



MARINA NOORDEGRAAF

# DETOURS THROUGH THE PARKINSONIAN BRAIN

A BOOK FULL OF TIPS FROM PEOPLE IMPACTED BY PARKINSON'S  
TO RECOGNIZE, DISCUSS AND CIRCUMVENT THINKING OBSTACLES.



# DETOURS

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A BOOK FULL OF TIPS FROM PEOPLE IMPACTED BY PARKINSON'S  
TO RECOGNIZE, DISCUSS AND CIRCUMVENT THINKING OBSTACLES.





FOR AND BY PEOPLE WITH PARKINSON'S AND THEIR LOVED ONES

## Detours through the parkinsonian brain

Detours through the parkinsonian brain is made possible by all the people with parkinson's and their loved ones who donated their experiences and time to the COPIED study. The COPIED study was a scientific study into thinking obstacles in Parkinson's disease and the detours that people with Parkinson's and their loved ones use to circumvent them. It is the collected obstacles and detours of the study participants that are the focus of this book, that was first published in Dutch.

The experiences of the research participants merged together by Marina Noordegraaf, MSc †, Dr Ingrid Sturkenboom, Jolanda van Omme, Dr Esther Steultjens † and Edwin Barentsen, MBA. The project was made possible with a grant from the Dutch Parkinson's Association (Parkinson Vereniging) and ParkinsonNL.

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You can find the underlying research data (in Dutch) here: Noordegraaf, drs. M.A. (Radboud University); Sturkenboom, dr. I.H.W.M. (Radboud University); van Omme-van Laarhoven, MSW J. (2022): COPIED studie. DANS. <https://doi.org/10.17026/dans-zrn-a92u>

**I've got more detours  
than I thought.**



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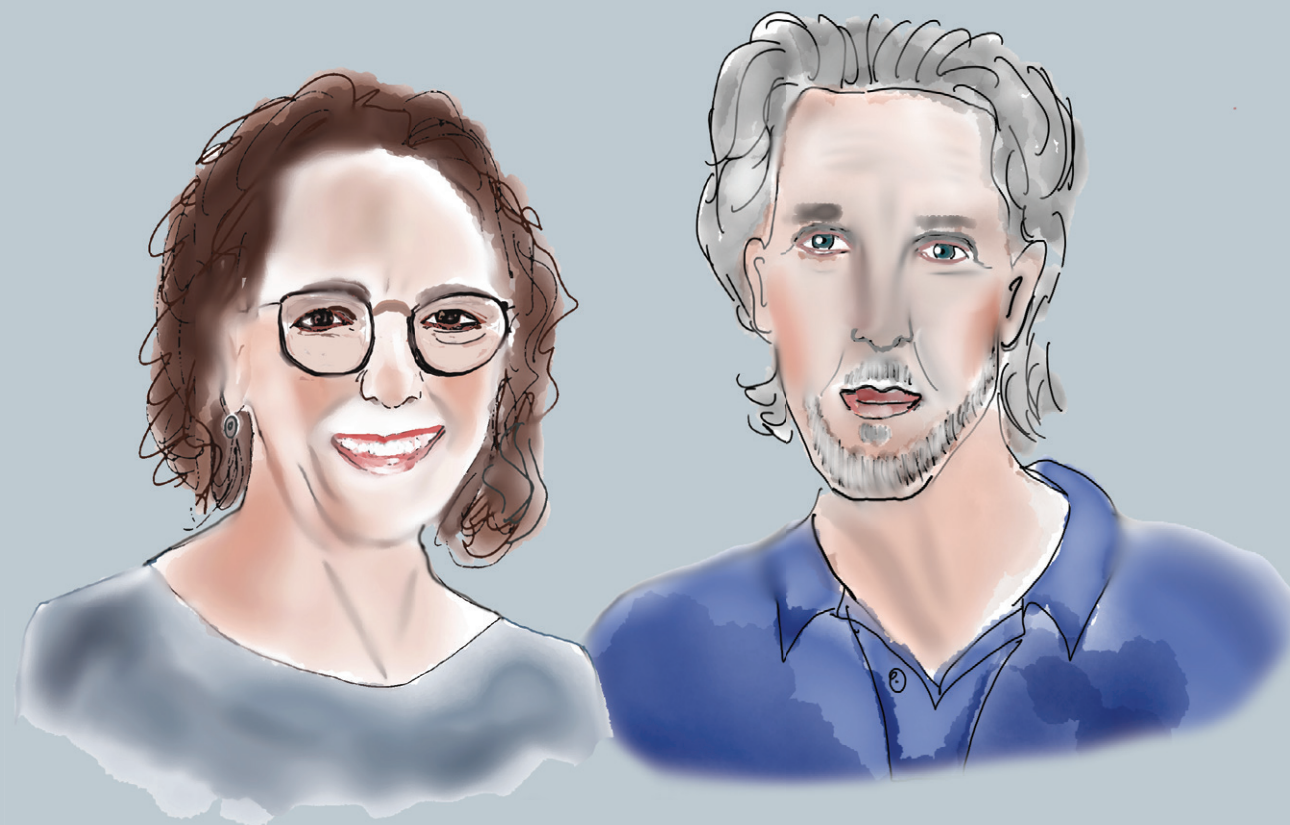
## Preface in two parts

### MARJAN OVERDIEP

*Marjan Overdiep is an expert by experience, (ex) patient researcher, member of the working group 'Parkinson's and work at the Dutch Parkinson's Association (Parkinson Vereniging) and initiator of Yoga4Parkinson*

### BAS BLOEM

*Prof. dr. Bas Bloem is neurologist and head of the Radboudumc Expertise Center for Parkinson's & Movement Disorders in Nijmegen, the Netherlands*



## Preface in two parts

### MARJAN OVERDIEP

*Some years ago, when I still was a patient researcher, I met Marina when she joined the patient researchers' group. One of the first things I saw of her was the poster with detours for freezing that she had created (see source). Clear, readable, well-organized and displaying the results of the research of Dr. Jorik Nonnekes on compensatory strategies in gait disorders in one poster. I was impressed. I remember that I was with her in Nijmegen for a meeting with a researcher and that she was going to hand over the poster to Bas Bloem.*

Marina quickly expressed her wish that there would also be such a study on detours in cognitive freezing, getting stuck in thinking. She found an audience for this with Edwin Barentsen, also a patient researcher. Some time later Marina told me that she herself, as a researcher, was going to carry out the research she so desired with a subsidy from the Dutch Parkinson's Association. Rightful attention for this common but invisible side of Parkinson's.

#### **Contact with fellow sufferers**

When we sit together as a group of people with Parkinson's after a boxing class or yoga4parkinson's class, it is striking how much we learn from each other. We exchange experiences about medications, the treating healthcare professionals, parkinson's symptoms. When you are among peers, you take advice

from each other more easily. I think this is because you recognize the issues of others and are more open to try their tricks (detours in Marina's words) to compensate. Sometimes that works even better than the words of wisdom of the professionals.

#### **Lay language**

I was and am a huge fan of Marina and her work as a (as I call it) "translator" of complex research into understandable language for lay people with the help of striking illustrations.

In this book, too, she makes it easy and appealing for readers. By publishing both a digital and a printed version, she reaches a wide audience; from YOPD (young people with Parkinson's) to seniors with or without Parkinson's, from health professionals to sports trainers. The supporting illustrations beautifully capture the heart of the matter.

Naming the obstacles first, results in recognition and understanding with the reader. And it is fantastic how many detours there are and how diverse these are named by participants in the study. A handy book for and by people with Parkinson's disease. Therein lies the power of this self-help tool.

A must-read for people with Parkinson's disease, their loved ones and professionals who work with us (people with Parkinson's) such as Parkinson's care professionals, employers, sports trainers and so on.

**MARJAN OVERDIEP**



## Preface in two parts

### BAS BLOEM

*Marjan has already expressed everything in a beautiful way. I share her admiration for Marina, who, like a true ambassador, is constantly working to draw attention to the strength of people with Parkinson's and their loved ones. And in this respect, this project speaks volumes. Unfortunately, there is still far too much attention in healthcare on what people with a chronic illness no longer can do, instead of focusing on what people CAN still do. And in that respect, people with Parkinson's are extra special, because many of them show great creativity in finding ways to better cope with this complicated disease.*

Part of that creativity involves so-called compensatory strategies, which Marina also calls detours. What makes Parkinson's disease so special as a neurological disease is the fact that the so-called autopilot is damaged. Movements that healthy people don't have to think about, or barely have to think about, such as walking, become a lot more complicated once you have Parkinson's disease. Many other automatic actions also become much more difficult. At the same time, many people manage surprisingly well to perform these previously automatic movements, for example by thinking about them consciously.

The lay public has already become widely familiar with some of the workarounds that people develop themselves to improve mobility. Consider, for example, the almost world-famous man with parkinsonism who,

as a result of severe freezing, could barely walk anymore, but could still ride a bicycle seemingly effortlessly.

#### **Sharing inventions**

But if you look around you and especially listen carefully to people with Parkinson's, you will notice that dozens, if not hundreds, of different tricks have been found to improve walking or other forms of movement.

What I find so incredibly special myself is that people with Parkinson's generally do these kinds of "inventions" themselves. In an international publication we made an overview of all the different inventions of people with Parkinson's take to circumvent freezing, and discovered that there are seven overarching strategies, each with several variations on that theme.

Marina has mapped out all these compensation strategies in a very expressive way in a series of beautiful illustrations, which are, in turn, brought together in an orderly poster. The beauty of this is that the inventions that people with Parkinson's made themselves can now also be shared more widely with other people all over the world. For example, the physiotherapists from ParkinsonNET, the Dutch national Parkinson's network of health care professionals, use Marina's poster to systematically look at the most appropriate compensation strategies for people with Parkinson's.



Excerpt from poster showing detours at physical freezing

### Tip of the iceberg

Much less well known is the fact that these kinds of detours can also help with the obstacles in thinking that people with Parkinson's experience.

It is and remains a persistent misconception that Parkinson's disease is characterized solely by the physical limitations, such as altered gait, slowness, stiffness or tremor. While these are easily recognized on the outside, in reality they are only the tip of the iceberg. People with Parkinson's typically suffer from the much larger part of the iceberg, which is located under water, and which therefore remains largely invisible. An example is the fact that people with Parkinson's often have more difficulty logically organizing activities.

At the same time, detours exist for these invisible symptoms of Parkinson's, but this is much less well known, even among experts in the field of Parkinson's disease. That's so incredibly important that Marina has used the COPIED study to create an inventory of this important category of detours.

A beautiful overview, with striking illustrations, is herewith presented. As far as I am concerned, it is required reading for everyone who cares about people with Parkinson's, whether you have the disease yourself, are a family member, a friend or other close person, or are active as a care provider.

**PROF. DR. BAS BLOEM, NEUROLOOG**

**Sources** Nonnekes, J., Růžička, E., Nieuwboer, A., Hallett, M., Fasano, A., Bloem, B.R. (2019). Compensation Strategies for Gait Impairments in Parkinson Disease: A Review. *JAMA Neurol.* <https://doi.org/10.1001/jamaneurol.2019.0033>. De poster: 55 omweggetjes bij freezing is te bekijken en downloaden via Noordegraaf, Marina, & Nonnekes, Jorik. (2019). 55 Detours with which Parkinson patients bypass freezing (Poster) (1.0). Zenodo. <https://doi.org/10.5281/zenodo.3293107> (Open Access).

## FAQ

### **What is this book full of detours all about?**

Parkinson's disease may be associated with obstacles in cognitive functioning. In these book we call them "thinking obstacles". Before you lies the first English edition of a book that will help you learn to recognize, discuss and - where possible - avoid these kinds of obstacles. The book was originally published in Dutch. The first edition found its way to the research participants first.

With this book we want to draw attention to bringing 'movement' in your thinking. Sometimes that can be done very well by moving physically, but there are also countless other ways to look at thinking differently or to think differently. We call that: detours.

### **What makes this book special?**

This is a book for and by people with Parkinson's. The detours you find in this book were collected from 470 Dutch people with Parkinson's and 136 relatives as part of a scientific study: the COPIED study. The obstacles and detours have been collected, ordered and visualized by Marina Noordegraaf. Apart from being the

principal investigator and author of this book, she was diagnosed with Parkinson's in 2018 at the age of 49. In 'Once upon an idea' you can read more about the journey that led to this book and about the people who contributed to the book, that lies before, you along the way.

### **How can I use this book?**

This book is made up of six parts that can be viewed separately. It is a collection of conversation starters and detour maps. You can start wherever you want.

This is not a book to finish in a day. It is a book to flip through. To stop at a page that appeals to you. To filter out those things that are important to you and your loved ones. To initiate conversations that matter.

Nothing more, nothing less. And tomorrow ...A new day and a new page awaits.

### **Can you describe the content of the book?**

In chapter 1 we outline a global overview of the thinking obstacles that may occur in Parkinson's disease. We consider the possible effects of such obstacles and zoom in on the role of detours.

Chapter 2 consists of so-called detour maps. We use practical examples to show how people with Parkinson's and their loved ones circumvent common obstacles in thinking. Each map stands on its own and aims to show that there are multiple detours around thinking obstacles. Each detour was mentioned by at least one of the COPIED research participants.



Chapter 3 is short. It's about detour accelerators, so that seems appropriate.

Chapter 4 goes a step further. With the communication starters from this chapter you can learn to understand yourself a little better and you can learn to share your user manual with others.

In chapter 5, Prof. dr. Odile van den Heuvel, Dr. Annelien Duits, Dr. Rick Helmich, Dr. Ingrid Sturkenboom and Dr. Jorik Nonnekes answer a number of questions from research participants.

We asked each research participant about their favorite detour. Chapter 6 is a tribute to all the beautiful answers they sent in. Here you will find an almost literal representation of their many detour favorites.

The book ends with an "Once upon an idea .." - where you can read more about the expedition that led to this book - and a and a word of thanks.

### **What is the purpose of this book?**

With this book we want to:

- Enable people to name the obstacles in thinking that get in their way the most;
- Facilitate discussions on a relatively invisible topic;
- Inspire people to try the detours of their peers;
- Inform and raise awareness;
- Help ensure that the invisibility of thinking obstacles in Parkinson's is no longer an obstacle in itself.

### **What are possible side effects?**

Possible side effects are:

#### *Inspiration*

One of the detours that people with Parkinson's use is to literally imitate something that becomes more difficult. That makes this book a detour in itself! Learning from each other by copying each other. Gaining inspiration from your peers. That's what it's all about.

#### *Confrontation*

How, when and whether obstacles in thinking occur, differs per person. We do not want you to adopt problems that you do not have. It is about learning to recognize, acknowledge, discuss and circumvent the obstacles that DO bother you. Where you desire to, where it is possible for you and in a way that suits you.

