's parents have jobs, but Lenny's mother reduced her working hours to part-time to better support their special needs, which takes up about 30 hours each week for dressing, washing and general support in everyday life.
The family's income of around €80.000 allows them to manage their day-to-day life, even though they had to invest in home modifications and special equipment for Lenny.
Altogether, they spent almost €8.000 on necessary changes and equipment, of which almost half were reimbursed by their health and care insurances. Now, they're saving €3.500 to install a climbing frame in the additional room they hope to turn into something of a gym, helping Lenny to exercise and strengthen their muscles at home.

LANDSCAPE OF CARE

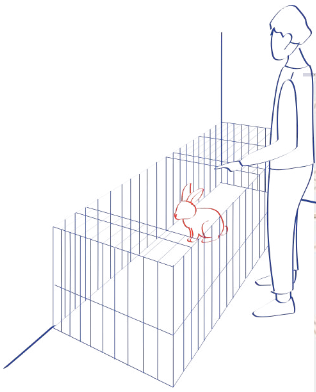
Nearby, Happy and Increasingly Confident

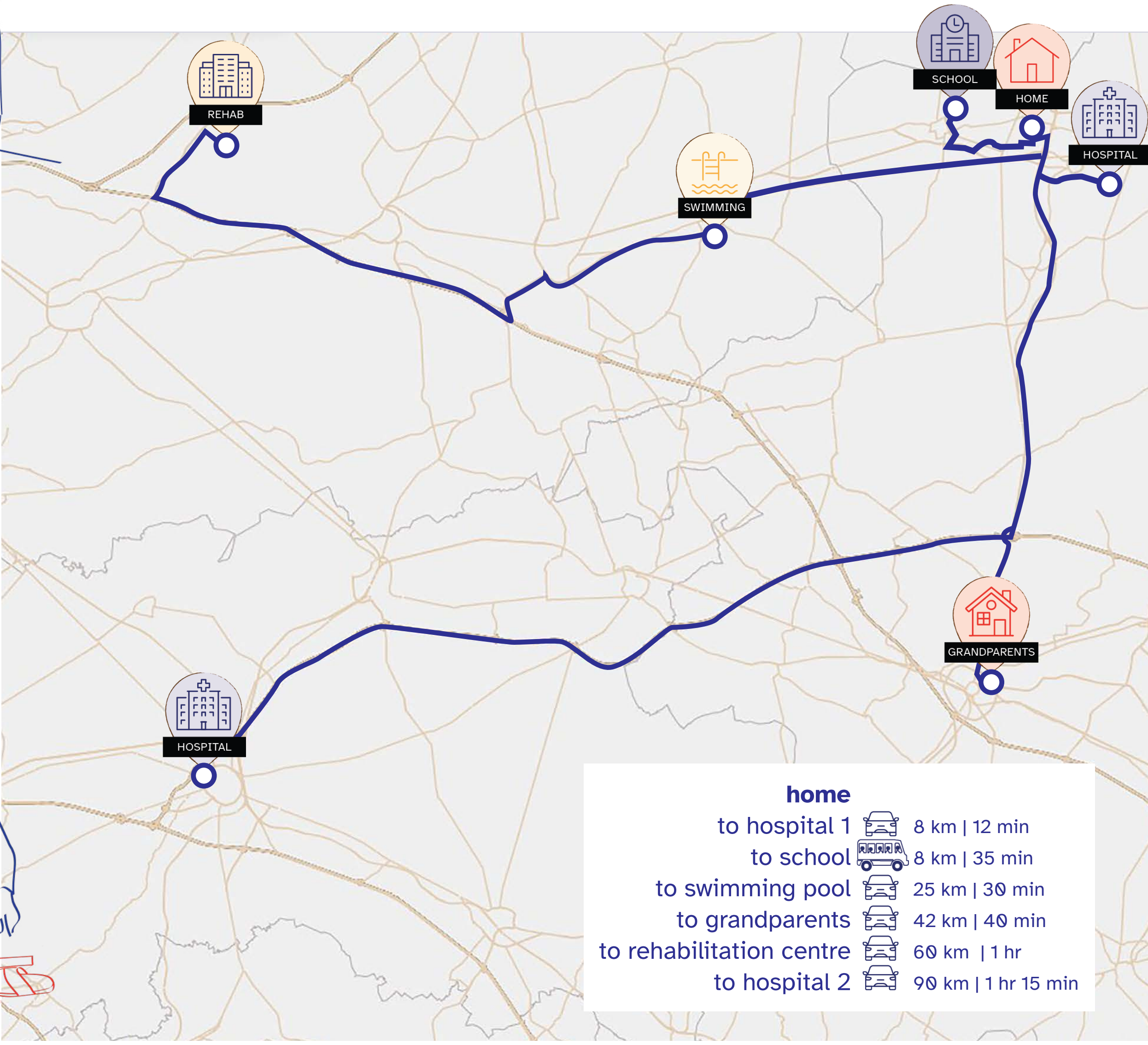
Grandmother: “As a grandparent, I find comfort in knowing the places where my grandchildren feel safe and happy. One of those places is with us. I don't remember a time when Lenny was without their parents, except for those moments when they’re with us. Lenny loves to visit because they get our full attention.

School is of course another exception and a place that is important for them. Therapies, like physio, are integrated at school, as are regular check-ups by doctors from the university hospital. The staff there truly understand how to support such children. With small classes of no more than 8 children and always 2 or 3 teachers present, the environment is less overwhelming for Lenny than when they were in a regular class. They feel confident doing stuff there.

The class and furniture is made in such a way that they can reach things and help each other. Since they started attending this school, Lenny has blossomed. They love going to school so much that even when they’re sick, they don't want to stay home. School is something of a second home.”

Lenny: “The playground is my favourite place, especially the





home

to hospital 1 🚗	8 km | 12 min
to school 🚌	8 km | 35 min
to swimming pool 🚗	25 km | 30 min
to grandparents 🚗	42 km | 40 min
to rehabilitation centre 🚗	60 km | 1 hr
to hospital 2 🚗	90 km | 1 hr 15 min

Extra Care and Concerns

Mother: “I worry about what could go wrong with Lenny. With our son, it’s different—he’s healthy, and I don’t feel the same concern. Lenny is healthy too, but it’s not the same. Everyday we find ways to encourage them. We have to struggle against the effects of paralysis by practising, stretching and massage. Tigo doesn’t face the same challenges, and I know he’ll be fine. Sure, every child gets sick now and then, but with Lenny, this overprotectiveness remains.

