



# Life with PIMD+

A glimpse into the future for parents and carers of children with  
profound intellectual and multiple disabilities and more (PIMD+)

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**Disclaimer:** We have compiled this book with the greatest possible care, yet the editors cannot guarantee that the content is error-free and/or complete. The information in this book is intended for general use, and we cannot be held responsible for any content errors. If you have any questions, we advise you to always contact your child's specialist.

**Note:** The gender-neutral 'they' is used when talking about a child (18-/18+) with PIMD+. We use the words 'parents' and 'family' to indicate the people that feel responsible for and connected to the child. This includes their carers.

## COLOFON

### LIFE WITH PIMD+

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Any comments can be sent to [info@2CU.nu](mailto:info@2CU.nu)

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# Introduction

A map for parents of children with profound intellectual and multiple disabilities and more (PIMD+)

As soon as you hear that your child will have severe intellectual and multiple disabilities, your life is turned upside down. All of a sudden, everything is different. You may have only just come out of hospital. What to do? Future dreams and plans make way for uncertainty, loneliness and many, many questions. You now know that your child's development will not be as you had hoped. What will your child be able to do and what not? What medical care will it need? What will your daily life look like?

With this guiding map, we want to help you on your way, so that you do not have to figure everything out yourself. At 2CU, we are happy to share our knowledge and experiences with you because we were once where you are now. Above all, we want you to know that there is not one 'right' way. Every child, every family walks their own path. Hopefully we can remove a few obstacles for you along the way.

Do you still have questions after reading this book? Please feel free to contact us at any time.

2CU will continue to adapt and expand this book in the future. Have you come across something along the way that you think really belongs in the book? Please let us know! Send an email to [info@2cu.nl](mailto:info@2cu.nl) and for our convenience add '2CU roadmap' as the subject.

# Table of contents

## Chapter 1 Life phases 9

- 0 to 4 years 11
- 4 to 12 years 12
- 12 years and older 15

## Chapter 2 Caring together 17

- Customary care 19
- Care request 21
- Contact with the care providers 22

## Chapter 3 Parents and doctors as a team 23

- Which hospital should I choose? 25
- Specialists 25
- The role of the family doctor 26
- Emergency situations 27
- What if we disagree with the doctors? 28

## Chapter 4 Difficult decisions 29

- *Advanced Care Planning* 31
- Quality of life 32
- Treatment phases 33
- No-resuscitation/no-treatment statement 37
- Possible arrangements 38
- Sample questions 38

## Chapter 5 Eating & Drinking 41

- Tube feeding 43

## Chapter 6 Language & Communication 45

## Chapter 7 Care & Resources 47

## Chapter 8 Family & Surroundings 53

- Daily life 55
- Brothers and sisters 56
- Taking care of yourself 58
- Free time and holidays 59

## Chapter 9 Support & More information 61

- 2CU; From parents, for parents 63
- Support 64
- Books 65
- Information on the internet 66
- Glossary 68

## Epilogue 71

## Appendix 72



1

# Life phases

Every life goes through different phases. The life of PIMD+ children and their parents do as well.





You now know that your child's future will be very different from what you had imagined of while dreaming about the future. What you usually do not know yet is how exactly your child will develop. Will your child be able to walk, eat, communicate? And in what way? What medical care will your child need? What will your daily life look like? We often see that parents face the same challenges during certain phases of their child's life. When your child is between the age of 0 and 4, your focus will be on different things compared to when your child has reached adulthood. The boundaries between these phases are, of course, fixed.

### **Age 0 to 4 years**

A healthy child takes many big steps between the age of 0 and 4. However, sad as it may be, this is very different for children with profound intellectual and multiple disabilities. They quickly fall behind. Many children with PIMD+ have a turbulent start in life. Their physical problems are often much more present and noticeable in the beginning than their intellectual disability.

Some children cry a worryingly amount of time without any understandable reason or without you really being able to do anything about it. They have problems that greatly affect their sense of well-being and security. Difficult digestion and spasms are common, as is epilepsy. Naturally, these symptoms do not necessarily have to affect your child, but unfortunately, they do occur regularly.

### **Fighting the symptoms**

Still, every parent wants their child to feel as good and happy as possible. And doctors want that too. That is why they often start by fighting the symptoms, even when the cause is still unknown. This can include medication against pain or constipation, spasms or epileptic seizures.



## Uncertainty

So much is happening in such a short time. The future of your child and that of your family suddenly looks very different. How exactly, no one knows. This uncertainty is difficult to cope with. On top of that, you become acquainted with the medical world. You talk to experts, try to understand what is happening. Such contact with doctors and nurses requires you to be articulate.

Do you have questions? Write them down, ask them. Don't understand something? Have it explained to you, more than once if necessary. Many parents feel like 'nagging parents' when they send yet another email. But doctors (should) know how insecure parents can feel and they really are here to help. You and the doctor are here for your child, together. A relationship of trust between you and the medical professionals is therefore very important.

## 4 to 12 years

It is probably starting to dawn on you that your child will not make any great developmental progress. This can hurt tremendously, sometimes in the most crazy and unexpected situations. Your child's care needs may also be constantly changing during this phase. Some things are easier to deal with, other changes can be very upsetting. Nevertheless, we often see a little bit more stability in the medical care during this period. For example, children are less likely to get sick from viruses during this phase.

## A big baby

'What can your child do and what can they not do?' A question that people often ask the parents of PIMD+ children. It then seems easiest to say that your child has the developmental level of a baby. But in fact that is not quite true. It is actually much more complex than that. Changing your child, moving them, cuddling... it all becomes more and more difficult as your child grows.

The 'cuteness' disappears and there is more and more physical strength needed for caregiving, which can make it increasingly difficult for parents to find caregivers. Some PIMD+ children experience little to no pleasure. This is not only emotionally taxing, but also a huge challenge, for both parents and carers, to find something that stimulates the child.

### Development

Despite their enormous limitations, PIMD+ children can learn things. However, the steps are much smaller, and you have to learn to look for them in the smallest details. Learning to walk and talk is usually far too ambitious, but what can your child do? Perhaps they will learn to indicate when they want something. Perhaps they can learn to roll over or hold something. This learning process can be a great challenge not only for the child, but also for the parents. For example, is it wise to remove as many stimuli as possible because they make the child restless? Then the child cannot learn to cope with them. Yet some children really cannot learn to process stimuli. Sensory integration therapy can help them get used to different stimuli step by step.



### WHAT COULD STIMULATE YOUR CHILD?

Snoezelen (MSE), music therapy (BIM), massages, brushing-therapy, swimming, listening to music, music therapy at home, different types of lamps, a disco ball, a bubble tube, vibrating toys, an electric toothbrush.



### **Pain**

Unfortunately, during this phase, it will also become increasingly clear that your child is not developing in the same way as their peers. Usually, going to a regular day care centre is not possible. Perhaps you had already chosen a primary school. It hurts to have to cancel your child's spot. Just like it hurts to see their peers develop. That does not make you a bad person. No one dreams of a life with a PIMD+ child, but that does not mean that you don't love your child.