**The one who isn't fast  
can still be smart**

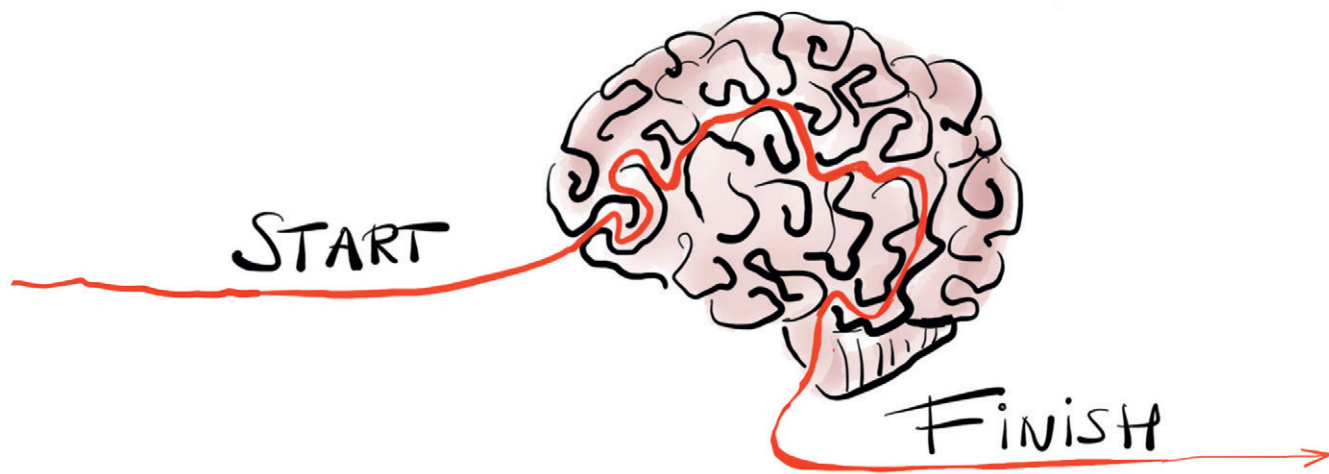


1.

## Warming up



*Every now and then I feel like there is a cog constantly turning in my head, and I can't think straight. When this is over, everything goes well again.*



## Obstacles in thinking and Parkinson's

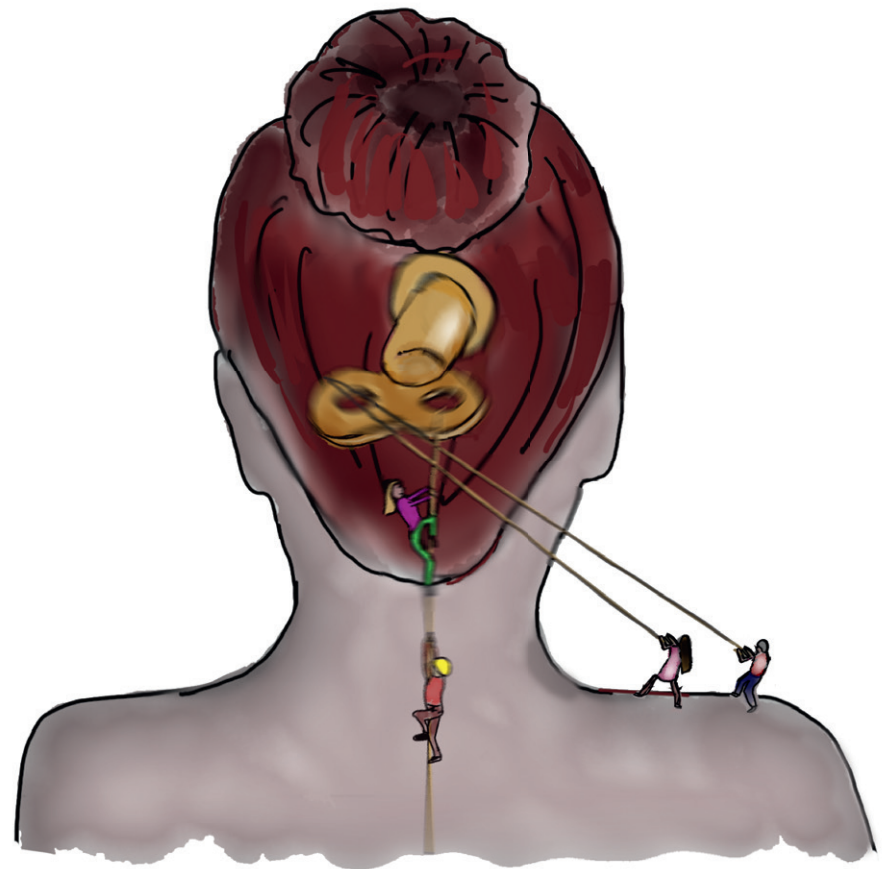
In people with Parkinson's disease, their autopilot fails more and more. The whole reason our autopilot exists is to accelerate the processing of information without (our) conscious interference. When this malfunctions, the processing of information slows down. A shortage of so-called neurotransmitters - messenger substances that pass on instructions from cell to cell - leads to a delay in information processing and prompts are executed more sloppily. This leads to all kinds of problems in daily life.

The COPIED study specifically focused on the obstacles in thinking - also known as cognitive functioning - that may accompany a person with Parkinson's disease. Examples of such obstacles are: difficulty with focusing attention, planning and keeping an overview, remembering appointments, words, where things are, with doing several things at the same time, with making choices, with getting started and also with timely stepping on the brake again to stop yourself.

The thinking obstacles that people with Parkinson's and their loved ones encounter can be divided into four categories: obstacles in perceiving, remembering, planning and executing. The four quadrants and the underlying sub-processes are described in detail in the so-called Perceive Recall Plan Perform model (PRPP), the theoretical model that was used in setting up the COPIED study. The model is depicted on the next page.

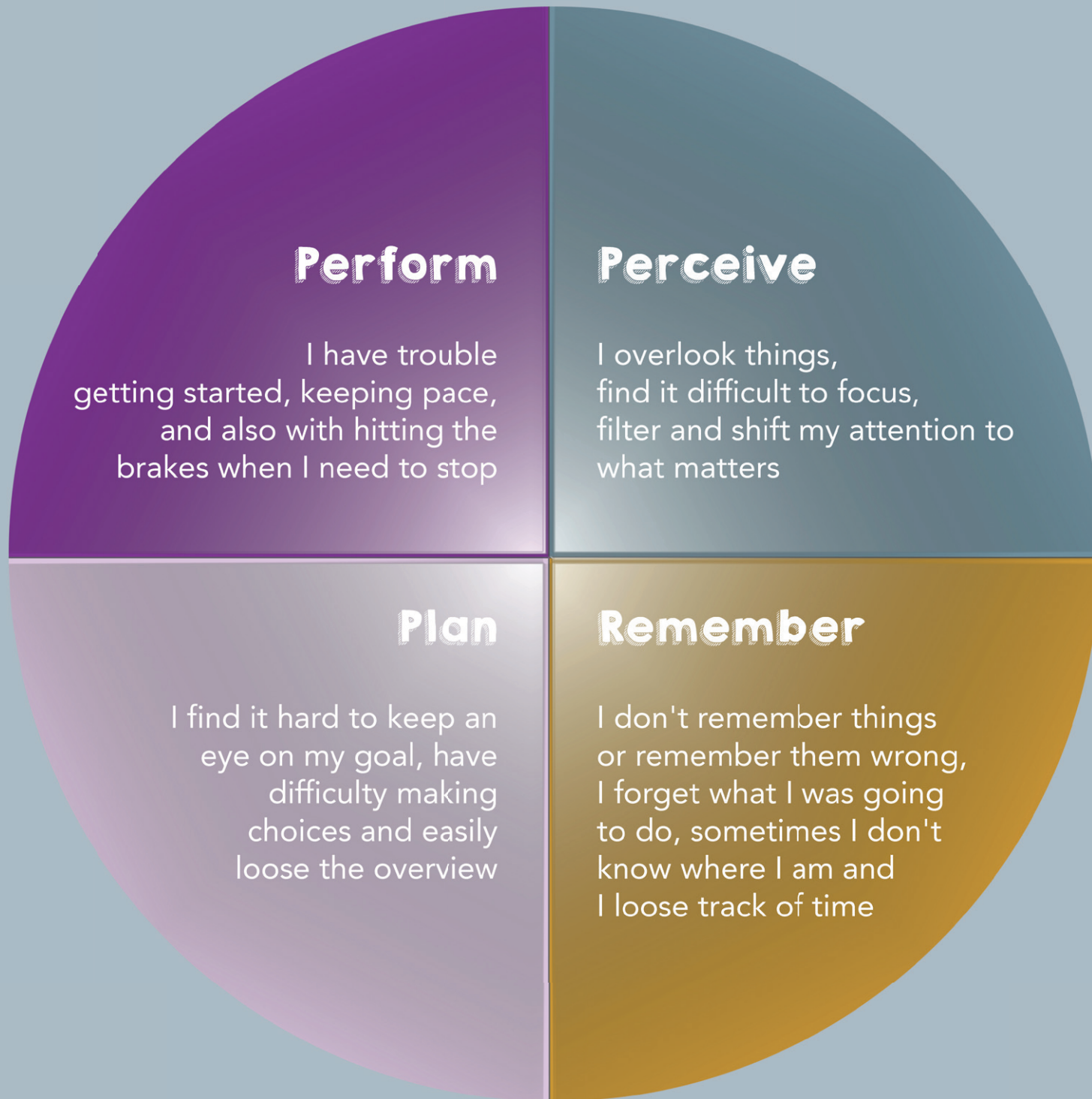


*What bothers me is that I'm too slow for the life I had before Parkinson's. A week should last 10 days.*





# PRPP-model



## Obstacle domino

In this book we focus on obstacles in thinking. In practice, the distinction between thinking obstacles and motor limitations is not always so easy to make. Indeed, physical symptoms can reinforce thinking obstacles and obstacles in thinking can provoke physical symptoms.

During the analysis of the data, the word obstacle domino emerged to give words to this undeniable interdependence. The quotes we collected during the COPIED study show that obstacle domino is daily practice for people with Parkinson's disease.

For example, not being able to find the right words, combined with a soft voice, increases the difficulty to express yourself and to come across as you would like. In addition, the stress this can cause will not be conducive to the volume of your voice, nor your ability to find the right wording.



*During cooking I suffer, not only from a lack of overview, but also from locomotive limitations, such as stirring in pots and pans.*



*I forget a lot of appointments and when I do write them down I can't read and understand my own notes and so I don't know what to expect.*

Or if you can't type that fast, and also make errors in spelling and then stress about that, the bricks fall over easily too.

Furthermore, there appears to be a relationship between problems with attention and 'physical accidents', such as bumping into someone else. In chapter 5, rehabilitation specialist Jorik Nonnekes talks some more about the relationship between getting stuck in movement and in thinking.



*You might even say that in Parkinson's disease you can hardly distinguish between "mental" and "physical." In the end, they are all brain processes that are influenced by substances such as dopamine | Rick Helmich, chapter 5 of this book.*



## Consequences of thinking obstacles

Participants in the COPIED study indicated that obstacles in thinking lead to visible and invisible consequences such as:

### 1 A shaky self-image

Obstacles in thinking reverberate in virtually all daily activities. Participants from the COPIED study report that the obstacles lead to disorientation, confusion and alienation, to feelings of shame, insecurity, powerlessness, frustration and sadness. With that, obstacles undermine self-confidence.

### 2 Trouble getting things done

The delay occurs on several levels: not only does the processing of information slow down, but because it is more difficult to make the right turn, more errors are made. Correcting these errors leads to 'double delay'. All in all, it becomes more difficult to get things done.



*My children are fast, they expect it from me, they don't know better, they always had a fast mother who could do everything at once. But slowly they realize that I am changing in this respect. I will have to indicate it myself first but if I could, I would ask if the radio or music in the background could be turned off and if they would give me more time to react.*

### 3 Feeling excluded

Being able to make yourself clear less easily and less quickly can lead to you coming across differently than you want; not being understood. That can feel like a loss of equality and autonomy. Research participants indicate that they sometimes feel excluded and that thinking obstacles can lead to difficulties in the relational sphere.



*Cognitive symptoms lead to insecurity. You can't depend on yourself.*

## Consequences for loved ones



*Actually, I think the obstacles in thinking are the most determining factor for your relationship and not the physical symptoms. Thinking obstacles are understudied.*

Thinking obstacles also have a great deal of impact on the loved ones of people with parkinson's. The COPIED participants mention the following aspects:

### **I** Equivalence is at stake

When your loved one develops Parkinson's, you have to deal with a changing relationship. There is more on the plate of their loved ones, with all the consequences and feelings that accompany such a shift.



*Our relationship changes from lovers to patient and caregiver.*

This is difficult for both parties, as can also be read from the quote below from someone with Parkinson's.



*What would help me is if my husband could deal with the fact that I'm no longer the stronger of the two of us anymore.*

What is also striking is that the loved ones want to ensure that people with Parkinson's maintain autonomy as much as possible. Understanding is the key word here.



*A little more awareness of the invisible, cognitive symptoms will hopefully lead to being able to function independently longer. It is the daily things such as giving each other space at the cash register at the supermarket that determine whether you still dare to go outside or to the clubhouse. It determines whether you can continue to live at home.*

### **2** Feelings of powerlessness and loneliness

A changing relationship can lead to fear, guilt, feelings of loneliness, irritation and a loss of energy, especially if the environment cannot empathize with what a living with Parkinson's can feel like.

And what if the thinking obstacles are there, but the person with Parkinson's does not recognize them? That was one of the questions asked by the research participants. Several people mentioned that this made them develop self-doubt, even before the diagnosis was made (read: before the problems were recognized).



*Well before the diagnosis I noticed changes in my partner's behavior. I thought: something is not right. There's something really weird going on.*



If your partner does not follow, this can lead to feelings of loneliness and powerlessness.



*I often feel lonely. Sometimes I feel like I'm "escaping" the house. I feel guilty when I think so negatively about my partner. Can be sad when I think about the future.*

Getting annoyed by a thinking obstacle of your loved one and at the same time feeling guilty about it "because someone simply can't do anything about it" is also something that is mentioned by several loved ones.

## Detours

Detours are self-invented ways to deal with an obstacle in thinking. By people with Parkinson's or their loved ones. For example; one can change the environment, the demands that someone places on a task, or one one's own behavior. It also includes changing the way one perceives an obstacle.

There are roughly two types of detours:

### **I** *One changes the obstacle itself*

Both with coping (how do I see it) and self-management (how do I deal with it) the following question takes central stage: How do I influence the shape and size of the thinking obstacle, so I suffer less from the consequences? Can I look at it differently? Can I overcome the obstacle? Prevent it? Can I ask someone else to do the activity where the obstacle arises, in order for the obstacle to become smaller or disappear?

### **2** *You find a way around the obstacle*

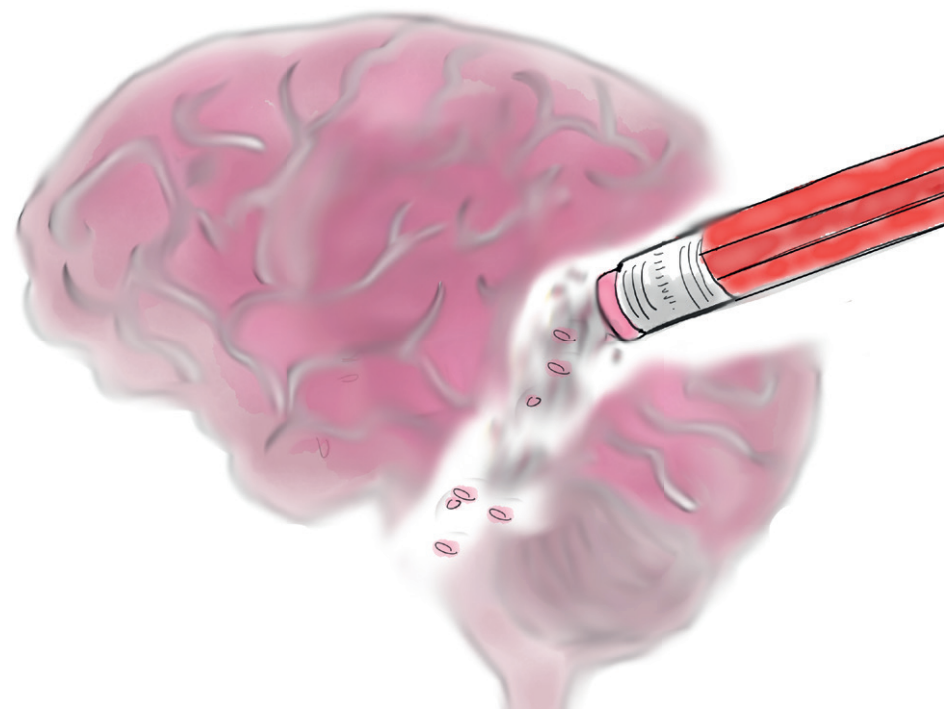
In this category the obstacle is what it is, neither bigger, nor smaller. It gets in the way of doing what you want to do. At that moment you check whether it is possible to create a different route to reach your goal. That is called a cognitive strategy.