This is reflected in other things as well. Our son for example finds his own way to and from school by bicycle - as long as the weather is OK - while we organise transport by bus for Lenny all year round. Although one of us always tries to join Tigo for his tennis classes, he is quite aware that his sibling constantly gets extra attention.”

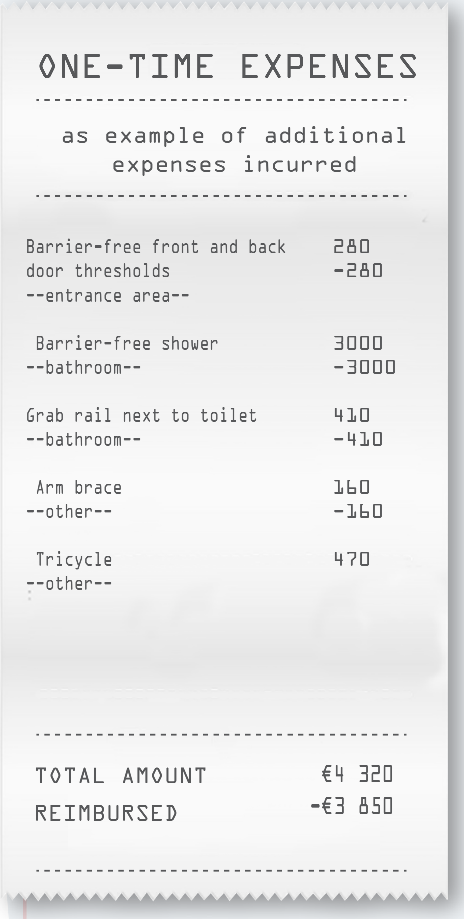
Lenny: “My mother always helps me with dressing, in the morning, at bed-time, for bath time or when we go swimming. I can’t do clothes that go over my head. Also, swing. I can just keep swinging, and sometimes my parents have to remind me to let other children have a turn. Swinging makes me feel good!"

> ***"They feel understood and safe there, making it something of a second home."***
>
> *grandmother*

A Continuous Process of Adjusting

Father: "When they were younger, it was simpler to manage their needs by using a buggy. However, as Lenny grows older, the differences between them and other children become more pronounced and harder to handle. They need help with everyday activities, like making sandwiches. Also hitting a ball with a tennis racket or skateboarding, highlight their struggles with balance, sight and coordination.

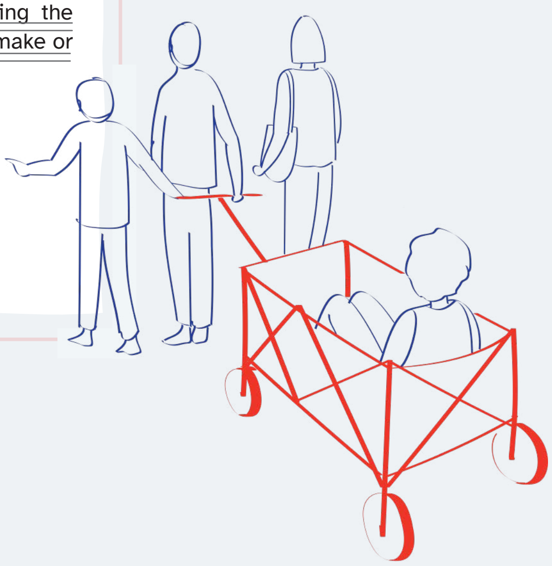
Initially, after the stroke, there were so many unknowns, and we thought Lenny might need to use a wheelchair. At that time we made our home step-free to ensure easy accessibility. However, more recently we've realized that having steps and stairs could have actually helped with their rehabilitation. Taking Lenny into account – also in terms of the changes we make to our home – is a continuous process of learning and adjusting to support their development and independence. At the moment we are turning the guest room into a kind of gym and we try to make or provide things that can help them exercise."



ONE-TIME EXPENSES

as example of additional expenses incurred

Barrier-free front and back door thresholds --entrance area--	280 -280
Barrier-free shower --bathroom--	3000 -3000
Grab rail next to toilet --bathroom--	410 -410
Arm brace --other--	160 -160
Tricycle --other--	470
TOTAL AMOUNT	€4 320
REIMBURSED	-€3 850



shoes are difficult. When we go swimming, I take off my brace."

> ***"I like going in the water with my dad. I also like going in the shallow pool by myself."***
>
> *Lenny*

LEGEND

Situations that for the child ...

———	are impossible
·······	require help
- - -	require tactics
〰	allow independence
═	are enabling

Mia

PERSONAL

- 6-year-old girl
- Parents (divorced), brother (4) and family dog
- Lives in a flat with her dad, in a detached house with her mum
- Attends a regular school
- Energetic and curious; highly competitive but quickly frustrated; popular in school

Likes:
Sports, especially soccer; cuddling her dog

Dislikes:
Hospitals

STROKE

At age 4 (2 years ago)
In the left hemisphere of the brain

This has not caused any lasting motor impairments or obvious cognitive deficits

CARE GIVERS

- Both parents work full-time
- High socioeconomic background
- Grandparents

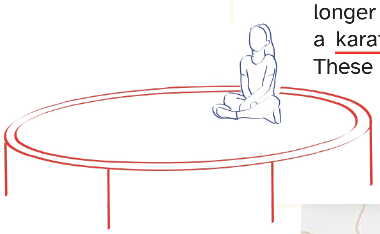
Mia's parents are both working a lot, so Mia often spends time with her grandparents. Her parents are divorced and live separately. She and her brother alternate between staying with their father and their mother.
Luckily with a combined income of around €140.000 the family has enough money to manage their everyday lives easily and her parents are able to finance some extra horse riding lessons (ca. €50 per lesson) for Mia every month.
Since Mia's impairment is not severe, no additional expenses for home adaptions or therapeutic measures are necessary.