### **Adjustments and arrangements**

As a parent, you need to think about how you want to and how you can organise the care of your child. What will your child do all day? Do you want them to be at home? How much care do you want to provide yourself? Which care providers can help you? What care resources will you need? This world of rules and applications can be quite overwhelming. Fortunately, however, you do not have to do it all by yourself. In the chapter 'Information on the internet', you will find information that can help you answer your questions.

### **Comments**

'I have so much respect for you!' You will often hear this when people talk about the care for your child. While you may think: 'What else am I going to do?' Sometimes there may be people close to you with very strong opinions that in fact only hurt you. This can cause a lot of tension, especially among family members. And yet, support or practical help often comes unexpectedly. A neighbour who brings you food. A friend who takes your other children to the park. Don't hesitate to accept this help!

## Contact with other parents

It's tempting to scour the internet for information, support and hope, and, to a certain extent, it can be useful. But always keep in mind that there are many nuances within the group of PIMD+ children. What is true for one child is not necessarily true for your child. Do not be discouraged by negative stories or remarks. Be careful in choosing where you look for information.

## 12 years and older

PIMD+ children also reach puberty, physically, hormonally and emotionally. Your child may still be at a baby or toddler level mentally, but the rest of their development continues, although puberty can be very different from 'average' children. For example, your child may start to grow hair or smell of sweat quite early on. Hormones can also derail any epilepsy they may have.

### WHAT CHANGES DO WE OFTEN SEE DURING THIS PHASE?

Your child will grow and gain weight. Puberty hits, often earlier than it does in children that do not have any disabilities. This means: your child will grow pubic hair and armpit hair and will smell differently. Boys often get an erection which makes changing them very difficult. It can be terrifying when you all of a sudden hear deep and dark noises coming from the baby monitor. You all of a sudden realise your son's voice has dropped. Girls will get their periods and develop breasts. As hormones can derail your child's epilepsy, some PIMD+ girls will be given a birth control pill to better control their epilepsy.



## Housing

A child with a 'normal' development will leave their home sometime around the age of 18. This, of course, will not be the case for a PIMD+ child. Some PIMD+ children leave home when they are much younger because caring for them at home has become too difficult. Other children stay at home much longer because their parents cannot find a suitable care facility in the area. In an increasing number of regions, special living arrangements that have been created by parents are emerging. Which option best suits you and your family? The answer to this question usually takes some time to develop. Start thinking about these matters early on. This way, your child's housing will be your decision, and you will remain in control.

## Adulthood

The 'system' sees a PIMD+ child as an adult as soon as they turn 18. However, a PIMD+ child will never be able to handle the responsibilities, rights and obligations that come with being an adult. This is why it is important to start applying for mentorship or legal guardianship in good time. A doctor must perform an examination to be able to apply for Wajong (Young disabled persons) benefits. Opening a bank account, applying for benefits, taking out insurances... it's all part of the deal, as is leaving your now familiar children's hospital. The right to day care that includes therapies and interest for developing and maintaining skills often ends as well, as does supervised transport.

## What if we...?

At 2CU, we work hard to make the transition to adulthood smoother for PIMD+ children. It is very important to make a list of all that needs to be done. Perhaps this is also a good time to consider who will look after your child if you and your potential coparent are no longer able to do so. What will happen to your child after you die?



2

# Caring together

Caring is not something you have to do alone.

Even if you think, especially in the beginning, that you can.





If you have only just found out that you have a PIMD+ child, you will want to do everything in your power to take the best possible care of them. Everything revolves around the wellbeing of your child. Work, social contacts, your relationship, your own health... it all feels less important. And yet, you will not be able to avoid it: you will have to think about some form of support in the caring for your child. The common phrase 'You won't help your child by pushing yourself over the edge' is very true.

### Customary care

Customary care is the care that every parent is required to give their child on a daily basis. You cannot sign this away. In the case of children and youngsters, customary care mainly has to do with their age. There is currently a lot of discussion about this subject. Where does customary care end? It is now becoming increasingly clear to the various institutions that for PIMD+ children, nothing falls into the customary care category.

#### HEALTHY CHILD = CUSTOMARY CARE

- Learn to sleep through the night.
- Can be satisfied with their thumb or a pacifier.
- Distraction will help break the cycle of unrest.
- Care will become increasingly easier with time.
- Your child can entertain themselves.
- Your child will become less vulnerable with time.
- Everybody gives your child attention.

#### PIMD+ CHILD

- Has no day or night routine.
- Sucking their thumb or pacifier is often too complicated.
- The unrest cycle is difficult to break.
- Care will stay the same but will become more difficult as you and your child get older.
- You will be needed for everything, even playing.
- Your child will remain very vulnerable.
- You need to help people connect to your child.

## CARE FOR YOUR PIMD+ CHILD AND YOUR FAMILY

- Treatments at the hospital, your family doctor, the dentist, a physiotherapist, a speech therapist, the rehabilitation specialist, and a specialist doctor for people with intellectual disabilities etc.
- Day care, getting there and back.
- Adjustment and resources, (help when) applying for a special pushchair, a special car seat, all the adjustments all the adjustments you will need in your home for your PIMD+ child to grow up safely.
- Help with the care for your child, all the medical treatments, therapies both at home and at day care, a place to spend the night from time to time.
- Space for the family to also do things that are not possible with a PIMD+ child. For example: working, a day out with the other children, going to the theatre, having dinner with friends. In the long term maybe even a holiday.

## 24/7 direct care

Some people with a disability need care and support 24 hours a day. For them, it is vital that there is always someone nearby who can provide direct assistance. People who need this much care are covered by the Wet Langdurige Zorg (Long-Term Care Act - WLZ). The WLZ and health insurance provider combined, cover all conceivable care and assistance that your child might need.

## How can you get what you need?

You will have a final consultation when you are discharged from the hospital. The discharge nurse will help you make the transition to your home as smooth as possible from the familiar and safe environment in hospital with doctors and nurses everywhere, to your home where you and your possible partner will be primarily responsible for the care of your child. For many parents this is an emotionally challenging time. That is precisely why a smooth transition with clear agreements is so important. Who will look after my child at home? When is the next hospital appointment? Who can I call if I am worried or if something is unclear?

## Care requirements

First of all, it needs to be clear what the care requirement looks like. An employee of the Centrum Indicatiestelling Zorg (CIZ) will visit you to make an inventory.

During this appointment, it will become clear which type of care and support is needed and how this will be funded. When a child is still very young and does not have a clear diagnosis, this can initially be the Health Insurance Act (zvw in Dutch). In the case of a very extensive need for care, it may be that your child is immediately covered by the WLZ.





### **Care plan**

Together with the discharge nurse, you will draw up a care plan. This will list the care and support your child will need. At least once a year, the care plan will be evaluated to see if it still suits the child and their family. If, for example, a child cries day and night, it can be very useful to provide night care a few days per week.