Both types of detours are used interchangeably in this book.

The good news is that many people with Parkinson's and their loved ones succeed in circumventing the faltering autopilot, consciously or unconsciously. The best news is that the detours often have positive outcomes: more self-confidence, a sense of control, more energy, getting things done, less stress and more understanding. And new habits.



*Together we make new habits. That is not a problem. You always plan your life anyway. It is annoying, however, when there are visitors who know the new rules, but not yet the habits.*



## Tailor-made detours?

Problems in day-to-day functioning can arise if a person does not take the proper detour to perform a particular task. For example because the chosen detour itself leads to other problems. Or the detour was excellent, but the obstacle has already changed with the progression of the disease.



*My favorite detour is seeking distraction. But that also means delay, which may get me into trouble. This creates stress again. I find it hard.*

Some detours have varying degrees of success – such as approaching the obstacles with humor – and some also have negative effects. The strategy ‘Pretending’ for example – pretending to understand what is being said – has the negative effect that you really do not get things.

### The context matters

Ultimately, the situation determines which thinking obstacle occurs and whether the consequences are difficult enough for you to challenge you to find a detour (which doesn’t mean that you always succeed).



*Keep a close eye on the context: Is it a traffic situation you are finding yourself in or are you reading something out loud from the newspaper? Who are you talking to: a grandchild, child, other adult or are you talking to your neurologist. Thought is sometimes inseparable from doing.*

For example, the COPIED data shows that when taking medication - a fairly simple act - only ‘not remembering’ is mentioned as an obstacle.

In group meetings you not only have to deal with yourself, but also with the other person. Here being unable to find your words and - partly because of this - not getting the input on the table is mostly mentioned. And the more people that talk at once, the more difficult it turns out to be to switch gears and keep the common thread.

In traffic it is an obstacle if you forget where you are, when you can not switch properly from one part of the task (driving) to the environment (what is happening on the road), when you do not have the overview and lose your focus when you get distracted.

When doing the administration it is difficult not to see the big picture, with the possible obstacle enhancer of finding it difficult to accept an offer for help. As the pile

**Sources** Auduly, Å., Packer, T., Hutchinson, S., Roger, K. S., & Kephart, G. (2016). Coping, adapting or self-managing - what is the difference? A concept review based on the neurological literature. *Journal of Advanced Nursing*, 72(11), 2629–2643. <https://doi.org/10.1111/jan.13037> (Closed Access); Sturkenboom, I., Nott, M. T., Bloem, B. R., Chapparo, C., & Steultjens, E. (2019). Applied cognitive strategy behaviours in people with parkinson’s disease during daily activities: A cross-sectional study. *Journal of rehabilitation medicine*, 52(1), jrm00010. Advance online publication. <https://doi.org/10.2340/16501977-2635> (Open Access)

keeps getting bigger, some may not even be able to start at all (trouble choosing and/or starting). And in an activity such as driving, a lack of overview and a delayed reaction time can lead to dangerous situations, which may explain why 'quit driving' is the most chosen detour.



*I try to estimate in advance whether I can perform a task without danger. If I'm in doubt, I am not performing the task or modified.*

The level of importance you attach to the activity determines how easily you give up an activity and that is very personal. For example, if you can't focus on the news and you didn't like it very much anyway, you may decide to skip the news. Not being able to concentrate with your neurologists is a whole different story. Here you are more likely to look for a different detour than the emergency exit, which equals not doing something anymore. Due to a different context - and therefore often also a different interest - the same thinking obstacle may lead to a completely different detour.

### **Interaction**

The detours that people with Parkinson's and their loved ones use have mutual effects. A strategy such as 'taking over an activity' - asked or unsolicited - can be experienced as helping and as shifting equality.



*I see I'm already taking over a lot. Not too fast?*

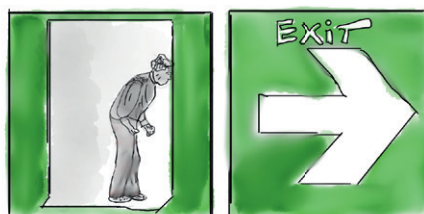


*He no longer wants to have responsibilities that he cannot dare not bear. He likes it when I or our children take over difficult things and choices. Always with his full permission and repeated explanations about what is going on in terms that he understands. In this way he still has the feeling of complete autonomy.*

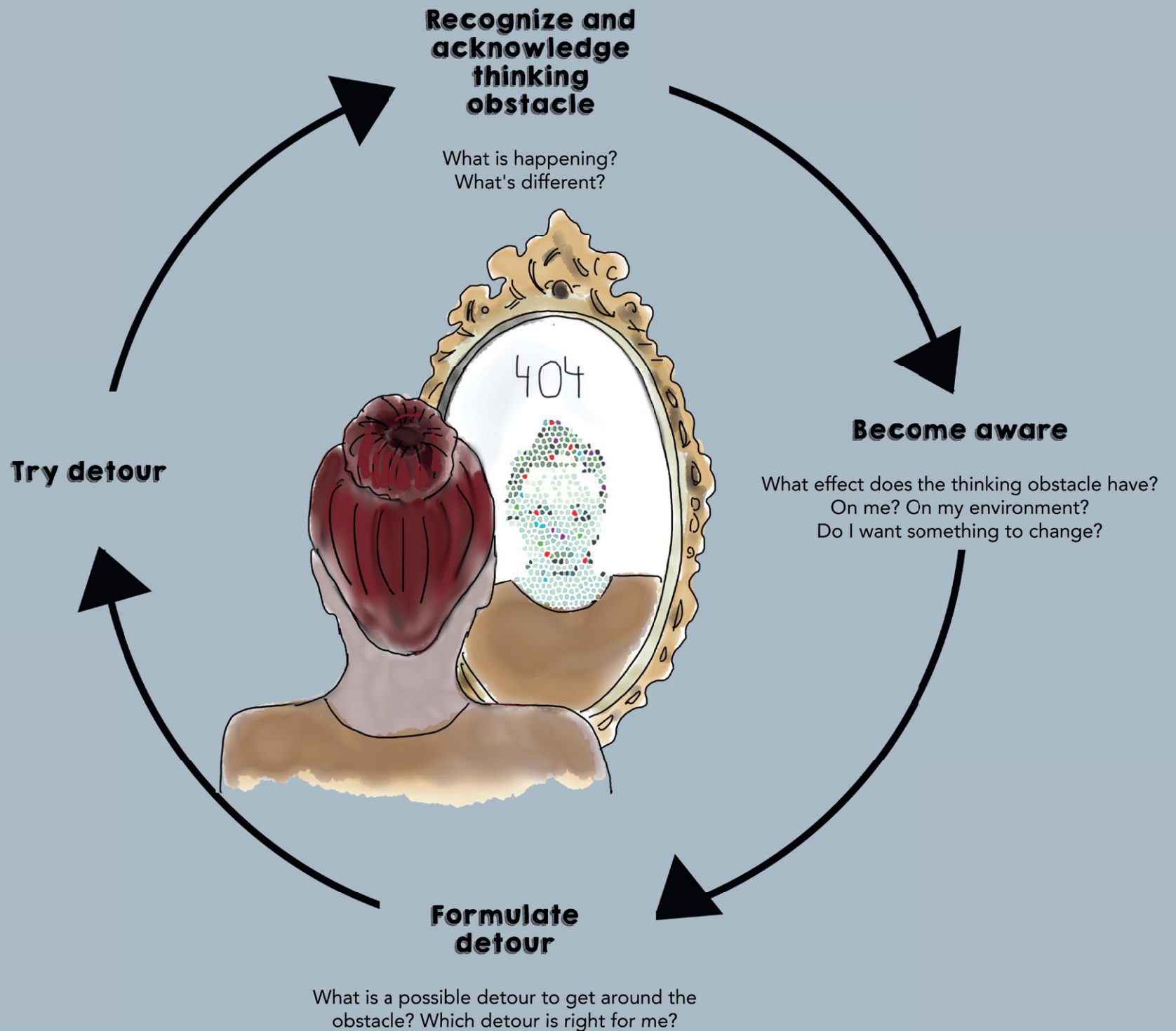
Looking for and finding detours that work for all parties is therefore not a one-off exercise. To illustrate that, one of the research participants sent in the detour explorer on page 23. This is how searching, finding and constantly adapting detours around thinking obstacles works for this person.



*A detour is, of course, still a detour. It's not a shortcut. It takes extra energy or time to reach your goal via a detour.*

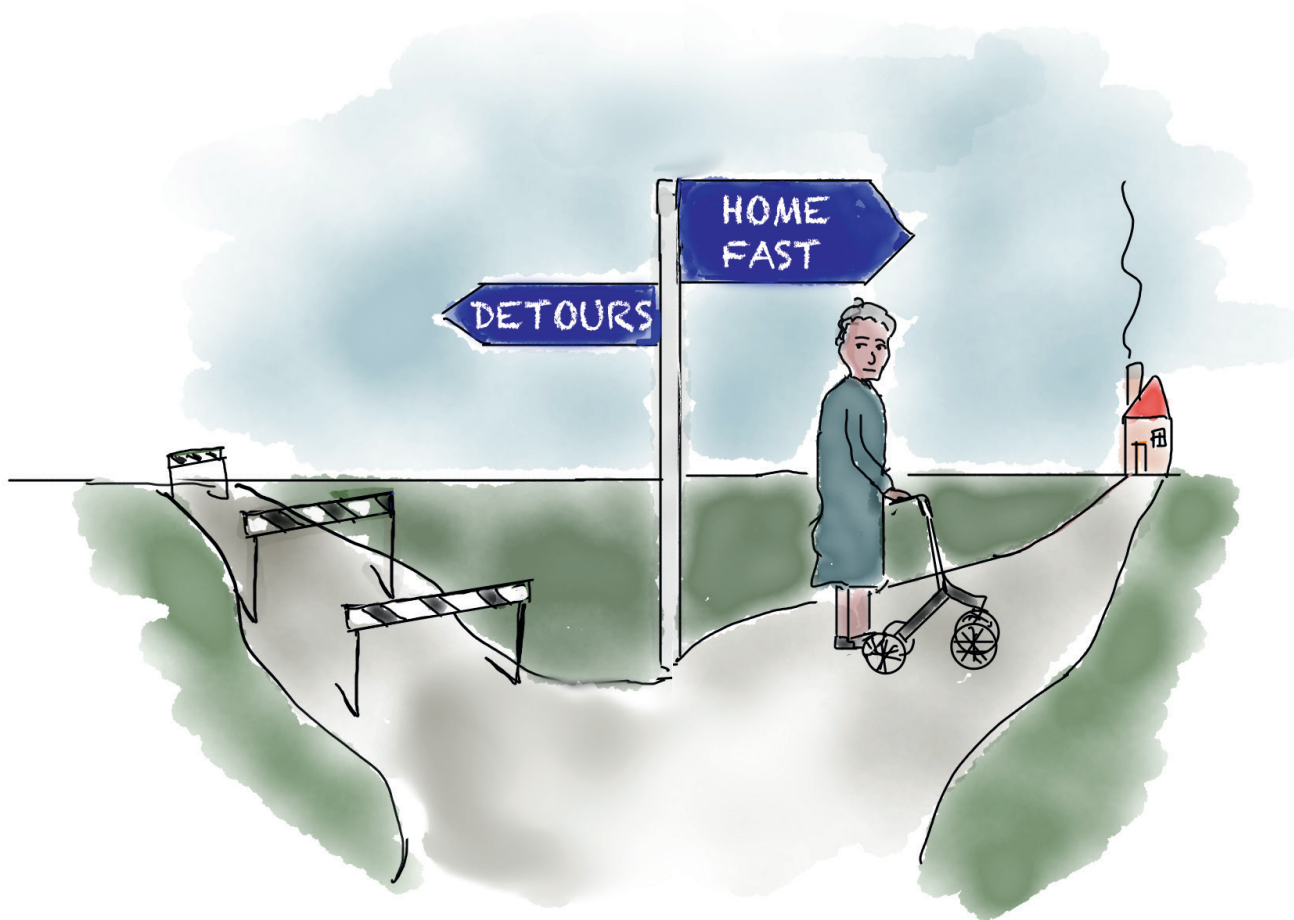


# Exploring detours





**To stop thinking obstacles  
to stop thinking may be all you need**



## 2.

# Detour maps



*Obstacles in thinking are just not funny and never will be. But perhaps they can be made smaller by seeing them not as 'obstacles', but as 'puzzles' that need to be 'solved', possibly with some help from others, in an accessible, respectful, but also stimulating way. This way the 'detour' may not be shorter, but it will be more pleasant.*

## About the detour maps

In this part of the book, the research participants of the COPIED study show how they circumvent fourteen common obstacles in thinking. Each detour is used by at least one of the research participants.

As shown schematically on the next page, the detour maps always have a fixed structure. All parts follow directly from the COPIED research project, except for the explanation at 'What's going on'.

We did not find new information about the causes of obstacles; we did match the obstacles with a literature search. Please note that the explanation is only one possible explanation. There is still ample research being done into the ins and outs of thinking obstacles in Parkinson's. But while researchers are trying to figure out what exactly goes wrong at the brain level, people with Parkinson's and their loved ones are already devising nice detours that we can already benefit from. Right now.

In the detour maps from page 28 you will find the detours mentioned by people with Parkinson's on the left page; those of their loved ones on the right-hand page. Of some obstacles input was gathered of only one of the two groups.