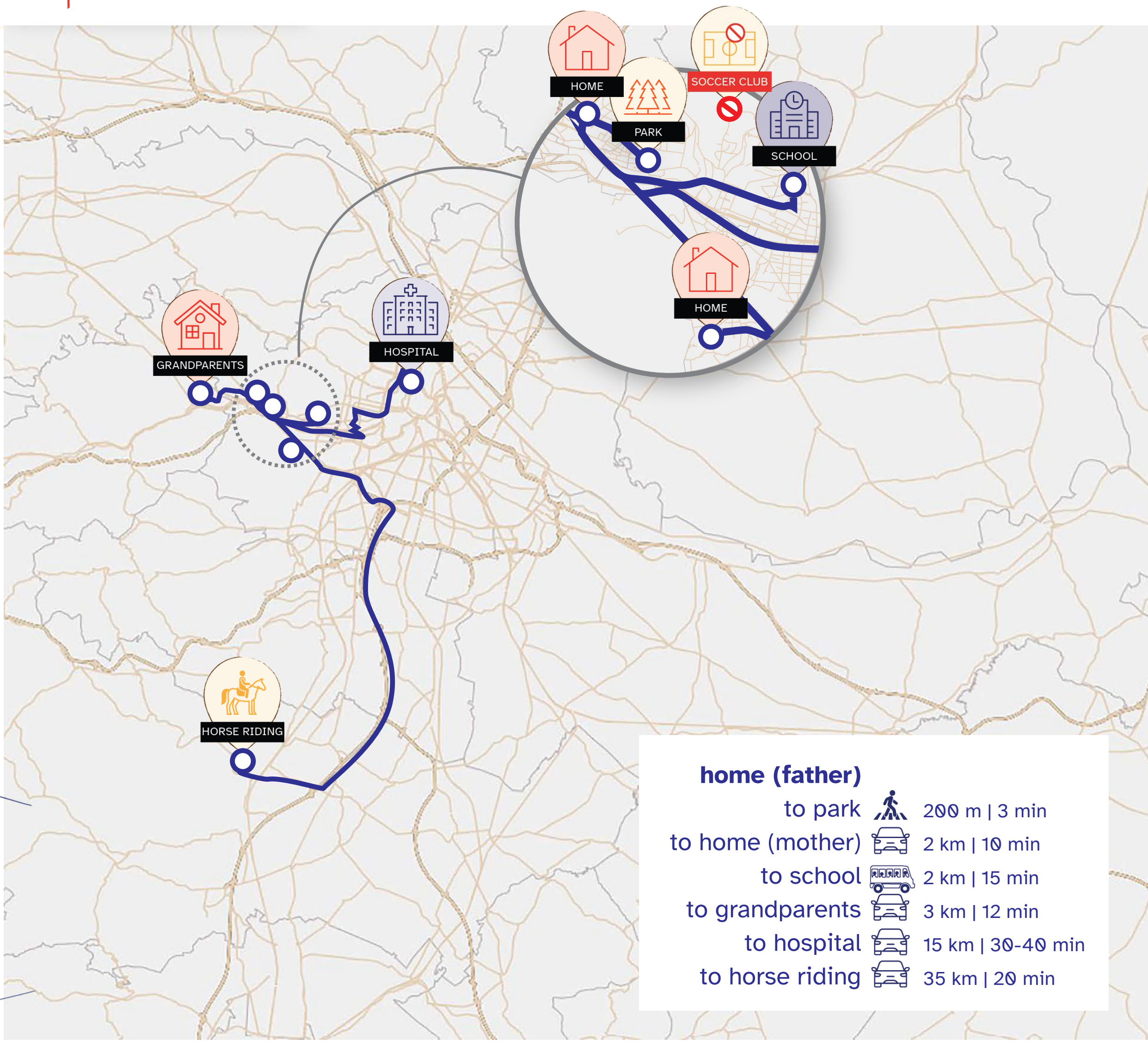
LANDSCAPE OF CARE

Too Risky

Mia's parents consider themselves very lucky – she has recovered remarkably well from her stroke, with no lasting motor or cognitive challenges. Yet, the fear of another stroke stays with them, shaping every decision they make. Her doctors take strict precautions, restricting her from engaging in most sports. Soccer, which she loves, is no longer an option. Also, when she expressed a desire to join a karate club, it was immediately ruled out as too risky. These limitations are frustrating for Mia, she gets very upset and her frustration is sometimes hard to deal with for her parents as she starts venting and hitting things at home. She needs an outlet for her anger.

They also used to visit trampoline parks. Technically, she can still go, but always under the shadow of her parents' unease. When they visit a friend of hers who owns a trampoline, she's allowed to walk on it or bounce gently while supervised, but not jump freely like the other children. To offer her an alternative, they try other activities, like





home (father)		
to park	🚶	200 m | 3 min
to home (mother)	🚗	2 km | 10 min
to school	🚌	2 km | 15 min
to grandparents	🚗	3 km | 12 min
to hospital	🚗	15 km | 30-40 min
to horse riding	🚗	35 km | 20 min

Struggling with MRI

Mother: "Since her stroke 2 years ago, Mia already had to undergo several MRIs, and each time was a distressing experience for Mia – and for her dad as well. Until now, she was so young that she had to be sedated and sober for the testing, turning each appointment into an exhausting, hours-long struggle. The process involved long periods of waiting, they often had to sit in the hallway for up to three hours. Mia received contrast medium, was scanned, and then waited again until she fully woke up. If she struggled with sedation, the situation became even worse, with no private space for care and often no staff available to provide support. It was always a horrible experience for both of them – she hates it so much that she refuses to even enter the hospital. Each visit is a real struggle, requiring extensive emotional preparation long before the day arrives."

horseback riding outside the city.
Father: “The horse riding is quite expensive, but the contact with the animals calms her, and it gives her something to look forward to twice a week.”