### **Contact with care providers**

In the beginning, you will see the paediatrician and other specialists very often. Over time, you will notice that this frequency decreases. This is often because the care for your child is evolving and improving, and you start to understand your child's signals better. You will also increasingly be able to cope with many aspects yourself. Stay in contact with your specialists otherwise it can be difficult to catch up in case your child's health suddenly deteriorates.

### **Multidisciplinary consultation**

Try to arrange a multidisciplinary consultation (MDO) twice a year or ask one of the care providers to do so on your behalf. During an MDO, all the relevant care providers such as the paediatrician, the neurologist, but also the rehabilitation specialist and nurses sit down with you and discuss in detail your child's situation.

This way, all parties involved can provide advice from their specific specialties to make the care as fitting as possible, for each child and each family, within the existing circumstances. The family's capacity is also carefully examined: how much care can the family reasonably take on given for example their job, any other children and their own capability. The care plan takes all this into account.



3

## Parents and doctors as a team

If there is something you do not understand, speak up!  
Do not think you are a 'nagging' parent; this is about your child!



A child with PIMD+ is not only disabled, but also not healthy. When a person does not move enough, they will develop problems with their bowels. And when problems with their bowels develop, urinating will often become difficult as well, which in turn causes inflammation in the bladder. If the muscles are weak, it is difficult to cough. If coughing isn't done properly, the person can easily choke and develop pneumonia. If understanding things is a challenge, it is difficult to learn to drink and eat. Epilepsy makes the body tired, but epilepsy medication can make a child even more sleepy or restless. In short: everything is linked.

You will form a team together with the doctors that will try to find the best possible solution for each problem.

### Which hospital should I choose?

Most PIMD+ children have a main practitioner in an teaching hospital. This is because of the complexity of the disabilities and conditions and the fact that they all affect each other. Sometimes another (smaller) hospital in your vicinity can also be useful. The paediatrician is your child's 'case manager', so it is helpful to have them close by. They can also help you if you are unsure whether it is necessary to go to an academic hospital. For example, if your child develops pneumonia, a bladder infection or an ear infection, this can usually also be treated in your local hospital. This will make caring a lot easier for the family.

### Specialists

You will see many different specialists in the hospital: a paediatrician, neurologist, perhaps a gastroenterologist or the doctor in charge of metabolism. You will probably meet a surgeon and an anaesthetist if an operation has to be done. All these specialists will do their best to help your child.

### The benefit of a family doctor

It is also important for the family doctor to see your child from time to time. They can get a better impression of you as a family this way and learn to assess how things are actually going. They can help with things such as writing authorisations or come and visit you after a medical emergency or operation.

#### DO YOU HAVE ANY QUESTIONS? ASK THEM!

Is there something you are not sure of? Say it! Do not feel like you are nagging, this is about your child. Indicate what you need. Always remain polite even if you do not get an answer straight away. Are you constantly worried and do you not hear back? Follow your gut feeling. Politely call or email again. Doctors are people as well which means some have more talent for compassion and communication than others. However, never forget you are in it together to help provide the best life possible for your child. You will need to work together for a long time, so try to build a relationship of trust and clarity. Nobody is expecting you to do this on your own. Stay in contact with the specialists. Sometimes it can be helpful to ask the hospital psychologist to help you to find answers to difficult questions.





## Emergency situations

It often makes no sense to take a PMID+ child to a general practitioner surgery where no one knows your child. Therefore agree with the primary care physician where you should go in an emergency situation, for example the hospital emergency department. They will make an entry in the system so that you can report to them without a fuss. If it is necessary to call an ambulance, let them know that your child has to go to the hospital where they are being treated. This avoids unnecessary confusion and loss of time.

Make a list of your child's medical problems and their current medication, including dosages and treatment appointments. Print this out on an A5 sheet, laminate it and hang this information on a key ring. This way you will always have all the important appointments and information to hand. Keep the overview up to date and put it in a bag that is carried with your child. This can be very important for doctors and specialists in an emergency situation.

Once a diagnosis has been given, or at least the most acute situation is under control, the paediatrician will suggest that you continue the care for your child at home whilst remaining in close contact with the hospital. The discharge nurse and the family doctor will help you to arrange everything so that the transition to home care goes smoothly. This will be a big step and can be very emotional. However, gradually, you will discover that you can do this. At some point, you too will know and feel exactly what your child needs.

### **What if we disagree with the doctors?**

It may happen that you do not agree with your child's doctors, for example, about a certain treatment. Parents' opinions about their child's care are very important. Sometimes doctors know something that you do not yet understand. They will then do their best to offer you the right support. Therefore, always stay in contact with the doctors and tell them what is on your mind. Let them know what you would like to do and how you see the future and quality of life for your child.

If your child's doctors cannot or will not follow your wishes, you can consider asking for a second opinion or a review by a hospital ethics committee. This is and will always be an option.

If all options have been considered and everything has been tried, but it is still not possible for you to reach an agreement with the doctors about what is best for your child, you can also seek legal advice about the remaining available options.



4

# Difficult decisions

Every well considered step you take for you child, is the right one!



As parents, you will regularly have to make decisions on behalf of your child. These include very simple ones, but also very complicated ones. Sometimes you have to choose the lesser of two evils. You want the best for your child as a parent, but at the same time you are also afraid to lose your child. Never forget, you are not alone.

### ***Advanced care planning***

PIMD+ children have major health problems that can affect each other. On average, they currently live much longer than they did a few decades ago. Yet the future is not always bright for them. Doctors will want to discuss the possibilities, but also the impossibilities of different treatments. This is called *advanced care planning*.

### **Making plans**

*Advanced care planning* is a great development, during which health-care providers discuss at an early stage with the parents what their child's future care should look like. This is important and will also make you feel less alone in the great responsibility of caring for your child. However, the reality is that not everything can be predicted. You can make many plans in advance, but things can still turn out differently. In any case, it is important to take plenty of time to talk to the specialists.

### **Taken by surprise**

A discussion about *advanced care planning* can be a huge shock when you have only just heard how serious your child's situation is. It may sometimes feel as if the doctors do not see your beautiful, sweet child, but only their illnesses and handicaps. Take your time. It is your child, and this is about your future. It is not at all strange that it takes a while before you can think about this, let alone speak about it. Feel free to share this with all parties involved.

The doctors and nurses of children with this kind of life threatening condition will continue to do everything they can to help your child. Nevertheless, some treatments are just not suitable. It is very important that your doctors avoid treatments that are harmful to your child, but it is also very important that you feel that you are heard and seen. You must have the confidence to travel this bumpy road with your specialists. For this, the advanced care planning meetings are essential.

### Quality of life

Quality of life can be seen as the balance between good and bad things in a person's life. The most important question is if there is a balance between the amount of pleasure, comfort or feeling of happiness on the one hand, and the amount of pain, discomfort, frustration or perhaps sadness on the other hand. Sometimes the answer is clear to all those involved, but sometimes the quality of life can be debated from different perspectives.