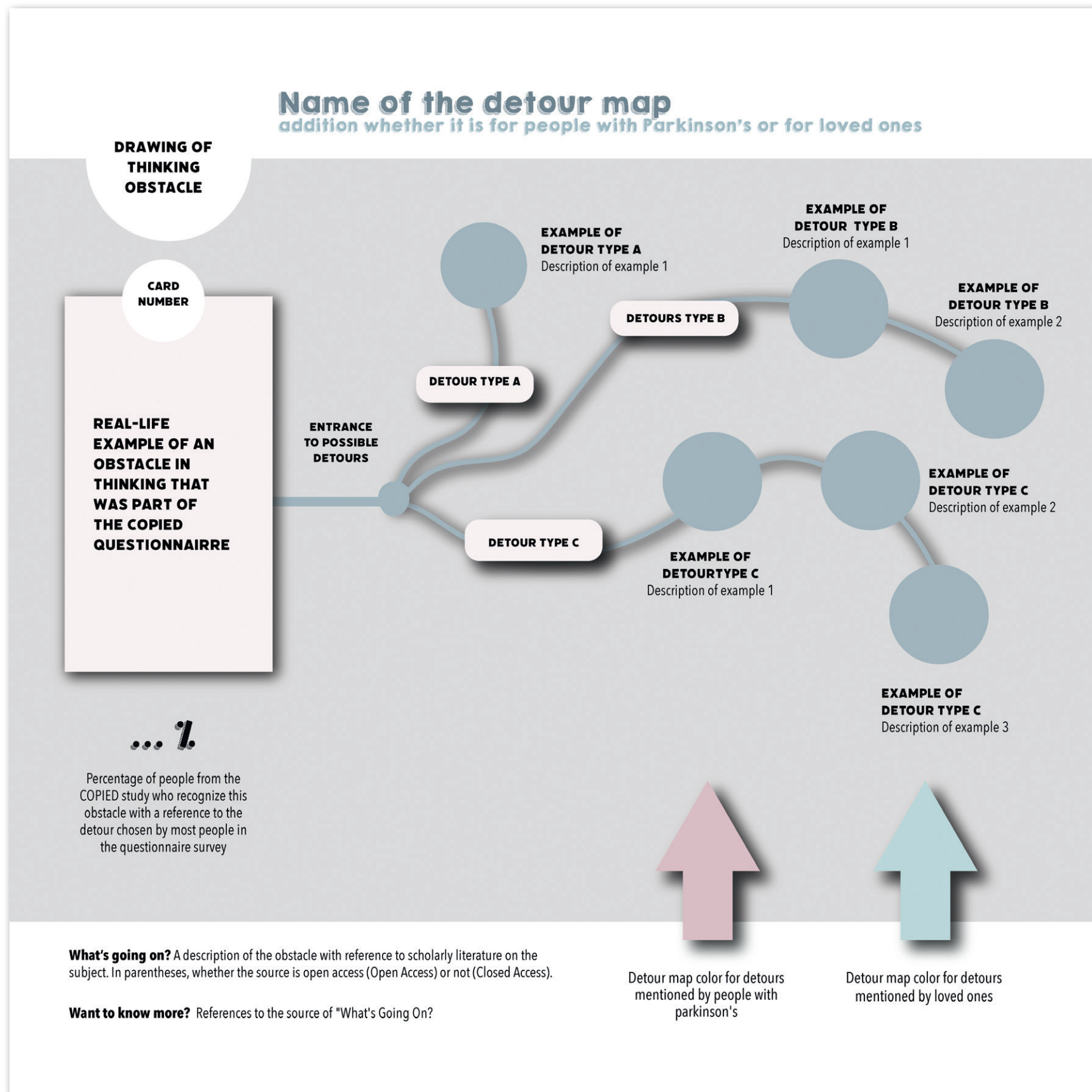
### Choosing a detour map

The detour maps are visual collections of the detours that participants use to deal with an obstacle in thinking. Each detour stands alone. They do not depend on each other.

Not every detour map will appeal to you, simply because you don't recognize the mentioned thinking obstacle. Just skip that one; it's for someone else.

Is there an obstacle in thinking that you do recognize? Then you can see, for example, whether your peers have used detours that you or your loved ones also use. You can talk about them with others, you can try the ones you did not use yet. And maybe you will find a completely different purpose for the detour maps.






Schematic representation of the structure of the detour maps

# Detours for filter failure for and by people with Parkinson's



la

## I CAN'T SHUT OUT STIMULI VERY WELL

 In group conversations I get tired at some point. In the beginning I am very enthusiastic and then I talk to everyone. At some point there's a lot of noise coming at you. And people are talking at the same time and I notice that it is an energy guzzler. Then I lose my concentration and I slowly fade away.

92 %

of people with parkinson's, from the COPIED study, recognize this obstacle. The detour most commonly used by all participants combined is attending a group discussion for a shorter period of time.

### DETOURS



**I PREPARE MYSELF**

#### MUTE STIMULI

I put in earplugs. They filter out half of the noise and I can still go to a meeting that I would otherwise avoid. Or I sit in a quiet workplace



#### REQUEST

I'll ask if people want to talk one on one, turn off the music, etc



#### SEPARATE

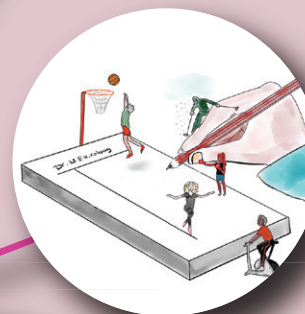
I'll go for a walk with someone



**I INVOLVE OTHERS**

#### PROVIDE SUBTITLES

I report in advance that I may suffer from excessive stimuli and that I then will distance myself for a while



#### CHANGE ACTIVITY

I'm going to draw or do something completely different

**I FOCUS ON SOMETHING ELSE**

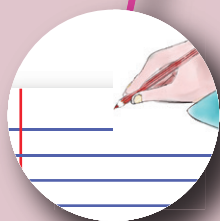
**I (TEMPORARILY) WITHDRAW**



#### ZOOM OUT

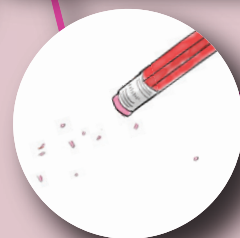
I'm going on standby

**BUILDING A CHECK MYSELF**



#### MAKE A BACKUP PLAN

I'll make sure there are good minutes



#### SHORTEN

I'll attend for a shorter period of time



**DISTANCE**  
I shut myself off



#### RECHARGE

I leave the meeting, take a power nap and then come back



#### AVOID

I avoid crowds and group conversations

### What's going on?

People with Parkinson's on average are less good at filtering visual and auditory stimuli than their 'healthy colleagues'. They are less able to distinguish the relevant stimuli from irrelevant stimuli. The part of their brain that determines which items are loaded into their working memory does not work as well. If your working memory is occupied by things that don't matter for the task at hand - such as the sound of the dishwasher, people talking at the same time - then you have less capacity left for the things that do matter. Like remembering things, focusing your attention on the other person, focusing on your work, and so on. Taking Parkinson's medication can reduce these types of filtering problems in some people with Parkinson's. This works less well for another part of the people with Parkinson's.

# Detours for filter failure for and by loved ones



## SHE CANNOT CANCEL NOISE

My partner regularly remembers things incorrectly. That never happened before. She makes more mistakes when there are more stimuli, for example when coffee is made in the room, when people are talking at the same time, when music is on during a conversation, when the TV is on, that sort of thing. And the mistakes are more noticeable when there are visitors.

# 67%

of the loved ones of people with Parkinson's (from the COPIED research) recognize this obstacle. The detour most used by all is accepting the situation as is.

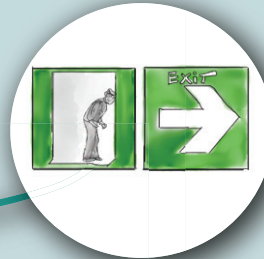
### DETOURS

#### TAKE PRECAUTIONS

If we know that a visitor is coming, we grind the coffee in advance or my loved one puts in earplugs that filter out the worst noise



#### WE PREPARE



#### MAKE ARRANGEMENTS

We have agreed that - to recover - she can (temporarily) leave the room if it really gets too much



#### REDUCE

We go to meetings less often



#### CHANGE ROLES

If my loved one makes the noise himself (grinding coffee, for example), then he does not have to participate in the conversation for a while.

#### WE SIMPLIFY

#### LIMIT

We do receive visitors, but not too many people at the same time



#### I MOVE ALONG

#### ACCEPT

It is what it is



#### I ACT AS FILTER

#### WE INVOLVE OTHERS

#### SHARING YOUR USER MANUAL

We explain that it is best to wait until we all sit quietly at the table before we continue talking



#### HELP FOCUS

I turn off jammers and ask for attention

### Sources

Lee, E., Cowan, N., Vogel, E., Rolan, T., Valle-Inclan, F., and Hackley, S. (2010). Visual working memory deficits in patients with parkinson's disease are due to both reduced storage capacity and impaired ability to filter out irrelevant information. *Brain* 133, 2677-2689. <https://doi.org/10.1093/brain/awq197> (Open Access).  
Bayram, E., Litvan, I., Wright, B. A., Grembowski, C., Shen, Q., & Harrington, D. L. (2021). Dopamine effects on memory load and distraction during visuospatial working memory in cognitively normal Parkinson's disease. *Neuropsychology, development, and cognition. Section B, Aging, neuropsychology and cognition*, 28(6), 812-828. <https://doi.org/10.1080/13825585.2020.1828804> (Closed Access).

# Detours for concentration problems for and by people with Parkinson's



## Ila

### IT'S HARD FOR ME TO CONCENTRATE

It's hard for me to keep my attention when reading, and I also have a hard time remembering what it said. Then I'm talking to people about a piece we both read and I think it said something completely different. Then I look it up and the other person is right.

## 61%

of people with Parkinson's from the COPIED study recognize this obstacle. The workaround they use most often is to turn off jammers

### DETOURS



#### TURN OFF JAMMERS

I make sure I can't be distracted by outside stimuli (e.g., I put the phone on silent, turn off the music, and sit in a quiet room)

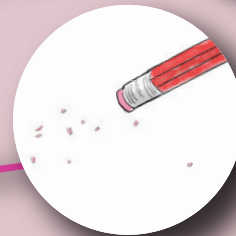


#### ACCEPT

I just read on even if I don't understand something for a moment. That understanding usually comes later. Better luck next time and keep going...

I TRY TO PREVENT IT

I LET IT GO



#### SHORTEN

I read for a shorter time, a small section. Not two chapters, but one



#### EXCHANGE

I read less complicated books that have shorter chapters.

I SIMPLIFY

I TAKE FIVE



#### RESET

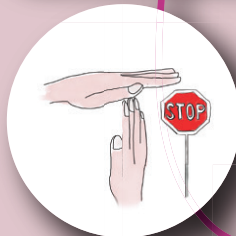
I speak to myself. I try extra hard to focus on what I'm doing



#### REPEAT

I reread a piece

I (TEMPORARILY) WITHDRAW



#### POSTPONE

I'm going to do something else. I'll try again later



#### CANCEL

I don't read anymore

I USE A DIFFERENT SENSE



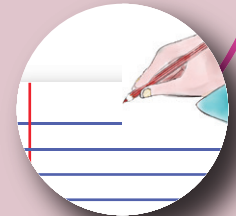
#### READ TO MYSELF

I read it out loud and listen to myself



#### BE READ TO

I ordered audiobooks and listen instead of reading



#### MAKING NOTES

I take notes on what I have read or I underline words

**What's going on?** People with Parkinson's may have difficulty sustaining attention (concentrating). The part of the brain that determines which stimuli deserve our attention, functions less well in them. Attention is one of the most important conditions for all other thought processes. For example, problems with attention can prevent you from absorbing information properly and therefore prevents you from remembering it. If there are problems with attention, this can have consequences for almost all daily activities.

# Detours for concentration problems for and by loved ones



11b

## NOT FOLLOWING ALONG



My loved one does not remember what is said during a conversation with a care provider. Then she says "Yes, yes, yes". Then she wants to be done with it. But she can't follow it at all at that moment. If I - now with corona - can't go in during a consultation, she won't get it at all.

74 %

of the loved ones of people with Parkinson's from the COPIED study recognize this obstacle. The detour they use most often is to prepare for the conversation

## DETOURS

WE TRY TO PREVENT IT



### PREPARE

Before every visit to the neurologist or Parkinson's nurse, we always prepare a questionnaire or send an e-mail about the current situation and what we want to tackle



### PREVENT STRESS

I help dose the incentives and time pressure around the appointment

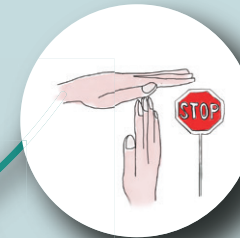
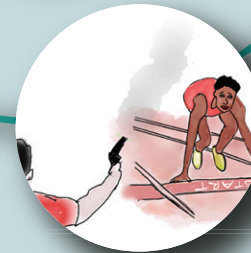
I LET IT GO



### ACCEPT

It is what it is

I TAKE FIVE



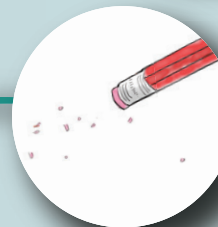
### TAKE A TIME-OUT

I notice when my partner with Parkinson's does not understand something. Then I pull the brake at that moment

### PROMPT

I tell my partner with Parkinson's to pay attention

WE CHECK



### TUNE IN

I ask my partner with Parkinson's what he has understood so far, and on that basis I explain what was not yet clear



### DISCUSS

We'll discuss it together

I TAKE CONTROL

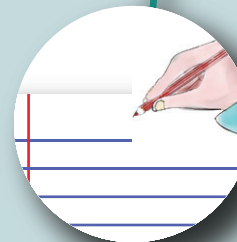


### TAKE OVER

I generally do the talking. Or I take notes. Then you can read it back later

### USE A TOOL

I suggest my loved one to record the conversation so that we can listen to it together later. Or I ask him to write down things that are said





# Detours for switching deficits for and by people with Parkinson's



## I FREEZE WHEN THINGS ARE DIFFERENT THAN EXPECTED

I was standing in front of an evening class and had prepared myself for a lesson from book A, it turned out that the students had book B. The lesson was well suited for the students, even if they had book B, but at that moment I completely got stuck. At once I was deflated.

# 41%

of the people with Parkinson's in the COPIED study recognize this obstacle. They try to avoid unexpected situations as much as possible

### DETOURS



**I TRY TO PREVENT IT**

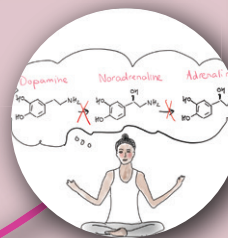
**PREPARE**  
Nowadays I almost always make a powerpoint. That keeps me on my toes and forces the audience into a straitjacket

**I LET IT GO**

**LET IT GO**  
I let it go. It's OK to be embarrassed

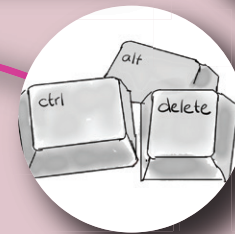


**RIDICULE**  
I make a joke



**TAKE A REST**

I take a deep breath so that the panicked feeling goes away and my head become clear again



**RESET**  
I speak to myself or I slap myself on the cheek

**I TAKE FIVE**

**I INVOLVE OTHERS**



**USE OTHERS**

I ask which student can explain the difference between book A and book B

**I TEMPORARILY WITHDRAW**

**ARTICULATE**

I mention that I'm stuck, explain that this is happening to me for a moment and take a short break to review my options



**DISTRACT MYSELF**  
I'm going to do something completely different, pull weeds in the garden for example



**AVOID**  
I try to avoid unexpected situations as much as possible. It's one of the reasons I don't work anymore

**What's going on?** We store an image of the environment in our working memory. That image is updated as information changes. In people with Parkinson's, the updating of this new information may be slower and less successful. To the outside world, it may appear that someone 'falls behind' and shows behavior that is not appropriate for the (new) situation.

**Source** Woodward, T. S., Bub, D. N., & Hunter, M. A. (2002). Task switching deficits associated with Parkinson's disease reflect depleted attentional resources. *Neuropsychologia*, 40(12), 1948-1955. [https://doi.org/10.1016/s0028-3932\(02\)00068-4](https://doi.org/10.1016/s0028-3932(02)00068-4) (Closed Access).