> ***“...the contact with animals calms her“***
> *father*

ONE-TIME EXPENSES

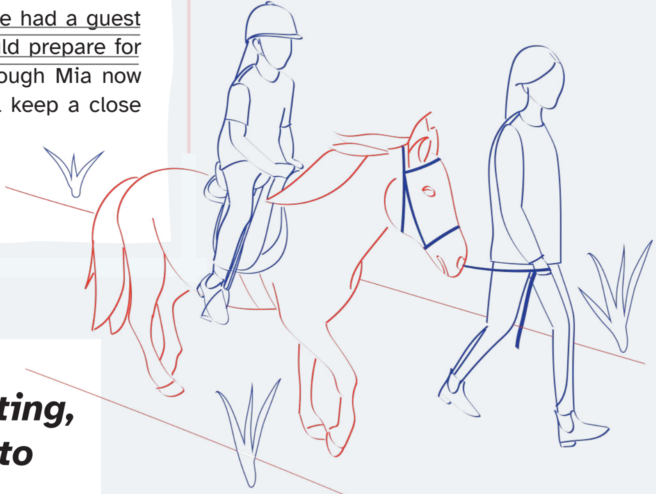
as example of additional expenses incurred

-- NOT APPLICABLE --

TOTAL AMOUNT € --
REIMBURSED -€ --

A Weekend Home

Mia has recovered well and no longer needs physical- and speech therapy, but the time shortly after her stroke was different. She spent a few months in the hospital with multiple therapy sessions each week. When she first returned home for a weekend, it felt like a family reunion – her dad, grandparents, and her dog were all at her mum’s house to welcome her. Her family was surprised by how quickly she progressed in her home environment. Even after just two days in the familiar environment, she suddenly dared to do things she hadn’t before: using the stairs by herself, yet always with a helping hand close by since initially she was afraid of falling and tired quickly, or moving around independently. She also explored the garden and brightened up while walking her dog. The familiar surroundings clearly boosted her confidence and independence.
Grandparents: “Mia loves spending time at our place. We often care for her in the afternoons after school and on weekends when both her parents have to work. The bedrooms are on the first floor, so the many stairs worried us at first, but luckily we had a guest room on the ground floor that we could prepare for her to make her stay easier. Even though Mia now runs up the stairs confidently, we still keep a close eye on her during visits.”



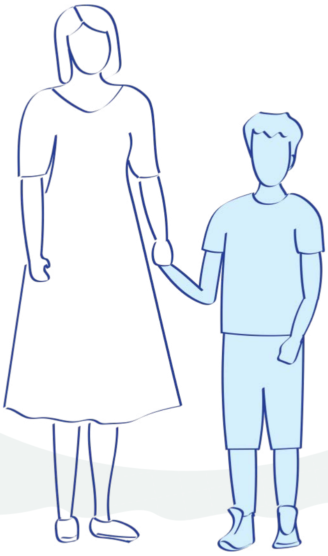
> ***“The process involved long periods of waiting, they often had to sit in the hallway for up to three hours.”***
> *father*

LEGEND

Situations that for the child ...

—	are impossible
⋯	require help
- - -	require tactics
〰	allow independence
═	are enabling

Theo



PERSONAL

- 10-year-old boy
- Single mum, no further family around
- Lives in a 3rd-floor flat
- Attends a regular school
- Sensitive and thoughtful
- Prefers solitude since stroke, does not want anybody to know about it

Likes:
Playing on his computer, spending time in his room

Dislikes:
Drawing, being around too many people

STROKE

At age 7 (3 years ago)
In the left hemisphere of the brain

This continues to cause
- Motor impairment (dyspraxia), affecting his right arm and leg
- Visuoperceptive deficits, attentional deficits
- Social withdrawal, anxiety, emotional processing difficulties

CARE GIVERS

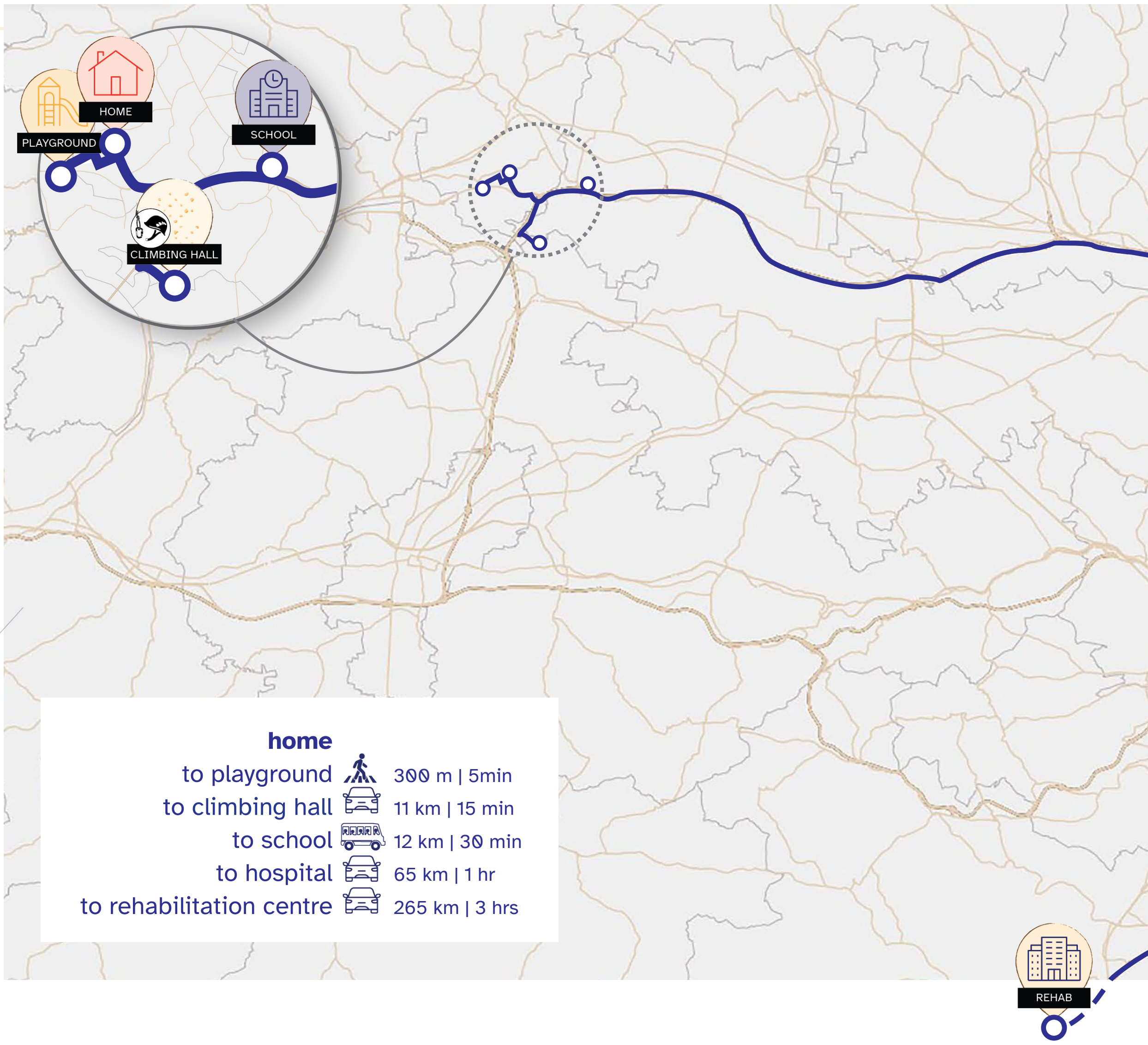
- Theo's mother works around 25 hours per week