When making decisions about medical treatments for children, it is important to take the quality of life into account. It is not only about the quality of life now, but also in the future. Every treatment has its advantages and disadvantages, and even if a treatment seems to have many advantages in the short term, you may regret it in the long term. Therefore, always talk to the doctors and discuss the impact of each treatment on your child's quality of life. Consider the consequences both now and in the future.



## Treatment phases

Living with a PIMD+ child is a process that will not be the same for every child or every family. There are however certain phases that every child and family will go through. How long each phase lasts differs from family to family and from child to child. It can, however, be very disturbing to read about these phases.

### The early stages: looking for answers and solutions

If a child turns out to be a child with PIMD+, a difficult search begins: what is the cause? What problems do they have? What medication might they need to suppress certain symptoms? Usually, a time of intensive investigations begins. From blood tests to MRI scans, from recordings in which your child is observed to X-rays. During this intensive time, the doctors will do everything they can to help your child right away or even to make them better.

This means many hospital visits and often living between hope and fear as it may all turn out better than expected. Because maybe it will all turn out better than expected? You want answers, but sometimes they are just not available (yet).

## NEVER BE AFRAID TO ASK QUESTIONS

Always feel free to ask your specialists questions about your child. Even more so, make sure you do not bottle them up. You are not alone. Some questions you could be asking include:

### *About a specific treatment*

- Could this treatment work? If so, what is the chance of it working or failing?
- Why do you think this treatment will be suitable for our child?
- What are the pros and cons of this treatment?
- What could go wrong during this treatment? What is the chance of it going wrong?

### *About the quality of life*

- How can we know whether our child is suffering if they can barely communicate?
- If our child lives, what will their life look like?
- They are so cute; they don't seem to be suffering. Or do you think differently?
- Is there any scientific evidence for the quality of life you are describing?

### *Support*

- I think I cannot handle this, who can support me/us?
- I find it difficult to understand what the impact will be on our family. Is there anyone I can talk to about this?



### **The phase of acceptance**

Unfortunately, there comes a time when it becomes clear that doctors cannot work miracles and your child really is not healthy. Conversations about this can be quite frightening for you as a parent, and it can even feel as if the doctors want to give up on your child.

Nothing could be further from the truth. The doctors just don't want to give you any more hope than is realistic. They don't want to promise you that they can help your child if they cannot.

What they can do is make sure that your child has the best life possible and that you get the most out of it together. This includes, for example, practising assisted standing, practising drinking, physiotherapy, speech therapy, placing a stomach tube. No, your child will not get better, but you may be able to improve their quality of life significantly.

### **The comfort care phase**

Despite all attempts to improve the quality of life, it may become evident at some point that it is just not feasible. It may turn out that your child is not becoming more alert or happy after all. Despite all the physiotherapy, the muscles become increasingly stiff and even though the speech therapist is doing their best, your child's drinking ability is getting worse. During this phase you and the doctors may come to realise that 'there is more input than output'. You may then prefer quality over quantity. Fewer activities, more comfort.

If, for example, your child feels more comfortable sleeping, you will no longer try at all costs to wake them up and be alert more often. Instead, choose to make sleeping as pleasant and easy as possible. If your child becomes stressed by all the attempts to wake them up, this may be painful for you to watch. But then, on the other hand, it may also feel like a relief to just not disturb them anymore. Your child does not have to adapt to life anymore. You now adapt life to your child.

### **The palliative phase**

Unfortunately, many PIMD+ children experience a lot of discomfort or pain at some point. There will be lots of crying, many epileptic seizures, many spasms... These symptoms can make you, as a parent, wonder if your child is still experiencing a sufficient quality of life. You may wonder how long their life should go on like this. A terribly sad realisation. Your child has now entered into the palliative phase.

This does not mean your child will die soon. Palliative care mainly means that everyone, doctors, carers and all those involved, takes away as much of the child's discomfort as possible. It's about relieving the symptoms of someone who really can't get better. Therefore, this phase can last years. You could almost say that PIMD+ children are actually palliative their entire life. During this phase, the doctors will also discuss treatment restrictions with you. What if..? More about this on the next page under 'The no treatment and no resuscitation statement'.

### **The terminal phase**

There comes a time when your child's body really can't take it anymore. Maybe your child only ever sleeps, is in constant pain and/or can no longer keep any food down. During this very difficult phase, even more intensive contact with the doctors is very important. They can tell you what options there are to prevent your child - and therefore you - from suffering.

Nobody expects you to do this all by yourself. Stay in contact with each other, with the doctors, with people you trust. Sometimes a hospital psychologist can help you find answers to difficult questions.

## **The no-treatment and no-resuscitation statement**

Sometimes, when doctors talk to families about the limits of life prolonging treatments, parents say they want 'to do whatever it takes', but when life support doesn't help, or does more harm than good, the best and most loving decision you can make is to write a no-treatment and/or no-resuscitation statement no matter how difficult this is. These statements are mainly there to prevent you from suddenly being faced with decisions in an emergency situation that you had not yet considered previously.

One of the doctors will bring up these statements at some point. They will give you advice but will also listen carefully to your wishes. You are not obliged to sign the declaration (immediately). If no more treatments and/or no resuscitation is the right choice for your child, the doctors will note this in your child's file. This way, other doctors and nurses will also know what should or should not be done.

Have you changed your mind? Then you can always discuss this with the doctor(s) again. Perhaps the specialists themselves will regularly bring up the statement during an outpatient visit.

Of all the sick children who die in the Western world, the vast majority have this kind of statement or something similar.

## **The no-treatment statement**

This statement indicates that any treatment should first be discussed in terms of its usefulness and necessity. In some situations, life-sustaining treatment can do more harm than good. When the doctors and the family have jointly decided that the child's life is hurting more than it gives them joy, and there is no prospect of improvement, they will always first discuss whether or not to do something with the parents.

### **WHAT COULD YOU LIST IN A NO-RESUSCITATION STATEMENT?**

- We do not want our child to be resuscitated under any circumstances.
- If our child's body all of a sudden gives in, we do not want our child to be resuscitated. If our child is in surgery and the heartbeat or breathing stops because of the surgical intervention, we do want our child to be resuscitated.

### **WHAT COULD YOU LIST IN A NO-TREATMENT STATEMENT?**

- If my child develops pneumonia, we only want to give them antibiotics orally because it is often difficult to put them on a drip.
- If my child develops serious scoliosis, we do not want them to undergo surgery.
- If my child's stomach does not accept tube feeding anymore, we do not want to give them a duodenal tube.
- We do not want our child to be connected to a heart-lung machine. We do want to give them oxygen via a mask.
- We do not want our child to be admitted to hospital anymore.

### **The do-not-resuscitate statement**

Resuscitation means the artificial maintenance of breathing and heart massage. So non-resuscitation means that when the heart or the breathing stops, the doctors only take care of your child's comfort. They will no longer try to get the heart and lungs going again. That may sound terrible but when your child is so seriously ill and can enjoy so little in life, it can still be the best choice. Resuscitation almost always means even more damage being done to your child.