*Everything that is known to him is almost no problem.  
Unexpected and unknown things are the problem.*

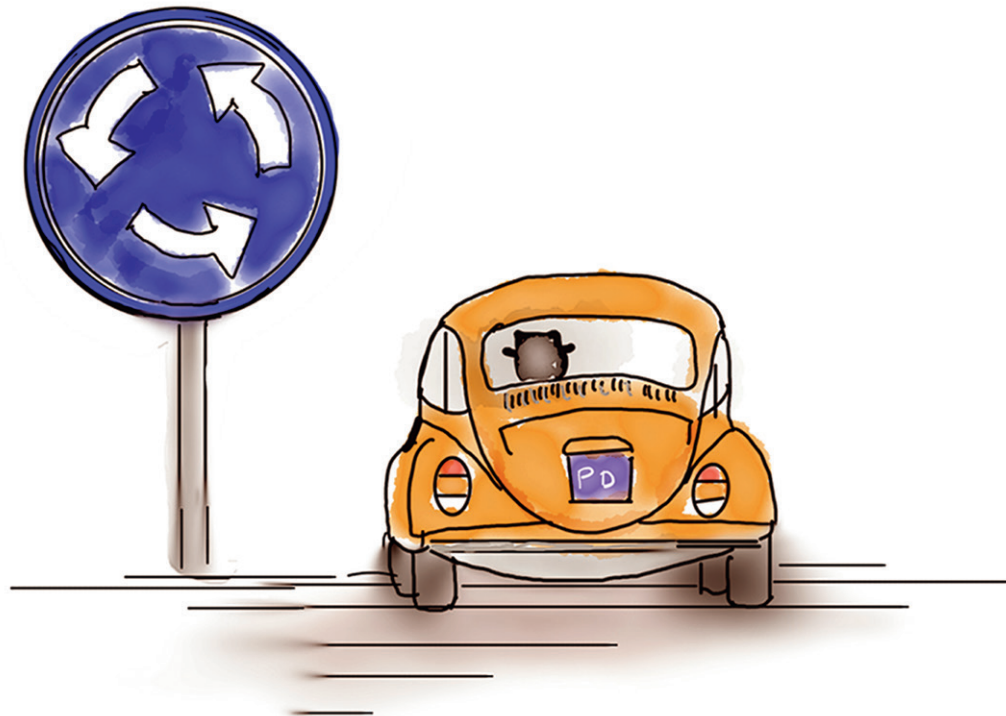




*I sometimes don't know where I'm driving in the car. This will only take a little while, a few seconds, but it's scary.*



*About a year ago he couldn't immediately find the toilet in the holiday home at night. Remarkable, because he used to be a firefighter. They must always be able to find their way, even in the dark and he was always able to.*



# Detours when getting lost for and by loved ones



IV

## GETTING LOST

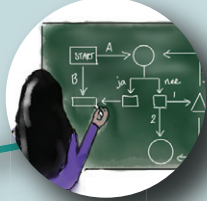
My partner with Parkinson's has difficulty with spatial orientation. Once we cycled away from somewhere and then she just cycled in the wrong direction. And then I was like, well, she'll come home on her own. At least that's what I said very bravely to myself...

43 %

of the loved ones of people with Parkinson's from the COPIED study recognize this obstacle. Their favorite way to deal with this is to show the way. Losing your way is recognized by people with Parkinson's themselves only by 12%

## DETOURS

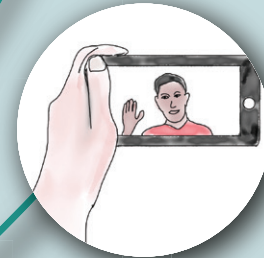
WE TRY TO PREVENT IT



### PREPARE

We discuss the route or set the route on Google Maps before my partner leaves

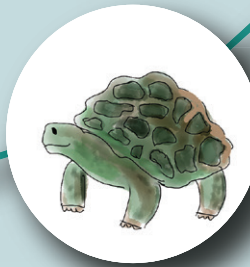
WE SIMPLIFY



### REASSURE MYSELF

I ask if I can install an app on the phone so that I always know where my neighbor is

I TAKE FIVE



### MAKE SPACE

I allow my loved one to get lost. It's gonna be okay



### TAKE OVER

I take over the activities in which getting lost is not so convenient. For example, we then go by car instead of bicycle

I LEAD THE WAY



### HIT THE ROAD TOGETHER

We always go on a trip together



### DEMONSTRATE

I show the way and literally cycle in front of my loved one



### GIVE DIRECTIONS

I point out landmarks in the area so that my partner can better orient himself

**What's going on?** In people with Parkinson's, it can become more difficult to perceive, process, place and update visual information in time. This can lead to an incorrect 'map' of the area.

**Source** Salazar, R. D., Moon, K. L. M., Nearing, S., & Cronin-Golomb, A. (2019). Spatial judgment in Parkinson's disease: Contributions of attentional and executive dysfunction. Behavioral Neuroscience, 133(4), 350-360. <https://doi.org/10.1037/bne0000329> (Closed Access).

# Detours for word finding difficulties for and by people with Parkinson's



Va

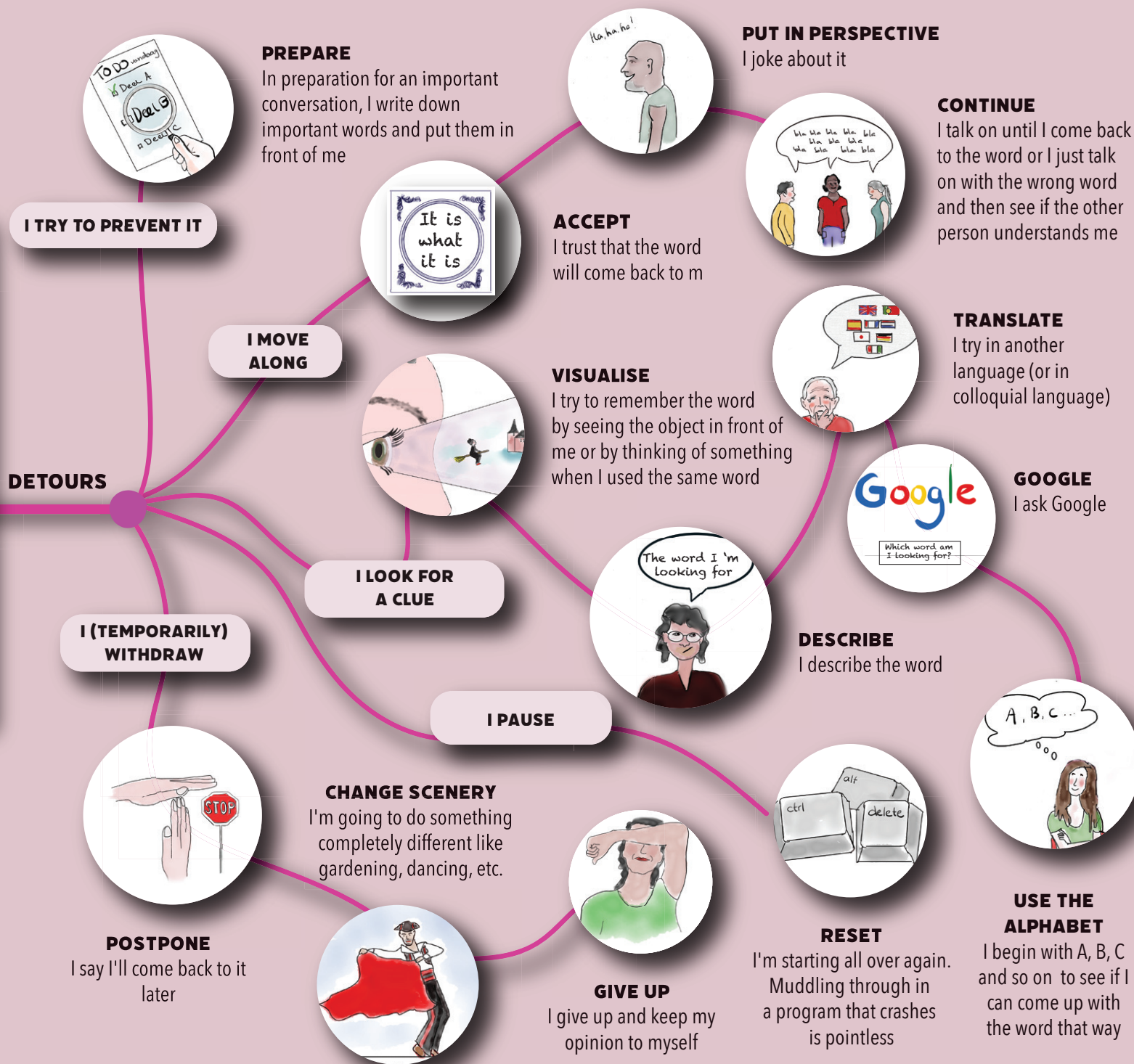
## I CAN'T FIND WORDS

I still know everything I need to know, just not always when I need it. Then I lose it for a while.

In a conversation with someone, for example, I often do not come up with the name of everyday objects such as the sink. Or then I call a raspberry a strawberry and mix up place names.

84 %

of the people with Parkinson's in the COPIED study recognize this obstacle. The detour most commonly used by all participants together is looking for a clue



**What's going on?** People with parkinson's may have difficulty with spoken and written language. One component of this is "anomia," the temporary inability to retrieve words. Visibly, this manifests itself in people with parkinson's by dropping more pauses in their sentences and/or continuing to talk with a word that is incorrect but similar, in terms of image, sound, because it falls into the same category, and so on. Those are also detours, of course.

# Detours for word finding difficulties for and by loved ones



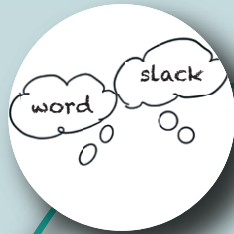
Vb

## UNABLE TO FIND WORDS

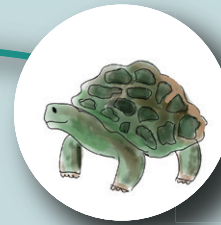
My loved one with Parkinson's has more difficulty putting things into words. She also uses different words than before and goes on about something for a long time.

### DETOURS

I MOVE ALONG



**GIVE AN EYE**  
My loved one invents new words, makes shorter sentences. I think that's creative. And between the lines, I understand anyway



**GIVE SPACE**  
I give my loved one the space to find the right words

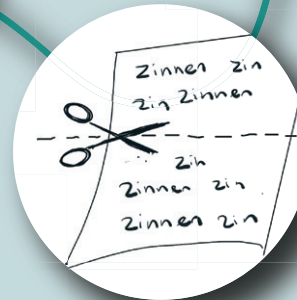
I repeat  
I repeat  
I repeat

**REPEAT**  
I try to repeat what my loved one said

WE PAUSE



**ASK**  
I ask what my loved ones means



**SUMMARIZE**  
I try to summarize and check if what I have understood is correct

I (TEMPORARILY) TAKE OVER



**MAKE AN APPOINTMENT**  
We agree on when I can take over. For example, we have an agreement that my loved one looks at me if he doesn't find a word. Only then do I say the word

**PROPOSE**  
I suggest my loved one to start all over again



**RECITE**  
I put words in my loved one's mouth

75%

of the loved ones of people with Parkinson's from the COPIED study recognize this obstacle. The detour most commonly used by all participants combined is to give space

**Sources** Johansson, I.-L., Samuelsson, C., & Müller, N. (2019). Patients' and communication partners' experiences of communicative changes in Parkinson's disease. *Disability and Rehabilitation*, 1-9. <https://doi.org/10.1080/09638288.2018.1539875> (Open Access); Smith, K. M., Ash, S., Xie, S. X., & Grossman, M. (2018). Evaluation of Linguistic Markers of Word-Finding Difficulty and Cognition in Parkinson's Disease. *Journal of Speech Language and Hearing Research*, 61(7), 1691. [https://doi.org/10.1044/2018\\_jslhr-l-17-0304](https://doi.org/10.1044/2018_jslhr-l-17-0304) (Open Access); Saldert, C., Ferm, U., & Bloch, S. (2014). Semantic trouble sources and their repair in conversations affected by Parkinson's disease. *International Journal of Language & Communication Disorders*, 49(6), 710-721. <https://doi.org/10.1111/1460-6984.12105> (Open Access).

# Detours for trouble finding things for and by people with Parkinson's



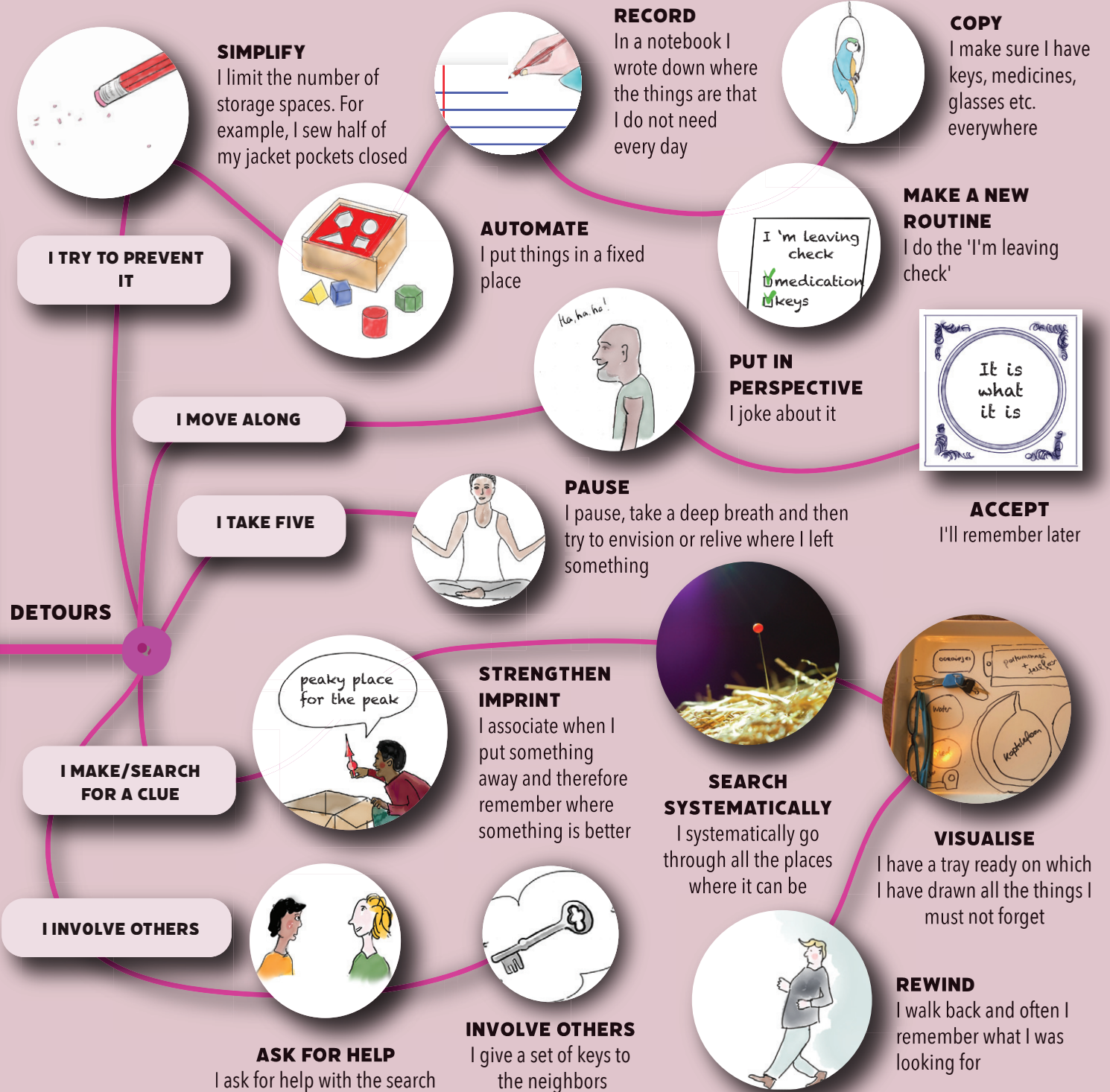
VI

## I FORGET WHERE I LEAVE STUFF

I notice that more and more often I do not remember where I leave things. At home, but also on the road. For example, if I put my bicycle key in my trouser pocket when I stand in front of the bakery, then a little later - when I leave the bakery again - I no longer know which pocket I put it in. Everyone has that from time to time, but for me it is striking.