Theo's mother struggles to take care of her son and work at the same time; she has no time for herself. He needs around 10 hours of extra care every week for household tasks and personal support. Even though she would like to increase her working hours, with the help and support Theo needs it is not possible since he relies only on her.
With an income of €20.000 per year they get by in their everyday life, but there is nothing left at the end of the month.
Theo needed some special equipment that further tightens their budget. In total his mother spent €3.600 on special equipment to make Theo's life easier. None of these things are covered by insurance.

LANDSCAPE OF CARE

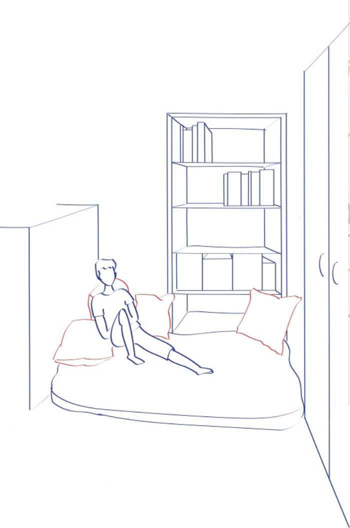
Gradually Exploring New Areas

Mother: “Theo loves rehab. It’s the only place where he feels confident, curious, and accepted by his peers. As he got older, he became more aware of his challenges and felt increasingly disconnected from other children. But in rehab, he feels a sense of belonging. It felt like an ever-expanding environment – each day in the first year, he was able to explore more of the facility, overcoming one challenge after another: In the first years at the rehab facility, we weren’t able to do much. He spent most of his time lying in bed and needed a wheelchair for assistance. Our room became our castle – I used sheets to turn his bed into a little fortress. As he improved, we gradually discovered new areas. At first, we took short walks in the hallways, down to the lobby and back. Later, we walked outside, where he could experience the textures of different surfaces beneath his feet, surrounded by trees and nature in the summer. And as he recovered even further, we explored the city where the facility was located, visited



home

to playground	🚶	300 m | 5min
to climbing hall	🚗	11 km | 15 min
to school	🚌	12 km | 30 min
to hospital	🚗	65 km | 1 hr
to rehabilitation centre	🚗	265 km | 3 hrs



A Place for Retreat

Mother: “School has been a big challenge for Theo since the stroke. He is in a regular school and can follow lessons well, especially with the support of his assistance teacher. However, he struggles with noise and craves both acoustic and visual privacy. He was always a very sensitive child, but the stroke has made him seek solitude even more – he needs a space to withdraw.”

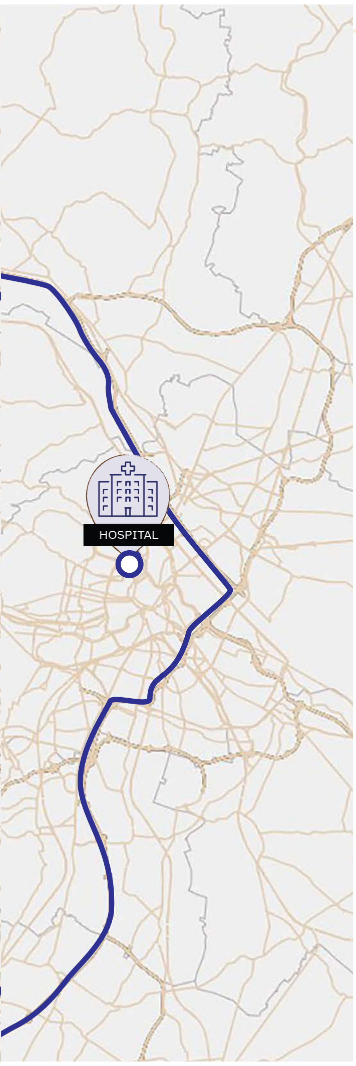
Teacher: “Having a space where he can retreat a little, is super important for somebody like Theo. It means he can stay in class and really get on with his tasks, keeping up with the other children but at the same time choosing to have time apart from the others.”

Mother: “The cuddling corner at school helps him a lot, and his attentive teachers allow him to go there when they notice he is struggling with others or losing focus. Headphones help as well, but what he really needs is a small, sensory-reduced space where he can rebalance.

I have to admit – I need to recharge my batteries too. Our daily life is so packed with appointments and hectic... In rehab, for example, the bathtub that I was kindly restaurants, and treated ourselves with some ice cream. He is looking forward to go back every year.”

“As he improved, we gradually explored more of our surroundings.”

mother

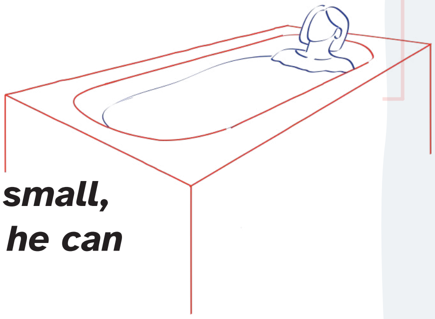


Bringing Therapy Home

Mother: “Theo has occupational therapy every week. Previously, we had to travel to the next town for therapy, which was quite exhausting and annoying for him. Now, we’ve switched to a 10-session therapy block at a climbing hall nearby and he loves it.”

Theo: “I like the climbing therapy. The coach is always showing me new ways to make my hands and fingers stronger. In the beginning I could only do the very, very easy bouldering routes but last week I went to the top of a harder one. My legs are very important but I wouldn’t have been able to do it without gripping with my hands too. Even my helping hand is getting stronger.”