The moment when the breathing or the heart stops, it is very difficult not to do anything. Doing nothing is very unnatural, not only for the family, but also for doctors or other caregivers. Therefore, it is important to discuss this regularly.

### **Cultural or religious beliefs about life support**

Culture or religion can influence the way people think about treatment. You should mention this during your meetings with your child's specialists. They may ask for help from social workers and/or a spiritual counsellor. If it is important to you that someone from outside the immediate family is part of this, that person can also be included in the discussions for example, a family member, a friend, a social worker, a minister or imam. If Dutch is not your first language, you can always ask for an interpreter.

### **Contact with experts**

Sometimes it is difficult to understand what doctors are trying to explain about your child's situation. At the Complex Care United Foundation (2CU) we stay in contact with parents and families who have parted with their PIMD+ child. Many of these parents are willing to speak with you about the considerations that are involved in your child's life. Ask your child's doctor to contact 2CU or do it yourself. We will help to put you in contact with one of our support parents.



5

# Eating & Drinking

Eating and drinking need to be safe, above everything else.





**Eating and drinking do not come naturally to most PIMD+ children. Often, their swallowing ability does not function properly, resulting in choking and sometimes malnutrition.**

Some children are able to eat and drink a little, but this is often only possible with the proper guidance and a lot of patience. Choking can lead to dangerous pneumonia. Difficulty eating can lead to malnutrition. Many PIMD+ children are smaller and lighter than their healthy peers. They also tend to have less muscle and bone mass.

### **Pneumonia**

Because many PIMD+ children are not strong enough to cough properly, pneumonia can develop unnoticed. You often only discover it when your child already has a very high fever. One of the telling signs of pneumonia is 'nose flapping'. If your child's nostrils move with each breath they take, it is very likely that they are developing pneumonia. In case of doubt or concern, remember: one visit too many to the doctor has fewer consequences than one too few!

### **Tube feeding**

A large proportion of PIMD+ children will eventually receive a feeding tube. Although this almost always feels like a huge issue for parents, it can often prevent malnutrition and pneumonia caused by choking.

If your child chokes regularly, it makes sense to consider a feeding tube. Eating and drinking must be safe. Tube feeding is designed to ensure that your child receives all the necessary Nutrients, so that they can grow optimally within their capabilities. The dietician will discuss with you which type of tube feeding is suitable and how much food your child should receive.



### **Nasogastric tube or PEG**

Your child may initially be given a nasogastric tube to find out if tube feeding is a suitable alternative. However, many children do not like having a nasal tube. In the worst case, your child may repeatedly pull the tube out. The nasal tube runs along the back of the throat towards the stomach which can make children feel nauseous. Using a nasal tube for a long time can make children stop eating and taste different flavours altogether.

The PEG tube is a different and more sustainable alternative. When a PEG tube is inserted, a surgeon makes an opening in the stomach and stomach wall, onto which a sort of cap is placed. You can attach a tube to this, through which you can then feed food and medicine directly into the stomach.

### **PEG tube and food**

For many parents, it is a huge step to choose this procedure. They see how their child can still enjoy their bottle or snack despite choking. They don't want their child to miss out on that. A PEG does not mean that a child will never eat or taste again. Very often, the PEG is used to ensure that a child stays healthy, while also allowing them to experiment with different tastes and very small favourite snacks .

Some children experience a lot of choking when they are young which improves as they get older, so that it might encourage them to slowly start eating food again.

Not all children respond well to the synthetic tube feeds. They cough up a lot, cry inconsolably and are restless because they seem to have problems with their intestines. In this case you should also try home-made tube feeds. This is what we call a blended diet. This is a way of making your own tube feed by grinding up freshly cooked food and blending it.



6

# Language & Communication

PIMD+ people always need more time to realise something is happening around them.

Even though most children with PIMD+ will not learn to talk, they can still communicate. All we need to do is adjust our definition of communication.



PIMD+ people communicate differently than you and me. They don't speak and usually don't understand much of a spoken language. They don't know sign language and they usually can't point to something to make something clear. Sometimes PIMD+ people even need to be nudged and challenged before they can interact with people close to them such as their parents, family and carers. They almost always need more time to realise that something is happening around them.

Crying means that something is happening. A smile or a satisfied look tells you that what you are doing is okay or even fun. Clenched fists, an accelerated heartbeat or heavy breathing are often a sign of tension. This may be physical, but can also be caused by frustration, overstimulation, pain but also by pleasure and excitement

Language can be found in very small things. Take your time to discover each other's language. You will see that you will be able to read your child like a book after a while!



7

# Care & Resources

Applying for care resources and adjustments can be very challenging. Try to think ahead..



Care resources and aids can support your child's development and make the care easier for both your child and you or other carers.

### **Personal care**

Nappies, wipes, Sudocreme, baby shampoo, a bath chair, toothpaste that can be swallowed, bibs, a baby monitor, a pushchair, romper suits, a sunshade and foot bag, rattles and cuddly toys... these are all things that your child will need for the rest of their life. The care for a PIMD+ child remains the same as that of a very young baby, only your child is trapped in an ever growing body that does not always cooperate. This demands a lot from parents and carers. How do you change the clothes of a PIMD+ boy who is now 1.80 m tall (6 feet)? Or how do you transport a child whose muscles are always tensed?

### **Aids and devices**

PIMD+ children and their parents can benefit from devices or aids mounted onto for instance a bed or bath from an early age, whether you already have a diagnosis or not. It is helpful when a rehabilitation specialist discusses possibilities with you, so be sure to ask for this support. A rehabilitation specialist and an occupational therapist can work with you to assess whether you need to apply for any new care equipment or whether adapting something that already exists is enough for now.

### **For children and parents/carers**

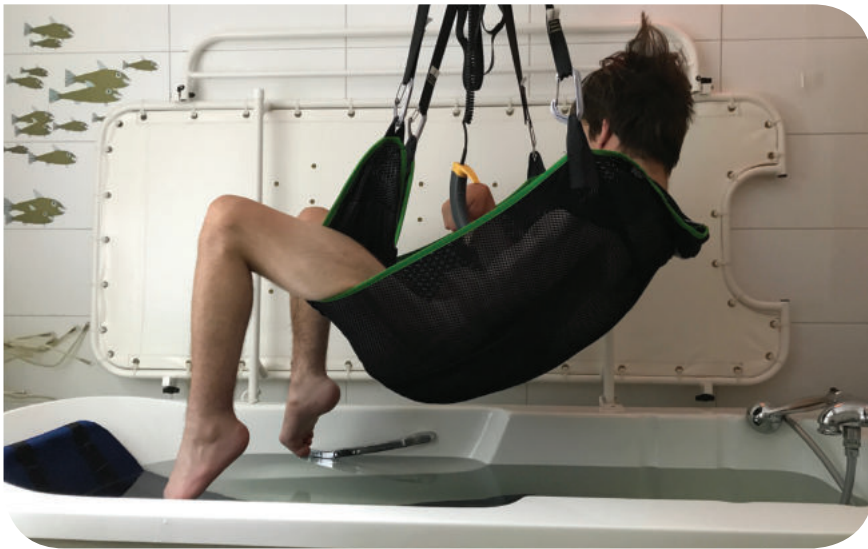
An important rule is: 'normal' when possible, adapted when necessary. As long as regular resources are sufficient (possibly with small adjustments), no extra aids or devices will be provided.