69%

of the people with Parkinson's in the COPIED study recognize this obstacle. The detour that they use the most together is to put things in a fixed place

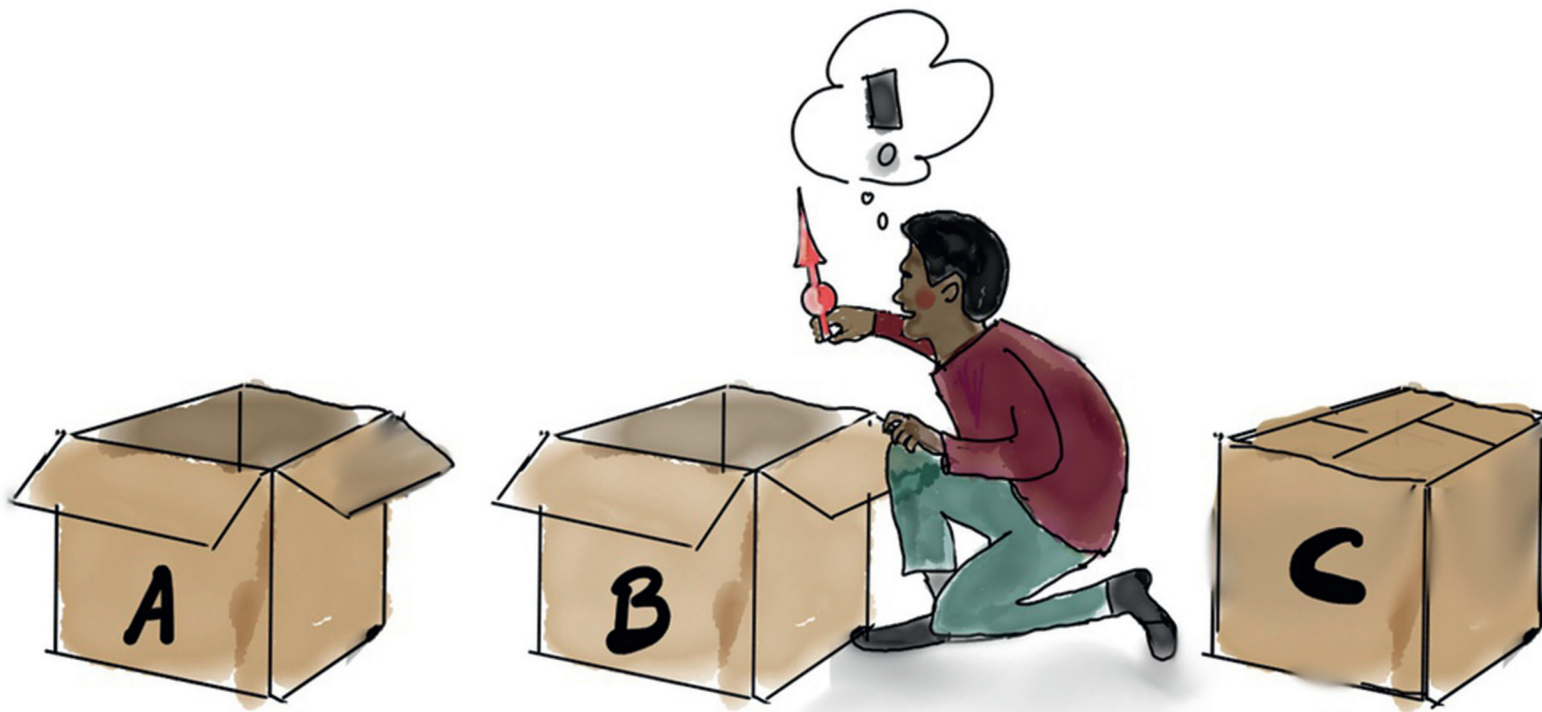


**What's going on?** People with Parkinson's may have trouble placing an experience in place and time, such as the dress you wore to the party last night and the key you left in one place when you got home. The problems may be related to the attention paid to storing the information as well as greater difficulty in retrieving the memory.

**Source** Siquier, A., & Andrés, P. (2021). Episodic Memory Impairment in Parkinson's Disease: Disentangling the Role of Encoding and Retrieval. *Journal of the International Neuropsychological Society*, 27(3), 261-269. doi:10.1017/S1355617720000909 (Closed Access).



Everything has its fixed place. When my wife moves things I lose track.





# Detours for forgetting future intentions for and by people with Parkinson's



VIIa

## I FORGET APPOINTMENTS

I have an appointment with someone from 11 to 12 and I want to write that down in my calendar. Then something else pops up and I didn't write down the appointment in my agenda. Subsequently, I will forget about it all together.

58 %

of the people with Parkinson's in the COPIED study recognize this obstacle. The detour they use most often is to write down the appointment as soon as it is made

### DETOURS

I TRY TO PREVENT IT



**USE A MEMORY AID**  
I use a calendar, an alarm or a post-it

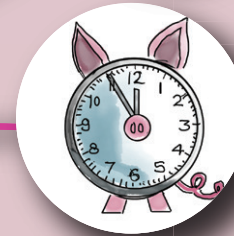


**TRUST**  
Usually I remember the appointment later and write it down

I LET IT GO



**DO IT RIGHT NOW**  
Don't be disturbed. If I make an appointment and I write it down immediately, I don't forget



**WIN TIME**  
By default, I ask some to repeat the appointment, then I can still put the appointment in the agenda

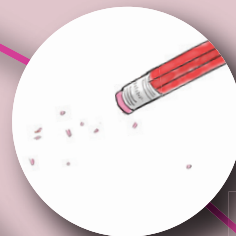


**CHECK BACK**  
When in doubt, I immediately call the person with whom I made an appointment

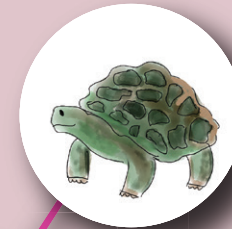
I BUILD IN A CHECK

I SIMPLIFY

I'LL COME BACK TO IT LATER



**DOSE**  
I make less appointments



**MAKE SPACE**  
I set aside all day for an appointment so that I have less chance of forgetting it

I INVOLVE OTHERS



**OUTSOURCE**  
My loved one now manages the agenda



**MAKE APOLOGIES**  
I offer my apologies when this happens



**ONE THING AT AT TIME**  
If I avoid doing several things at once, I'll remember the appointment

**What's going on?** Memory for future intentions, such as remembering to take your medicine, turn off a device, or remember an appointment, can be impaired in Parkinson's disease. In this particular situation, this is made even more difficult because there is a distraction involved, which means that the appointment may not even be saved, let alone be retrieved from memory. But even when there are no distractions, it is more difficult for people with Parkinson's to remember what they wanted to do. To help oneself with this, detours are essential.

# Detours for forgetting future intentions for and by loved ones



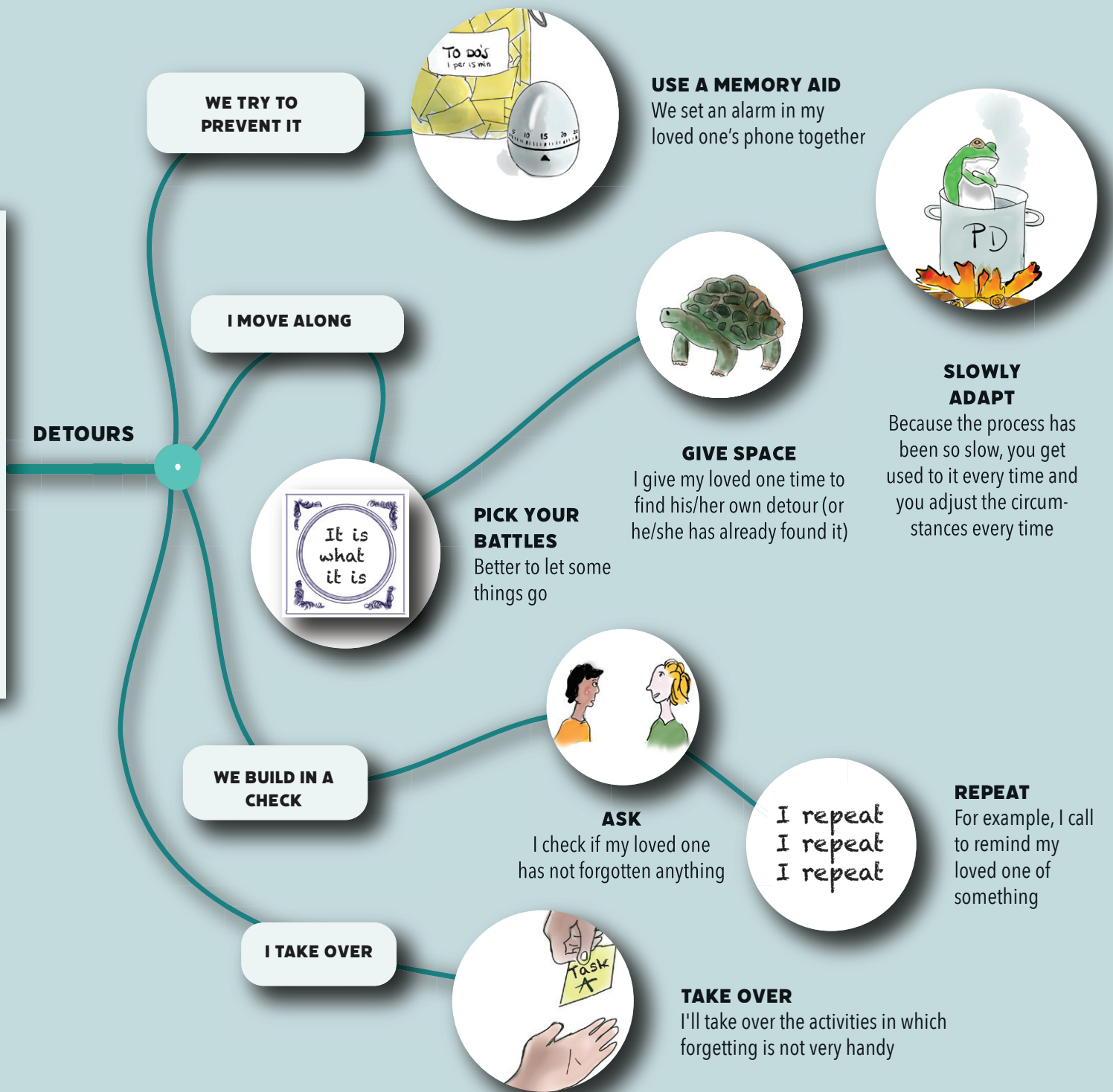
VIIb

## FORGETFULNESS

Last week my sister called but my husband forgets to tell me. Until I said: "I'm going to call my sister". Then he remembered and then he said: "Oh yes, she called". Also with the medicines. I have to check every day whether he has taken them. Sometimes I doubt whether he hasn't got a mild form of dementia.

73%

of the loved one of people with Parkinson's from the COPIED study recognize this obstacle. The detour they use most often is choosing what to let go and what not (pick your battles)



Sources Henry, J.D. Prospective memory impairment in neurological disorders: implications and management. Nat Rev Neurol 17, 297-307 (2021). <https://doi.org/10.1038/s41582-021-00472-1> (Closed Access); Foster ER, McDaniel MA, Repovs G, Hershey T. Prospective memory in Parkinson disease across laboratory and self-reported everyday performance. Neuropsychology. 2009;23(3):347-358. <https://doi.org/10.1037/a0014692> (Open Access).

# Detours for choice paralysis for and by people with Parkinson's



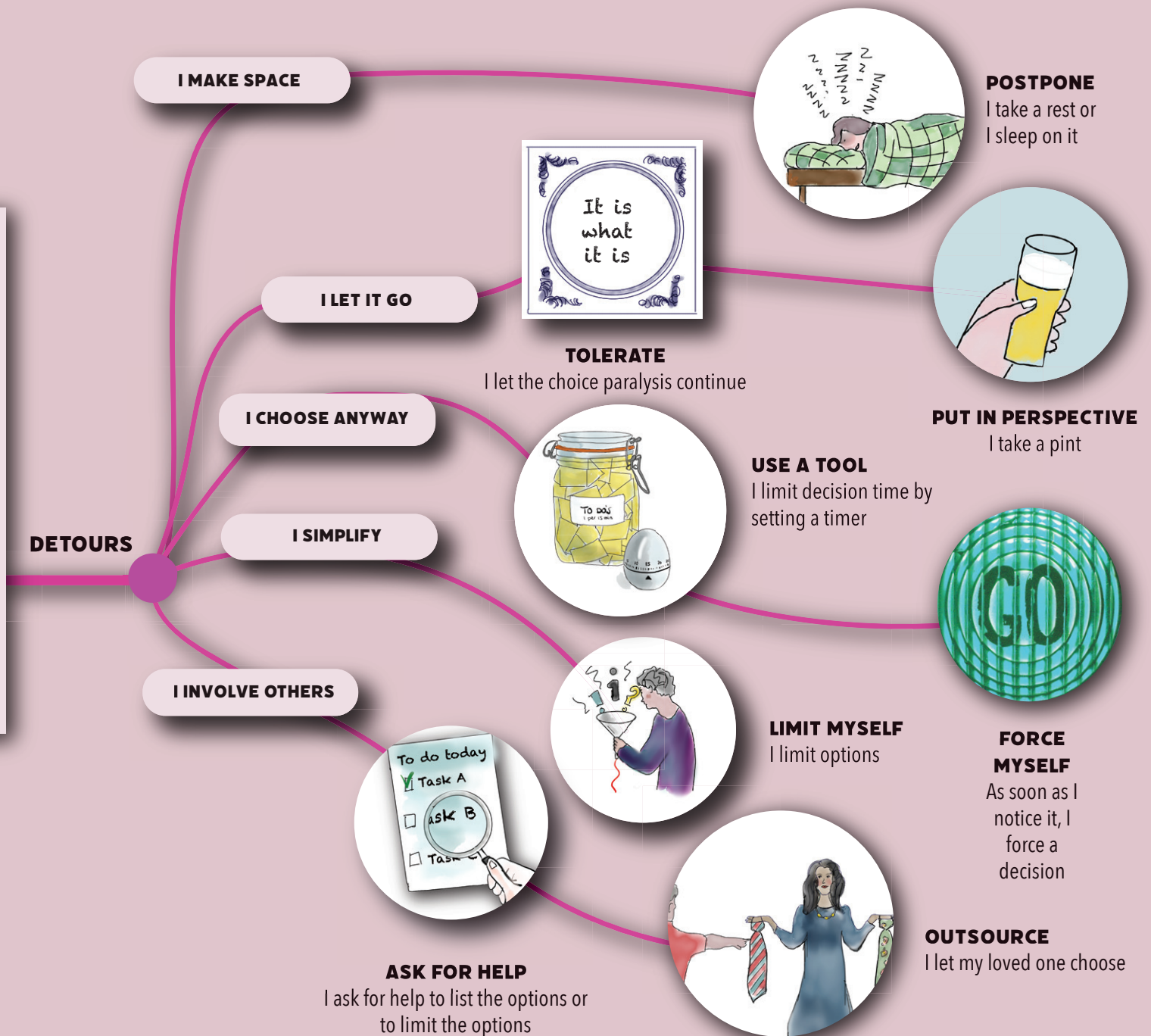
## VIII

### I CANNOT CHOOSE

I especially suffer from slowness in making decisions. I keep doubting for a long time. I can't get on with things. To give an example: I just moved. I need a bathroom cabinet but I can't figure out which one that should be. I'm endlessly searching and in the meantime it's a mess here. The boxes just stand there.