Mother: “He really feels alive again since he truly seems to enjoy climbing. It not only helps with his motor skills but also boosts his confidence. Since the stroke, he has been very reluctant to try new things. Last Christmas, he received a bouldering wall for his room as a group gift from me and some friends. I always try to bring therapy into our home – whether from occupational therapy or rehab – by incorporating tools like a sitting ball and swings, for example, or small games that he likes. Motivation at home is difficult though, I try to incorporate therapy in a playful way – that really helps.”

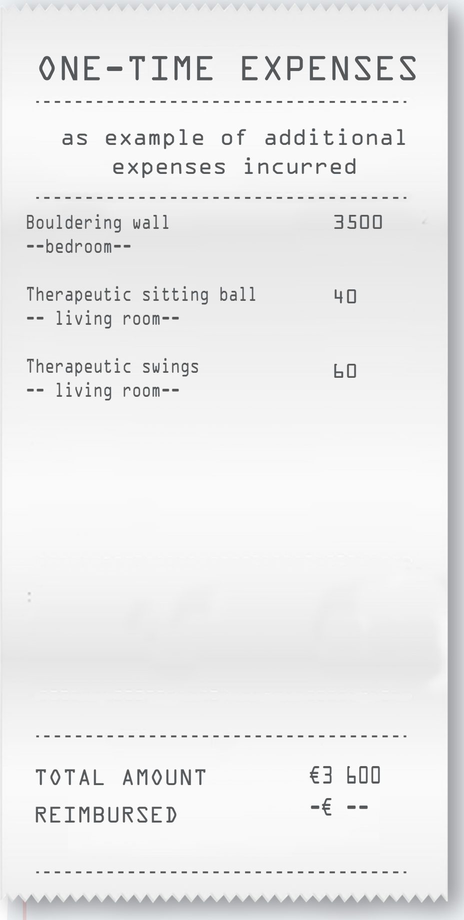


“… What he really needs is a small, sensory-reduced space where he can rebalance.”

“I need to recharge my batteries too”

mother

allowed to use – an exception – helped me a lot to calm down for a moment. At home, my bed is my absolute favourite space. When he sleeps, I can finally calm down and let go of all the worries.”



ONE-TIME EXPENSES

as example of additional expenses incurred

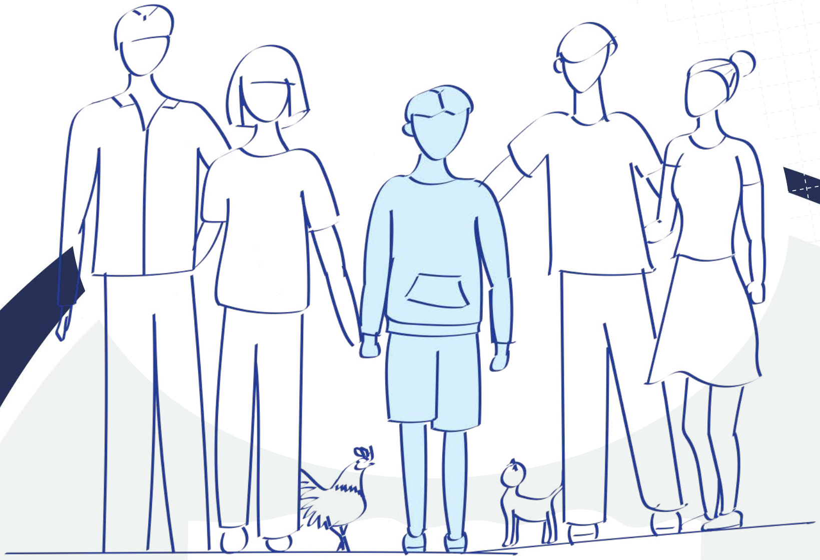
Bouldering wall --bedroom--	3500
Therapeutic sitting ball -- living room--	40
Therapeutic swings -- living room--	60
TOTAL AMOUNT	€3 600
REIMBURSED	-€ --

LEGEND

Situations that for the child …

——	are impossible
······	require help
– – –	require tactics
〰〰	allow independence
═══	are enabling

Zack



PERSONAL

- 14-year-old boy
- Family: parents, 1 sister (19), 1 brother (16), a cat, a rooster
- Lives in a row house
- Goes to boarding school Mon.-Fr.

Likes:
Trains, PlayStation, his electric drum kit

Dislikes:
Breaks in his routines

STROKE

Shortly after he was born
In the left hemisphere of the brain

This continues to cause

- Right-sided hemiparesis
- Cognitive impairment
- Epilepsy (therapy resistant)

Zack also has (not directly stroke-related)

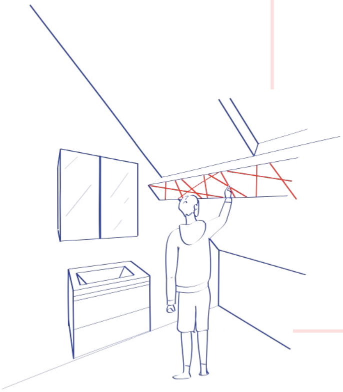
- A hearing impairment; has cochlear implant

CARE GIVERS

- Parents both work 80%
- In their spare time Zack's mother coaches handball, his father is a bee-keeper
- What keeps them awake at night is where Zack will live and who will take care of him in the future

While Zack's parents are both employed, his mother changed to part-time work to provide the roughly 28 hours a week for his special needs and to also have time to care for his siblings, especially when they were younger.
Their €87.000 annual income covers their essentials as a family, but they have had investments in home adaptations and specialized equipment for Zack, some of which have not been covered by insurances.
Zack goes to a special boarding school which they have to pay for. A care allowance of around €190 per month because of Zack's care level 1 helps to cover these costs. They have spent over €13.000 on special items and home adaptations, receiving around €6.500 back from their health and care insurances. Currently, they are saving around €3.000 to install a second handrail so Zack can navigate his home more independently since they are not sure if they will get reimbursement for this adaptation a second time.

LANDSCAPE OF CARE



Adapting the House to Zack's Routines

Mother: “As he got older, bath time upstairs became difficult. We had to think of solutions, and that’s when we decided to build a second bathroom downstairs.”