### **WHICH AIDS AND EQUIPMENT ARE COMMON IN THE CARE FOR PIMD+ CHILDREN?**

- A pushchair, pram, feeding chair, wheelchair, sitting and lying down orthosis, sun hood, rain protection, wheel chair bike, adjusted car.
- Height adjustable bed with guards, height adjustable playpen, bath and bath seat or height adjustable shower trolley, nappy bin with a lid.
- A bed and bathroom downstairs or a lift to be able to up-stairs. A ceiling hoist and manual hoist to be able to be lifted in and around the house, including straps. Saturation meter and baby monitor, sleeping bags and breathable pillows and duvets, an anti-decubitus mattress and protective cover, blackout curtains.
- A large cabinet for all the care products and aids, nappies, hygiene products, gloves, PEG tubes.
- An adapted and easily accessible home that has space for all these products and aids and that can be accessed easily. Special refuse arrangement for collection of medical waste, a disabled parking pass, a vehicle with all the necessary adaptations.

Of course not everything is needed from day one for everyone.





From the age of 6-8 months, more and more will be possible. The 'norm' is no longer always suitable either because it is not safe anymore or because it does not support your child sufficiently. Parents and other carers also benefit from good adaptations and equipment. It is of no use to anyone if you constantly have to nurse your child with a bent back and end up having back problems.

### **Be patient**

Applying for aids or adaptations can take a very long time. It usually takes months from the first request to the actual delivery. It is important to think ahead.





8

# Family & Surroundings

Everyday life



**Few things affect your life more than having children. The moment your first child is born, everything changes.**

### **Everyday life**

Having a child with a disability affects all aspects of your family. The situation demands a lot from you, no matter how much you love your child. Some people handle the stress and strain more easily than others. This depends on a lot of factors: from your own personality, your financial situation and the presence of other children, to your social network and your own health.

People with a 'normal family' cannot imagine life with a PIMD+ child. You can't blame them for that. You probably had no idea either before you had your child.

### **So much, so different**

Getting up extra early to bathe and change your child often after a sleepless night. Getting dressed, giving your child their medicine and food, even when your child is 6, 10 or 16. A child that can not speak, or tell what it wants. Which needs to be fed.

On top of that a family that provides home care spends many hours organising that care: from phone calls chasing service providers to completing numerous forms, paperwork, requesting home adaptations and checking of supplies. Your day will be filled with things that 'normal families' are unaware of

## **Capability**

What does it do to your family? The brothers and sisters? The relationships with your partner and friends, the mutual grandparents and relatives? Every hospital visit puts your career under pressure. Will you work less? Will you look for another, more flexible job, will you stop working altogether?

It takes time to find a new balance. Physical effects, sleepless nights and loneliness: the birth of a PIMD+ child is a heavy burden. Every day. This means thinking in a different way, adjusting your dreams, letting go, finding a new routine, as far as is possible for you. It can be beneficial to get help during this process, for example from a hospital psychologist or counsellor

## **Your ability to get through**

Whilst the burden on PIMD+ families is greater than on a regular family, their ability to cope also tends to be greater than you could have imagined. It is impressive to see that many families find their own way after a very difficult start, with space for each other and attention for all family members. As soon as the family learns how to make the best of their circumstances, life with all its difficulties will also have its highlights.

## **Brothers and sisters**

It is not always easy for brothers and sisters to grow up in a family with a PIMD+ sibling and they deserve to be supported properly. However, in the end, they too will go their own way. Their world is full of changes. They will prepare themselves for an independent life, while their disabled brother or sister stays behind in the same world. Their 'normal' development can be hard to see for you as a parent.

### **A special relationship**

It is touching to see how affectionately many siblings treat their disabled brother or sister. For them, their sibling's condition is natural. However, a family with a family with a special child naturally also creates tensions for the other children. They pick up on it when the parents are worried. In an emergency situation, they are momentarily 'less important'. Perhaps they are asked questions at school or other children make strange comments.

Talk about it. Don't just give siblings a chance to build their own relationship with their disabled brother or sister. Also give them the space to ask their questions and express their worries and fears.

How far you go depends on the age and character of your child, never forget that it also makes them more resilient to the hardships that every human being encounters along their path.

### **Contact with other siblings**

In some centres, brothers and sisters of sick or disabled children can talk and/or play with each other. Some like it, others don't. Just know that the possibility exists, but never force it. Especially during puberty, most children do not want to be different from their peers. Disabilities and their complexities are not very 'cool'. Sometimes it helps if home and school can be two different worlds. Give them that.

Many brothers and sisters adapt easily to their new role as carer. Not very deliberately, but simply because they have to or because they don't know any better.



## Taking care of yourself

'I can do it'. 'I don't have time for that'. 'Yeah sure, we are doing fine'. At first, you live in a fog powered by adrenaline. You hold yourself upright because you have to. There is so much coming your way that you just keep on going. Advice from others 'that you should also take good care of yourself' is ignored, because, that's something for later.

## Superpowers

Until suddenly you can't do it anymore. No matter how strong you are, you don't have superpowers. You too have to eat plenty of healthy food, get enough sleep and relax. Is that easy? No, but realise how important it is because before you know it, you will have exhausted yourself.

## Good is also good enough!

Learn to set new priorities. You don't have to strive to have a perfect household. It's okay to make pancakes from a packet for a change, go on an evening walk with your partner, without your phone, while

'Every single day, parents of children with PIMD+ face a number of challenges', explains *Manu Keirse*, clinical psychologist at the *Katholieke Universiteit Leuven*. 'This means that the entire family needs to adjust, each and every day. Not just the parents adjust themselves to the situation, but also the other family members such as grandparents and siblings. After all, they will need to cope without all the attention that goes to the PIMD+ child.'



someone else looks after your child. Say yes to that coffee date with a friend Go for a run (no, not the marathon). Look for opportunities. Try not to forget yourself, because it's true: if you can't do it anymore, you can't take care of your child and the rest of your family.

## Free time and holidays

### Without your PIMD+ child

Sometimes it is nice to have a break from the daily care routine, to have a conversation about something else than hospitals and how your child's health is doing. There are various solutions for this:

- Your child stays at home in the care of a trusted care provider;
- Your child stays with a foster family or in a respite home.

The first time, this may only be for one night or a weekend break. However, once everything has become familiar, your child may be able to stay there for longer. That way, you can go on holiday again. Will it be easy without your child? Probably not, especially not the first couple of times, but realise that it is necessary in order for you to be able to cope in the long run. Don't feel guilty if you just think about yourself for a while.