**72%**

of the people with Parkinson's in the COPIED study recognize this obstacle. The strategy they use the most together is to tolerate



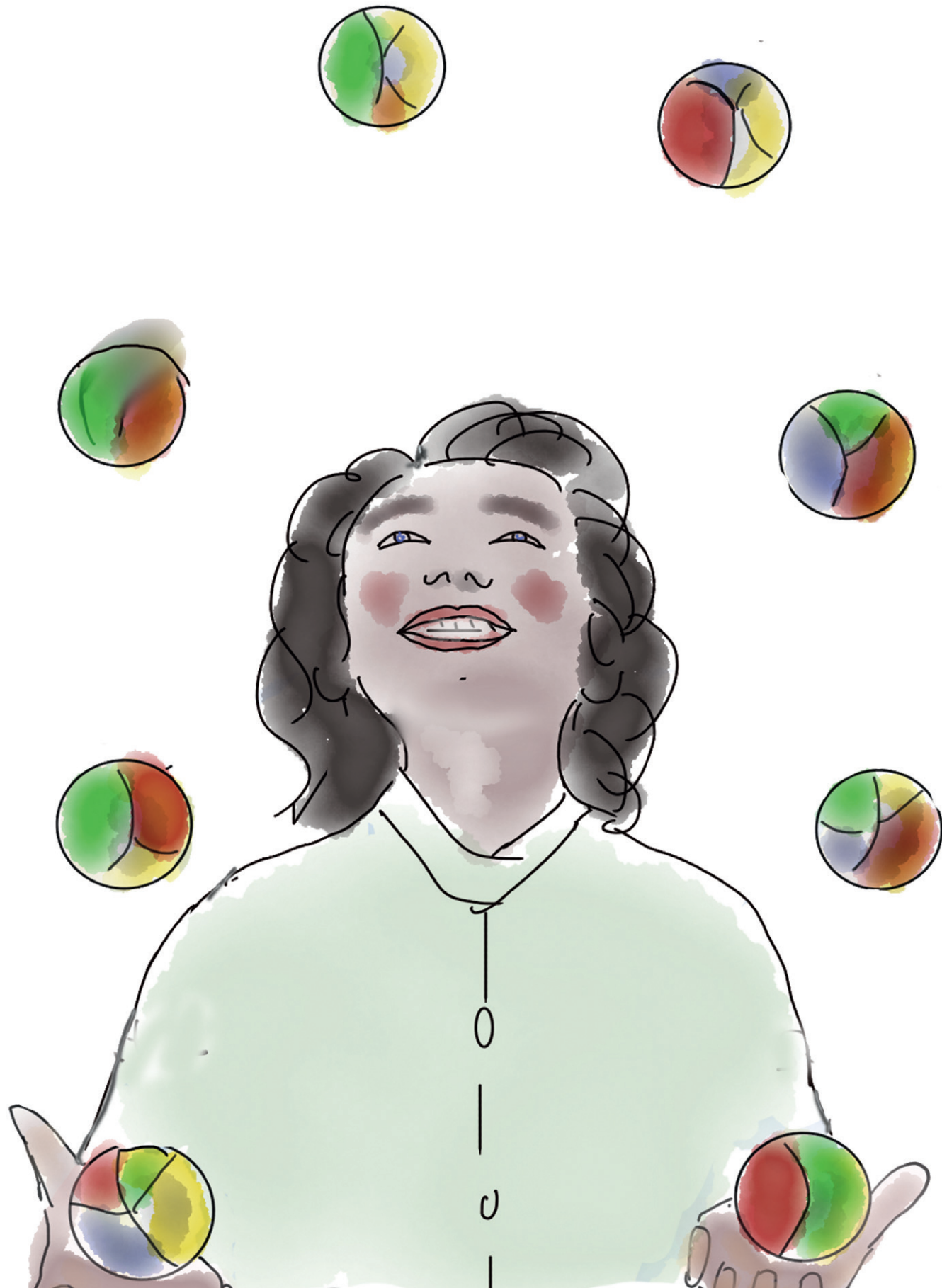
**What's going on?** When we have to make a decision, but are confronted with ambiguous information, it often makes sense to rely on our past experience, also known as prior knowledge. Cherries, for example, ripen earlier in a warm spring. This type of knowledge will influence our choices. People with Parkinson's appear to have difficulty using prior knowledge, even if it has just been acquired. If you can't easily gather the right information needed to make a decision, it can lead to difficulty making (the right) decisions.

**Sources** Perugini, A., Ditterich, J., & Basso, M. A. (2016). Patients with Parkinson's Disease Show Impaired Use of Priors in Conditions of Sensory Uncertainty. *Current biology : CB*, 26(14), 1902–1910. <https://doi.org/10.1016/j.cub.2016.05.039>. (Open Access). Perugini A, Ditterich J, Shaikh AG, Knowlton BJ, Basso MA. Paradoxical Decision-Making: A Framework for Understanding Cognition in Parkinson's Disease. *Trends Neurosci*. 2018;41(8):512-525. <https://doi.org//10.1016/j.tins.2018.04.006> (Open Access).



*Helping me sort out the options can be helpful.  
Limiting the number of options as well.*





# Detours for multitasking malfunction for and by loved ones



IX

## ONE THING AT A TIME

“ My loved one can only do one thing at a time. As a result, the pace of action and thinking is slower than before. That is difficult. At the checkout of the supermarket, for example, people are pushing the cart behind you. But my loved one really can't go that fast anymore. There is little tolerance for a different pace.

79%

of the loved ones of people with Parkinson's from the COPIED study recognize this obstacle. The detour they use most often is to give space

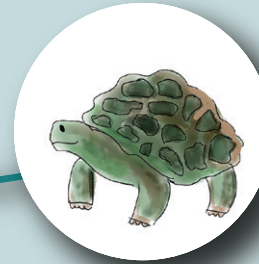
## DETOURS

I TAKE FIVE

I (TEMPORARILY) TAKE OVER



**GIVE SPACE**  
I let it happen



**SLOW DOWN**  
I'm getting slower too



**STEP BY STEP**  
I wait for my loved one to finish one thing before I disturb him for something else



**ADDRESS**  
I address the environment if it does not adapt to the pace of my partner with Parkinson's



**TAKE OVER**  
I take over the things that go too slowly. For example, I do the shopping

## THE TESCO EFFECT

It may seem that thinking obstacles occur less often than they really are. This happens when people with Parkinson's avoid certain situations or when their loved ones take over the activity in which the obstacles occur. In a previous study, a person with Parkinson's used the term "The Tesco effect" (the name of a British supermarket) to describe this phenomenon. He used this term to describe how difficult it is for him to cope with a crowded supermarket and that he, and other patients he has spoken with, actively avoid going to the supermarket for this reason.

**What's going on?** Our autopilot is extremely important to be able to multitask well. This 'driver' ensures that we can do several things at the same time without thinking, such as paying at the cash register and having a chat with the cashier. Because their autopilot falters, people with Parkinson's need to bypass their autopilot and consciously decide where to focus their attention. As a result, they can really only do one thing right at a time. To apparently do two things at the same time, they can make use of deliberately switching quickly between multiple tasks. When switching back and forth, mistakes are often made.

**Sources** Koerts J, Van Beilen M, Tucha O, Leenders KL, Brouwer WH (2011) Executive Functioning in Daily Life in Parkinson's Disease: Initiative, Planning and Multi-Task Performance. PLOS ONE 6(12): e29254. <https://doi.org/10.1371/journal.pone.0029254> (Open Access).

# Detours for a lack of overview for and by people with Parkinson's



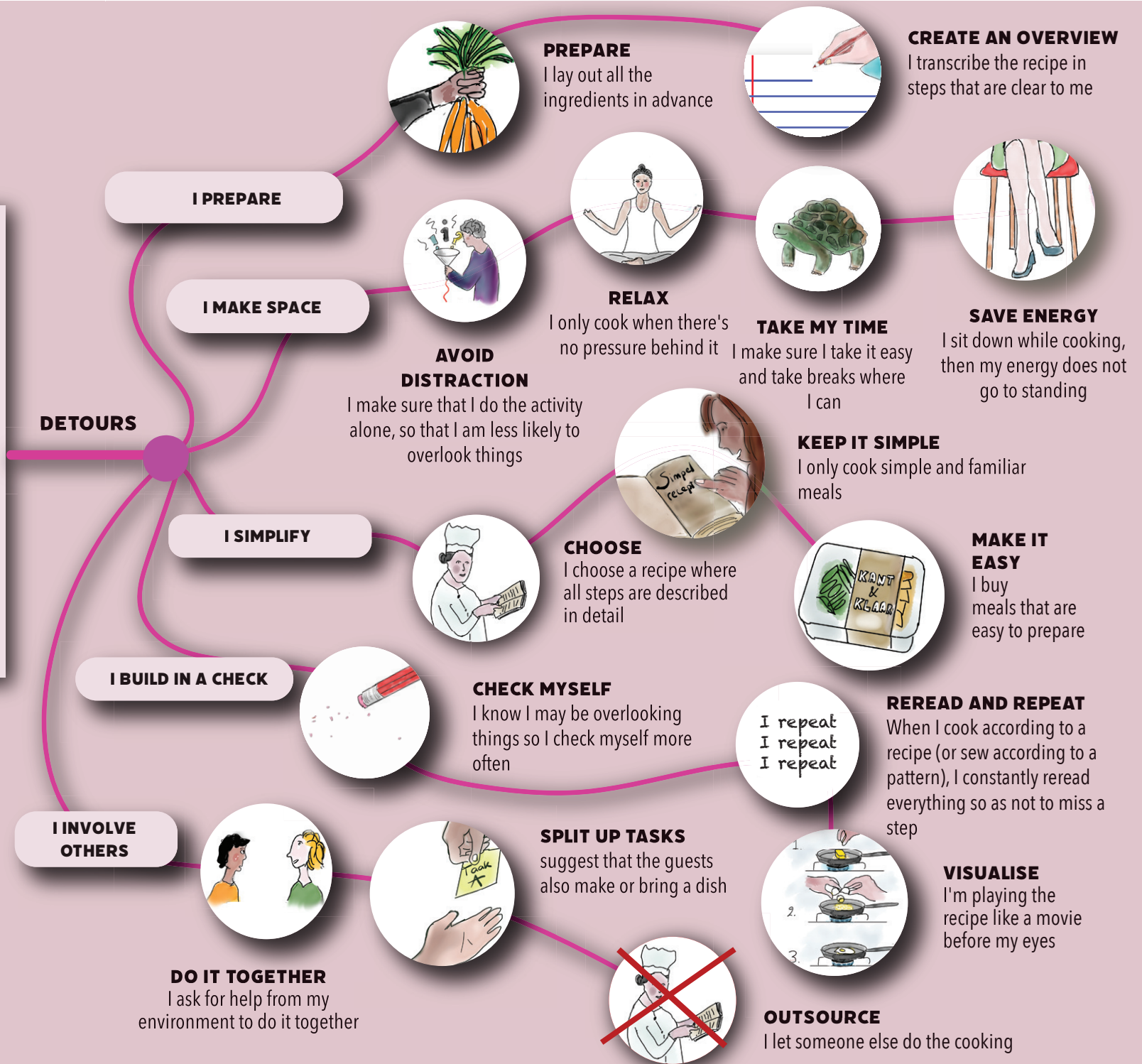
X

## I OVERLOOK STEPS

👉 Cooking is not so easy anymore. It consists of so many small steps and at each step you can go wrong, it seems. I regularly skip one of the ingredients, or I forget that it's time and then things burn.

52%

of people with parkinson's from the COPIED study recognize this obstacle. The detour they use most often is avoiding distractions



**What's going on?** Activities such as shopping and cooking are activities that require a lot from our thinking capacities, such as keeping track of where you are in the task, what is needed and what still needs to be done. Such complex activities can be difficult for people with Parkinson's, especially when time constraints are involved.

**Source** Foster, E. R., & Doty, T. (2021). Cognitive Correlates of Instrumental Activities of Daily Living Performance in Parkinson Disease Without Dementia. Archives of rehabilitation research and clinical translation, 3(3), 100138. <https://doi.org/10.1016/j.arrct.2021.100138> (Open Access).



*Cutting up activities in small pieces helps. Then it's not a mountain I look up to but manageable steps.*





# Detours for difficulty with complexity for and by people with Parkinson's



XI

## ANTICIPATING IS MORE DIFFICULT

Driving is getting more difficult. It is more difficult to estimate complex situations. For example, to be able to estimate which exit of the roundabout another car will take. That used to be completely automatic and now I have to think about it a lot.

72%

of the people with Parkinson's in the COPIED study recognize this obstacle. The detour they use the most together is not to drive a car anymore

## DETOURS

I TRY TO PREVENT IT



### AVOID DISTRACTION

I make sure I drive alone because then I'm less likely to overlook things



### TIMING

I make sure I'm well rested, well on the medication, only drive when the weather is nice and avoid rush hour

I MAKE SPACE



### RELAX

I only drive when there's no pressure behind it



### TAKE MY TIME

I make sure I take it easy and take breaks where I can



### SHORTEN

I only drive short distances



### ADJUST

I bought a car that helps to make driving more relaxed, such as automatic transmission, cruise control, reversing camera, etc.

I SIMPLIFY



### REQUEST

I ask if the co-driver will refrain from talking to me while driving



### FOCUS

I don't let myself get distracted. I must consciously concentrate on driving



### TAKE THE KNOWN ROAD

I only drive routes that I already know

I SWAP OR STOP



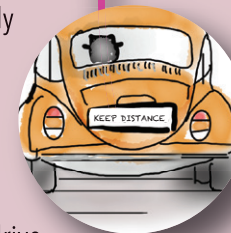
### SWITCH

I no longer drive a car but go by public transport or bicycle



### QUIT

I don't drive anymore or let someone else drive



### DEFENSIVE DRIVING

I keep more distance

**What's going on?** Driving is an example of a complex activity that requires different visual, motor and cognitive skills. In most driving situations, the driver must focus his or her attention, process information, adapt to ever-changing conditions, estimate what is going to happen and make a number of decisions very quickly. For people with Parkinson's, this is a combination that demands a lot from them.

**Sources** Ranchet, M., Broussolle, E., Poisson, A., & Paire-Ficout, L. (2012). Relationships between cognitive functions and driving behavior in Parkinson's disease. *European neurology*, 68(2), 98-107. <https://doi.org/10.1159/000338264> (Open Access); Crizzle, A. M., Classen, S., & Uc, E. Y. (2012). Parkinson disease and driving: an evidence-based review. *Neurology*, 79(20), 2067-2074. <https://doi.org/10.1212/WNL.0b013e3182749e95> (Open Access).