Zack: “I like the big shower! It’s fun, and it’s big enough for me—and even you, Mum! We can fit lots of people.”

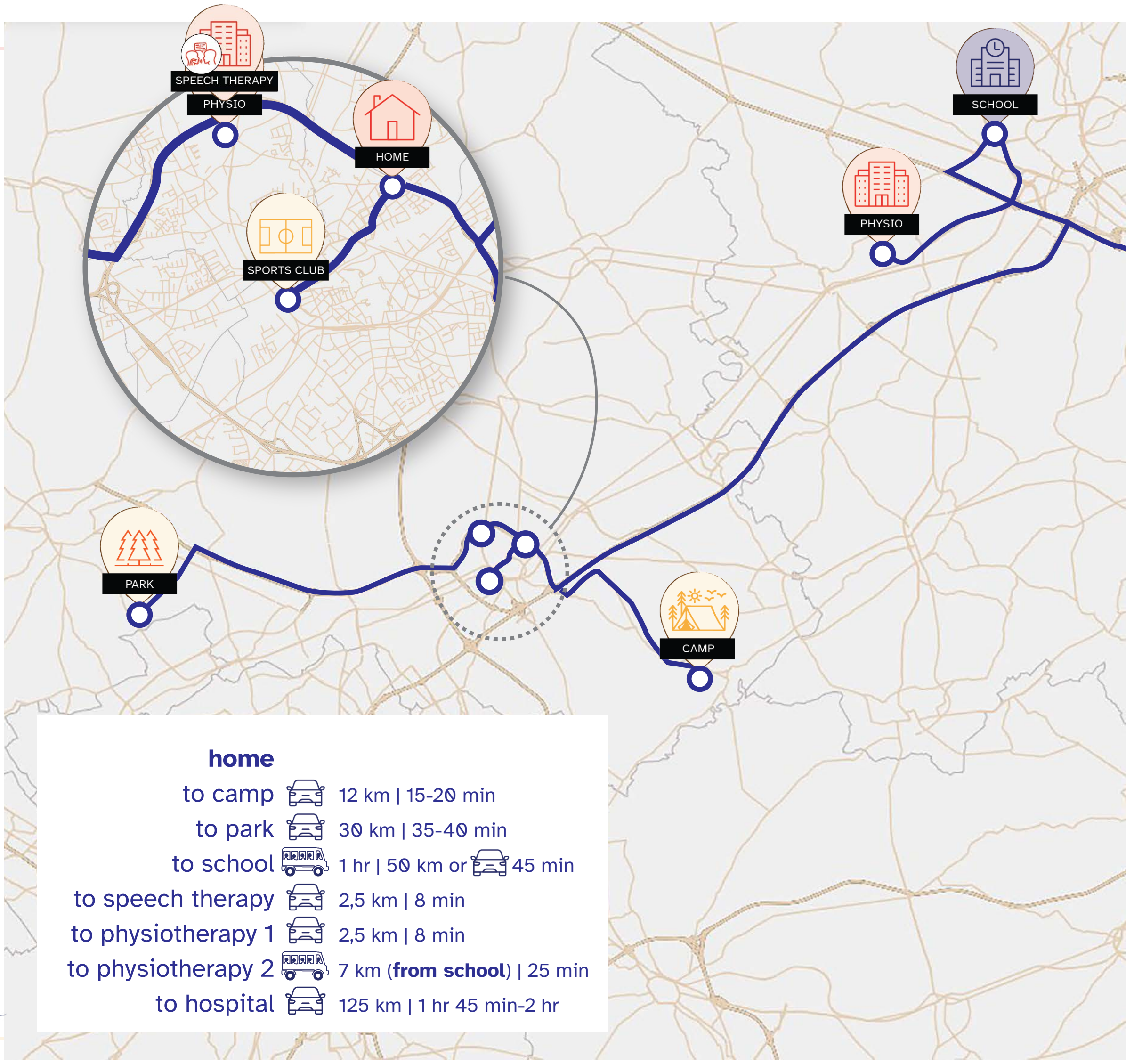
Mother: “The step-in shower downstairs is much more practical for us. It’s made a big difference. We’ve been fortunate to have enough space in the house.”

Zack: “I have lines in the bathroom. I love them! I trace them with my fingers.”

Mother: “The lines are an important part of his routine. The lines help him focus and feel calm, and it makes it easier for me to wash him. At the backdoor we also have lines.”

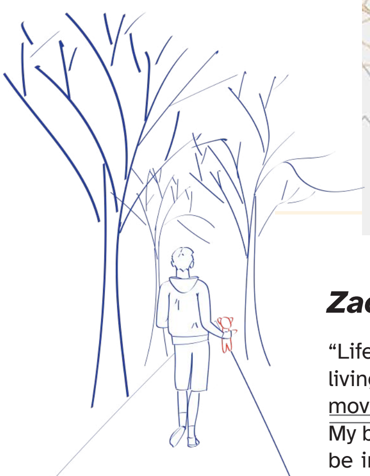
Zack: “Yes, downstairs. When I put on my shoes or take my rucksack. For when I go outside or to the garden to play on the trampoline or with the ball. We have a real goal with a real net. And a rooster in the garden.”

Mother: “The trampoline is used in a rather unique way as



home

to camp	🚗	12 km | 15-20 min
to park	🚗	30 km | 35-40 min
to school	🚌	1 hr | 50 km or 🚗 45 min
to speech therapy	🚗	2,5 km | 8 min
to physiotherapy 1	🚗	2,5 km | 8 min
to physiotherapy 2	🚌	7 km (**from school**) | 25 min
to hospital	🚗	125 km | 1 hr 45 min-2 hr



Zack's Footprint: From Kitchen Rails to Forest Trails

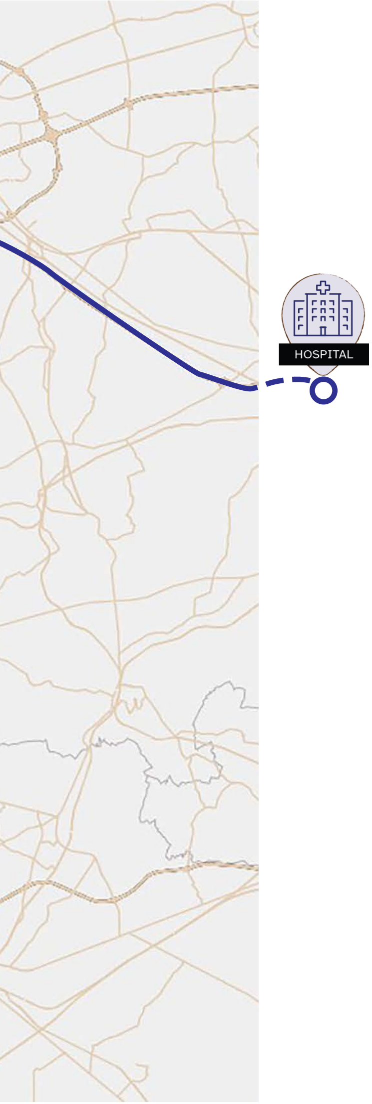
“Life with my brother is unique. His trains take over the living room, sometimes extending into the kitchen. Mum moves the coffee table to give Zack space.