### With your PIMD+ child

Some parents like to take their PIMD+ child on holiday. When your child is still young and small, it is relatively easy, and you can usually improvise. A bigger child also requires larger aids and things become a bit more difficult. There are however plenty of possibilities, for example you can look for adapted holiday homes or campsites or rent equipment and aids and have them delivered to your holiday location.



It is good to know which hospital is close by in case of any acute medical problems. Remember to take a summary of your child's medical file with you, possibly in the language of the country you are visiting. Indicate what current medications, special circumstances such as allergies, and other things that hospital staff unfamiliar with your child, should be aware of

### TIPS

- Discuss your holiday with your team of specialists
- Discuss what is required
- Research where the nearest hospital is before you book your accommodation
- Bring a medical declaration signed by your doctor (in English)
- Make sure you can sufficiently explain your child's situation (in English)
- Bring your insurance policy and documents
- Look up the phone number of a specialist you might need
- Realise that many epilepsy medications are on the list of forbidden substances and that you will not simply be able to travel with them
- Ask your pharmacist for an up-to-date list of all medications and a medication passport.

**And most importantly, do go on holiday!**



9

# Support & More information



### **ALWAYS STAY IN TOUCH WITH YOUR DOCTORS**

Even though we know a lot, we are not doctors. When it is about medical questions, we can help you structure your thoughts, but we also always tell you to contact your specialist.

Yes, this is quite a lot of information. Impossible to grasp all at once. There are some things you would rather not know. You cherish those moments of hope, but your grief is asking to be heard. How your future as a family will turn out is impossible to predict.

## **FROM PARENTS FOR PARENTS**

2CU was founded by parents of PIMD+ children because they have experienced how lonely you can feel when you have received the PIMD+ diagnosis. Everyone tries to comfort you, but no matter how heartfelt it is, you are just deeply sad and confused.

Again and again, at the most unexpected moments, in the supermarket, on your bike, at a birthday party or when the boy next door goes to school for the first time.

### **Outside and inside**

You can often not see from the outside what is wrong on the inside. Sometimes you don't understand all the negativity about your beautiful child. Then again, those around you don't understand your great concern when they see a very happy child lying in a pram. People give their unsolicited advice or ask confrontational questions that you cannot and do not want to answer. Try to stay true to yourself. Don't hesitate to ask for help and support.

### **We are here for you**

*Use our 2CU helpline!* In moments of uncertainty and worry. When you want to talk. When you need confirmation or an answer to a question about the care system.

Whether you are a parent, brother, sister, grandfather, grandmother, friend, caregiver or doctor, we offer a sympathetic ear and our expertise.

## SUPPORT

### Grief and loss therapists

Families with PIMD+ children often experience strong feelings of grief and loss. Their child is ill, will never get better, while they continue to need a lot of care, and will probably not die very soon. Grief and loss therapists can help you realise that your love and your grief can exist side by side.

We hope that there will be more attention and understanding for each phase and for all the loss that these families feel, each in their own way. The consequences of caring intensively for your child for years on end, full of passion and love, are huge. Maintaining a place in 'normal' life or finding a way back to participate in society is perhaps the greatest challenge of all.

*Tanja van Rosmalen* is one of many grief and loss therapists in the Netherlands. She shared her vision on PIMD+ children being the trigger for loss traumas within the family and their consequences, both in the short and long term. She spoke to us about *Life continues* and *Continuing to live*, a model that was first introduced by *Stroebe and Schut*. It indicates what a grief process looks like: *life continues* is about adapting to the situation, the improvement and the recovery. After all, life goes on. *Continuing to live* incorporates the feeling of loss, sadness and grief. During a grief process, you will continuously find yourself going back and forth between these two realities.

## BOOKS

### **The Brussenboek (Siblings book)**

*Anjet van Dijken* (journalist and researcher) has raised the issues for siblings of PIMD+ children on the map and has written the Brussenboek. Brothers and sisters of a PIMD+ child are called brussen. Most siblings are horrified by this term, but either way, the impact of a PIMD+ child in the family is great, and more attention should be given to it!

### **Als je kind niet kan beslissen (If your child cannot decide)**

This book contains questions and answers that show the way through the maze of (un)written laws, rules and manners. What can you do as a parent/carer? What can and may a doctor do? How do you start a conversation or discussion with your care team and what does the law say about this?

Written by *Mirjam de Vos*.

### **Bijzonder Babydagboek (Special baby diary)**

The Bijzonder Babydagboek is a beautiful book, designed for young parents who are not always on cloud nine during the baby phase. The diary does not contain the standard milestones that you often find in other baby diaries. In this book, you can define the milestones yourself. For example, returning home from the hospital, phasing out tube feeding or meeting other family members.

Authors: *Magreet Schijvens & Ellen Mullenders*



## INFORMATION ON THE INTERNET

**Kinderneurologie** is a site of a paediatric neurologist and offers reliable information on all kinds of syndromes and genetic disorders.

<https://www.kinderneurologie.eu>

**Ervaringskenniscentrum (Sch)ouders.** (Sch)ouders is a platform of, for and by parents of a child with a physical and/or mental disability, chronic illness and/or developmental disorder (care children).

<https://schouders.nl>

**Ieder(In)** is the largest network in the Netherlands for people with a disability or chronic illness.

<https://iederin.nl>

**Landelijk Meldpunt Zorg** is part of the Ministry of Health, Welfare and Sports. It provides advice and information on how to deal with complaints about the quality of care, answers questions and helps with practical tips.

<https://www.igj.nl/onderwerpen/klacht-of-vraag-about-care-or-youth-care>

**MEE** is an independent, cooperative association of 20 regional MEE-organisations spread across the country. MEE supports people with disabilities and their network during all areas and phases of life.

<https://www.mee.nl>

**Per Saldo** is the interest group of people with a personal budget (PGB). They are also responsible for the 'Juiste Loket' hotline. This is for people who have lost their way in care and do not know which care office is responsible for their care or support.

<https://www.pgb.nl>

**Programma Volwaardig Leven.** With this programme, the Ministry of Health, Welfare and Sports wants to make care for the disabled as well as complex care more suitable and better prepared for the future.

<https://www.volwaardig-leven.nl/over-volwaardig-life>

**Wij zien je Wel** looks for improvement opportunities in the quality and organisation of care and support for people with profound intellectual and multiple disabilities and more (PIMD+) and their families.

<https://www.wijzienjewel.nl>

**Kenniscentrum Kinderpalliatieve Zorg** (The Knowledge Centre for Child Palliative Care) is committed to high-quality child palliative care, locally and close to the family. Parents can go here for information and consultation.

<https://www.kinderpalliatief.nl/kind-gezin>



**Netwerken Integrale Kindzorg (NIK).** A NIK is a partnership between professionals from various organisations and disciplines from the 1st, 2nd and 3rd line of care, with a lot of knowledge and experience in the care for seriously ill children. A NIK offers support for families and care professionals when it comes to home care.

<https://www.kinderpalliatief.nl/kind-gezin/regionale-netwerken-kinderpalliatieve-zorg>

**Berendekens** makes handmade quilts for children between the age of 0-16 years who need a lot of love, bear cuddles and warmth. For a cosy feeling!

<https://berendekens.jimdofree.com>

**Stichting Kind en Ziekenhuis** (Child and Hospital Foundation) is a national patient/consumer organisation dedicated to improving the quality of care for children in a hospital.

<https://kindenzorg.nl>

**Kind met Handicap** is a site for parents with a child with a (multiple) disability.

The site offers useful links arranged by category such as: communication, resources, clothing, care and much more.

<http://www.kindmethandicap.nl/tips.html>

**Caren Zorgt** is a free website that helps you organise your care, share information and plan tasks. It's useful if there are several people/institutions involved in your child's care.

<https://www.carenzorgt.nl>

**Taxipassport** is a tool (not mandatory). It helps inform the driver of the patient transport of your child's particular needs, such as epilepsy, ADHD, asthma, or other things the driver should take into account. This enables them to take the right actions in case of emergencies. On the basis of the data mentioned on the passport, the driver could, if necessary, contact the parents or guardians directly.

<https://taxipaspoort.nl>

**Dubbele kinderbijslag** (Double child benefit). You can receive double child benefit for a child that lives at home and needs intensive care. The website of the SVB informs you about the conditions and how to apply for it.

<https://www.svb.nl/nl/kinderbijslag/dubbele-kinderbijslag/dubbele-kinderbijslag-uitwonend-kind.html>

**Financial allowances**

<https://www.opvoeden.nl/financiele-tegemoetkomingen-7117/>

**Thuisarts.nl** provides reliable information about health and diseases. This site is created and managed by general practitioners.

<https://www.thuisarts.nl>

**Pien & Polle** has an extensive range of customized clothing.

<https://www.pienenpolle.nl/nl/>

**Marks & Spencer online:** good quality rompers for 0-16 year olds (size 104-164). Prices range from €5 to €9.95 each.

<https://www.marksandspencer.com/nl/l/kinderen/gemakkelijk-aankleden/rompertjes-voor-speciale-behoefte/#page:1>

**SlabEnZo** has all sorts and sizes of functional and trendy bibs.

<https://www.slabenzo.nl/slabenzo-voor-volwassenen/>

**Wellyou** (Germany): sleeping bags up to size 158 (€40). Shipping costs €12.90.

<https://www.wellyou-shop.de/en/Bed-Time/Baby-sleepingbag?XTCsid=0c8de44017649d1a6546c3baa2677589>

**FunCare4Kids** organises fun days for children in difficult situations because of a chronically ill or disabled family member. All attention goes to them on such a Fun Day.

<https://www.fun-care4kids.nl>

## ABBREVIATIONS

Dutch healthcare is full of abbreviations and terms you have probably never heard of. To get you started, we have listed a few for you.

**AED** Anti-Epileptic Drug- abbreviation for epilepsy medication.

**AVG** Physician for the mentally disabled- successor to the paediatrician and more specialised.

**BIM** 'Bewegen in muziek' (Moving in Music)- activity focusing on music, touch and movement.

**CCE** Centre for Consultation and Expertise- institution for requesting additional care.

**CIZ** Centrum Indicatiestelling Zorg (Care Assessment Centre)- organisation for applying for WLZ care.

**Comfortzorg** Undivided attention, physical care, medical care, including pain relief.

**DV** Day care centre for adults (18+) with PIMD+.

**EVO** Splints to slow down foot drop.

**EMB** Severe multiple disabilities.

- KA** Paediatrician.
- KDC** Children's day centre.
- LG** Physically disabled.
- MDO** Multidisciplinary consultation: a consultation with several specialists involved, possibly your GP and the nurses.
- MEE** Organisation that helps to find the right care.
- Meer Zorg** To request more care from the care administration department when additional care over and above your entitlement is required.
- MIE** Difficult-to-cure epilepsy.
- MKD** Medical child day care centre.
- NIE** Non-controllable epilepsy.
- NIK** Network for integrated childcare.
- ODC** Orthopaedic day centre.
- PEG** Feeding stoma in the abdominal wall to the stomach.
- PGB** Personal budget- to be applied for in order to organise and pay for care.
- PIMD+** Profound intellectual and multiple disabilities and more.
- PV** Personal care.
- SI** Sensory integration therapy, helps when the processing of stimuli is not going well.
- Snoezelen** Experience with sound, light, smell and vibration.
- SV** Tube feeding.
- SVB** Sociale Verzekeringsbank (pays the child benefit but also processes the payments from the PGB. If you have a disabled child, you are entitled to a double child benefit).
- VG** Mentally disabled.
- VK** Nurse.
- VP** Nursing.
- WMO** Social Support Act.
- WLZ** Long-term care Act.
- ZK** Care administration.
- Zvw** Care Insurance Act.
- ZZP** Care package or self-employed without staff.

# Epilogue

Over 20 years ago, our son, who was born seemingly healthy, was diagnosed with epilepsy that cannot be controlled, and, as a result, he has severe intellectual and multiple disabilities. It was a roller-coaster ride and a future that could not be foreseen or predicted at the time. The lack of clarity, uncertainty and unfamiliarity made for a difficult and lonely process. A search with many disappointments. Only when we dared to admit that this might be it and that he would develop little or not, did our family find peace.

Our choices changed. At first, we tried to stop the epilepsy, but then we were looking for a balance. At first, we wanted him to experience everything with us, but now we increasingly chose to leave him at home with someone to care for him. Not because we don't want to take him with us, but because some activities are no fun for him at all and afterwards he has to pay the price.

It felt like failure at first. For years I tried to find a solution for his epilepsy, worked on his motor skills and tried to work on some independence, constantly pushing his boundaries. It took a while before I realised that good was good enough, especially for our children and our family.

Years later, I met fellow mother and colleague - and later co-founder of 2CU - Vanessa, who was fighting the same lonely battle with her family. It made me realise that in all those years very little had changed. That is why I have written this book. If we had been able to look into the future, we would probably have made different choices and taken more time to enjoy what was there and what was lost along the way.

I would not claim this book is complete, it is just a glimpse into the future, based on the knowledge and experiences of myself and other parents I have met over recent years.



It will give insight, and it raises some important questions. I hope it will contribute to your knowledge and understanding of the life of a PIMD+ child. Not just for parents and family members, but for all those involved, both in medical and supportive roles. I believe that when you dare to look at the whole, you do justice not only to the child, but to the whole family around that child.

I wish all young parents a lot of courage and all the people around them, patience and wisdom. With your help and attention, they will feel tremendously supported and make the right choices for their child and their family.

Kind regards,

*Sariko*

Mother of Bram and author of this booklet

## NOTES

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2CU

#ComplexCareUnited

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[www.2cu.nu](http://www.2cu.nu)