My brother stomps his feet and easily gets frustrated. It can be intense, so our parents keep him downstairs for safety, with his toys —often, he’s on ‘my’ PlayStation. He needs a bit of help with this but also has his own tricks to make it work for him. Dad and I focus on other things—I’m often in the attic, Dad has his bee-keeping activities and regularly works evenings. Weekends get busier when he’s home from boarding school, especially if our sister visits. Dad takes him to the forest while Mum jogs, does chores, or takes me to handball matches. The handball club is really an outlet to our family. Zack loves the sports hall, where the big open space lets him see everything during training—throwing the ball, zigzagging obstacles. It baffles me how he can navigate walking on quite a narrow bench there but needs help with something as simple as the toilet at home.

I struggled sometimes with how much attention he needed, so our parents converted the attic into my retreat.

playing on it for Zack involves quite gentle bouncing in a sitting or lying down position, often with a ball and one of us there with him.”

“I have lines in the bathroom. They’re yellow and white. I love them!” *Zack*



People and Spaces that Support Zack

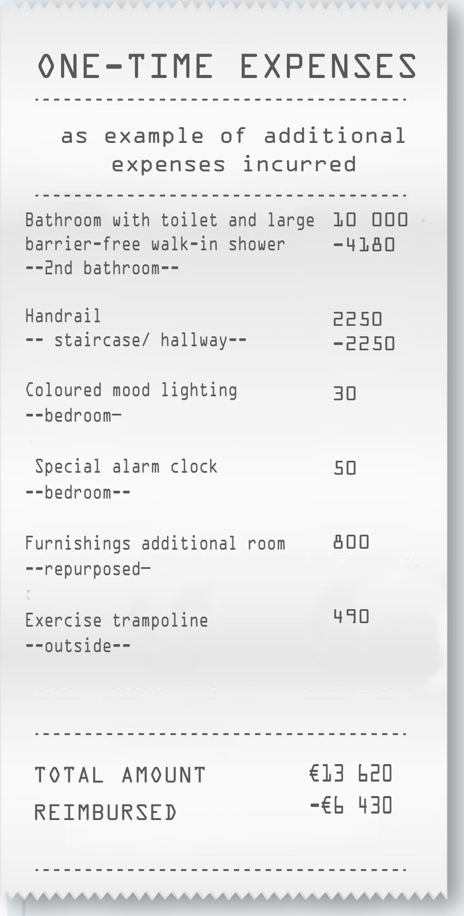
Father: “We’ve been to the hospital a lot, a lot: paediatrics, urology, psychiatry, immunology, special dental care … Currently, we’re going about once every 3 weeks. He is terribly afraid of hospitals. The main reason is because he really doesn’t like staying there alone overnight. If at all possible, my wife stays with him. For him, it’s completely different to his experience of the boarding school.

During weekends at home we go to therapy practices nearby, like for speech and physiotherapy. At boarding school speech therapy is included, but physio we had to organize ourselves. It’s not easy to find a good physio in a place where you don't live but at the same time close enough to the boarding school etc. School does help arrange the transport.

What truly helps us hold on as a family are the organizations that tailor their care and the environment in which this takes place to children and young people like Zack. Whenever we can we make use of the programs they offer. He loves it there—it’s nearby, and we trust that he’s in good hands. During school holidays, he attends their camps, where they combine social activities with therapy. They even have a specially designed garden where you can explore textures and smells through different types of paths and plants – they call this a ‘snoezel garden’.”

“I struggled sometimes with how much attention he needed, so our parents converted the attic into my retreat. ” *brother*

Mum says my brother is happiest with just her, Dad, and him at home. Even a visit from our older sister can upset him, making family balance challenging at times.”



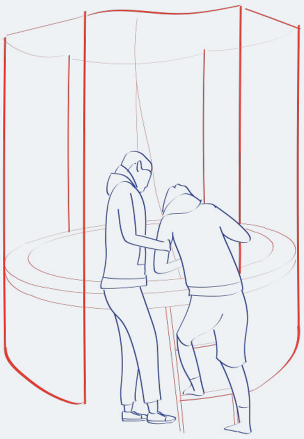
ONE-TIME EXPENSES

as example of additional expenses incurred

Bathroom with toilet and large barrier-free walk-in shower --2nd bathroom--	10 000	-4180
Handrail -- staircase/ hallway--	2250	-2250
Coloured mood lighting --bedroom–	30	
Special alarm clock --bedroom--	50	
Furnishings additional room --repurposed–	800	
Exercise trampoline --outside--	490	

TOTAL AMOUNT €13 620

REIMBURSED -€6 430



LEGEND

Situations that for the child ...

- ━━━ are impossible
- ┈┈┈ require help
- – – – require tactics
- 〰〰 allow independence
- ═══ are enabling


Ben


Ella


Lenny


Mia


Theo


Zack

BUILD CARE

BUILDING SUPPORT FOR CHILDREN AND FAMILIES AFFECTED BY STROKE

This persona-set was made in the context of the BUILD CARE research project which received funding from the European Union's Horizon 2020 research and innovation programme under the European Joint Programme on Rare Diseases (N° 825575) and the national/regional funding partner organisations: FWF (Austria), BMBF (Germany) and FWO (Flanders, Belgium). Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or national/regional funding agencies. Neither the European Union nor the granting authorities can be held responsible for them.

Project period: 2022 - 2025

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