*I have started to actively play chess. Anticipation is put to the test. I notice that my game gets better after a few months.*



*Sometimes I get stuck in complex situations and that manifests itself in a kind of blackout. Not in traffic, but it can happen while I am playing bridge.*

# Detours for hiccups in empathy for and by people with Parkinson's



XII

## EMPATHY ISN'T SELF-EVIDENT ANYMORE

Empathy no longer comes naturally when you have Parkinson's. I noticed, for example, that I forgot to ask if my wife also wanted soup. And if someone asks how I am doing, it is not self-evident that I also ask a question back. I really need to work on reciprocity in my relationships these days.

50 %

of the people with Parkinson's in the COPIED study recognize this obstacle. The detours are very diverse

### DETOURS

I PREPARE



#### PREPARE QUESTIONS

In planned meetings, I think in advance about the questions I can ask



#### PLAN

I put birthdays, reminders to call someone, etc. in my calendar

I LET IT GO

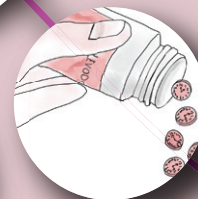


#### ACCEPT

I don't make a big deal out of it

#### TIMING

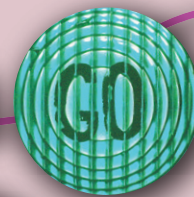
When I am well into my medication it goes better



#### BOEKJE BIJHOUDEN

I have a "don't forget empathy notebook" in which I keep track of what I must not forget

I FIND A WAY



#### FORCE MYSELF

I force myself to do it, because in the end it also distracts from myself



#### AUTOMATE

What I have taught myself: with every question I am asked, I automatically ask a question in return

I INVOLVE OTHERS



#### GIVE A HEADS UP

Agree on a heads up, e.g. a facial expression, poke in the back



#### SUBTITLE

I explain that I am interested but not always able to be attentive. I need time

I WITHDRAW



#### GIVE UP

I take the emergency exit. I have no contacts left, then it can't go "wrong" either



#### MAKE ARRANGEMENTS

I agree with my loved ones that they simply ask me with a wink if I am still interested in their story, because I am!



#### ASK FOR EMPATHY BACK

I wonder if you should, always be attentive You have a brain disease that you can't deny and then you have to continue to react "normally" to everyone? Maybe others can empathize?

**What's going on?** People with Parkinson's can sometimes appear less empathetic as the disease progresses, even though they are not or do not want to be. Empathy consists of "putting yourself in the other person's shoes" (cognitive empathy) and "feeling the same emotion as the other person" (emotional empathy). Emotional empathy does not appear to be affected. It is mainly about being able to put yourself (less quickly) in someone else's shoes.

**Source** Schmidt, N., Paschen, L., Deuschl, G., & Witt, K. (2017). Reduced Empathy Scores in Patients with Parkinson's Disease: A Non-Motor Symptom Associated with Advanced Disease Stages. *Journal of Parkinson's disease*, 7(4), 713-718. <https://doi.org/10.3233/JPD-171083> (Closed Access).



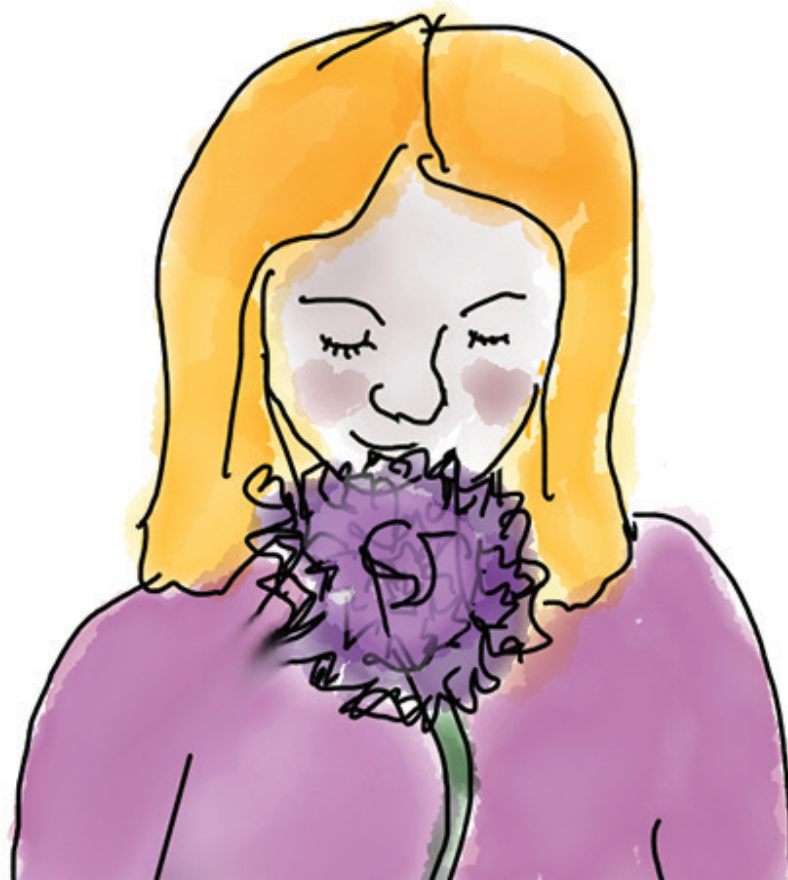
*I usually and sincerely start empathically, but have more trouble keeping the conversation going and formulating the right questions, which I do have in my head, but can't formulate the way I would like. The conversation then quickly dies.*



*Sometimes it feels like my partner doesn't want to hear my point of view. She then comes across as less empathetic, while it is simply the speed of information processing is faltering. She is expressing her own point of view and can't hear mine yet.*



*In the past, he indeed also came up with spontaneous things (going out, gifts, dinners, etc.). That's really less now. The other day he brought flowers, I was very emotional.*



# Detours for problems getting started for and by people with Parkinson's



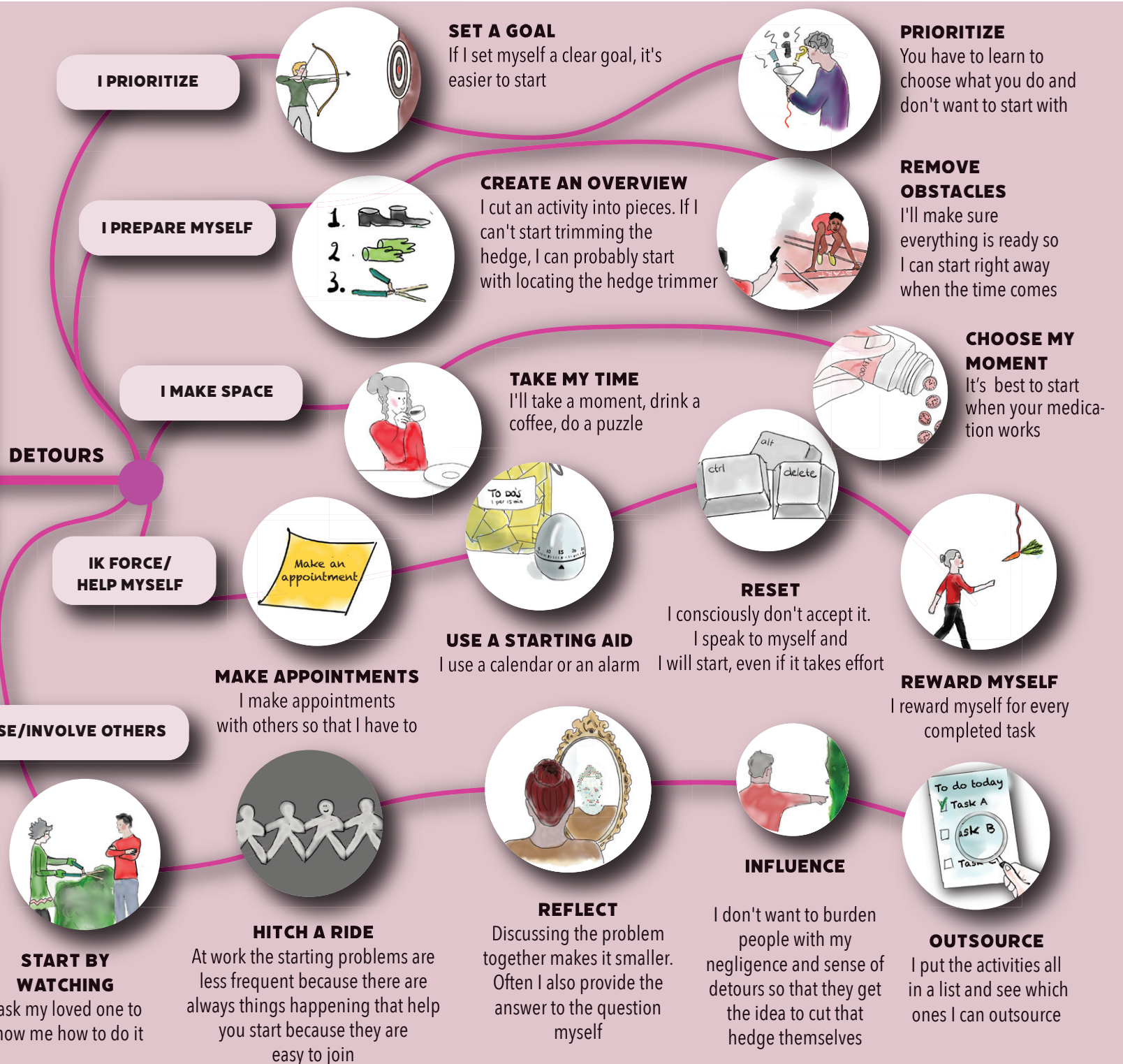
Xilla

## I CANNOT START

The difference between thinking that you have to do something and actually doing it is very big. For example, I have already trimmed the hedge quite often in my head, but in practice it has not yet happened.

77%

of the people with Parkinson's in the COPIED study recognize this obstacle. The detour they use most often is to use a calendar or alarm



**What's going on?** Starting and stopping problems are inextricably linked with Parkinson's. If people focus on starting, it leads to less control in stopping. When people with Parkinson's feel pressured to respond quickly, it becomes more difficult for them to suppress inappropriate responses. Speed at the expense of accuracy. Then when people focus again on suppressing errors, all other actions - which you might want to initiate - are delayed again. That can look like a loss of initiative. What plays a role here is that selecting options when making decisions can become more difficult for people with Parkinson's (see also Detour Map VIII). The detours that people with Parkinson's have found help to regain the balance between starting and stopping.

# Detours for problems getting started for and by loved ones



XIIIb

## IT FALLS QUIET



My loved one is taking less initiative. He is becoming very quiet. He withdraws. For example, he used to contribute ideas for what we should do for outings and that has actually stopped completely. Even when I ask him "where shall we get food?" he doesn't answer. Then he just hangs around.

## DETOURS

I SIMPLIFY



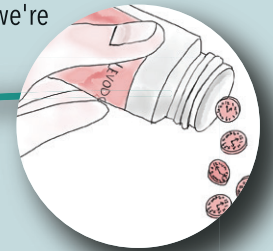
**ACCEPT**  
It is what it is

I MOVE ALONG

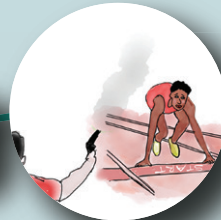


**GIVE SPACE**  
I give my loved one time until he starts by himself

**WAIT FOR IT**  
Timing is everything. I wait until the right time (when the medication works, when it's quiet, etc.).



I HELP PREPARING



**DAY START**  
We do a day start together: what's on the program today?

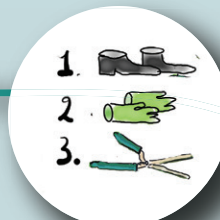


**GIVE TIPS**  
I suggest my loved one to use a tool such as an alarm clock, alarm, calendar



**ADDRESS**  
I appeal to my loved one to get ready for departure earlier

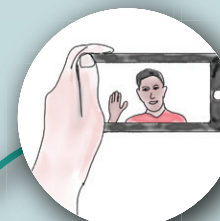
I ACT AS START ENGINE



**OFFER A STARTING POINT**  
I help my loved one to get started by breaking down the activity into manageable pieces



**SHOW**  
I show how it's done



**HELP REMEMBER**  
I repeat or remind my loved one to get started, for example, by calling

I MOBILISE HELP



**CALLING IN AN EXTERNAL AUTHORITY**  
It helps when an authority says my loved one should start



**TAKE OVER**  
I take charge and plan the outing, or whatever ...whenever possible



**CHANGE SCENERY**  
I take my loved one to a place where things are happening and where he can hitch a ride more easily. At home, everything has to come from him

78%

of the loved ones of people with Parkinson's from the COPIED study recognize this obstacle. The detour they use most often is to remind their loved one to start, for example by calling

**Sources** Wylie, S. A., van Wouwe, N. C., Godfrey, S. G., Bissett, P. G., Logan, G. D., Kanoff, K. E., Claassen, D. O., Neimat, J. S., & van den Wildenberg, W. (2018). Dopaminergic medication shifts the balance between going and stopping in Parkinson's disease. *Neuropsychologia*, 109, 262-269. <https://doi.org/10.1016/j.neuropsychologia.2017.12.032> (Open Access). Mole, J. A., Josephs, L., & Prangnell, S. J. (2020). Impaired option generation underpins deficient reasoning in Parkinson's disease patients with apathy. *Applied Neuropsychology: Adult*, 1-6. <https://doi.org/10.1080/23279095.2020.1712400> (Closed Access).

# Detours for a faltering sense of time for and by people with Parkinson's



XIVa

## I CAN'T STOP

I like gardening and then to tally forget what else I was doing. I forget that clearing up the tools also costs time. An other example a while ago I was clearing out my closet, which was going, wich was xx well and then forget an appointment I had.

47%

of people with Parkinson's in the COPIED study recognize this obstacle. Acceptance is the most used detour. It takes the time it needs/ takes.

## DETOURS

I SIMPLIFY



### LESS TASKS

I usually only plan one extra activity per day without an end time, so that I experience less time pressure.



### SMALLER TASKS

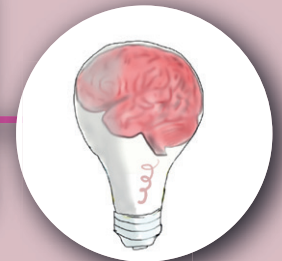
I plan an activity in parts. Then I can stop more easily.

I MOVE WITH THEM



### ACCEPTANCE

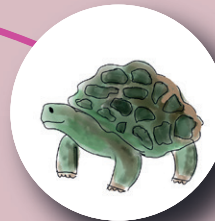
it is what is is.



### TO ENJOY

I enjoy the moments when things are going well. If I can't stop, it gives me a lot of energy.

I MAKE ROOM



### ADD MORE TIME

Start earleir to avoid being late

I REMIND MYSELF



### REMEMBER MYSELF

I put a clock in the shed and now I remind meself to stop sooner



### HULPMIDDEL GEBRUIKEN

I use an alarm

I ORGANISE HELP



### PUT A POINT ON THE HORIZON

I agree on a time to stop with my near and dear ones.

**What is goint on?** Dopamine influeunces out internal clock. Parkinson's can disturb the evluation of the time needed for a tasl. An external signal, for instance: someone saying: it is time to go, will start the internal clock that wil compare the passage of time to what is stored in the (working) memory of particulars of the current task. The faltering sense of time could appear to the on-looker as a stopping problem. That is strengthend as everything you do beside your task also needs more time.

# Detours for a faltering sense of time for and by loved ones



XIVb

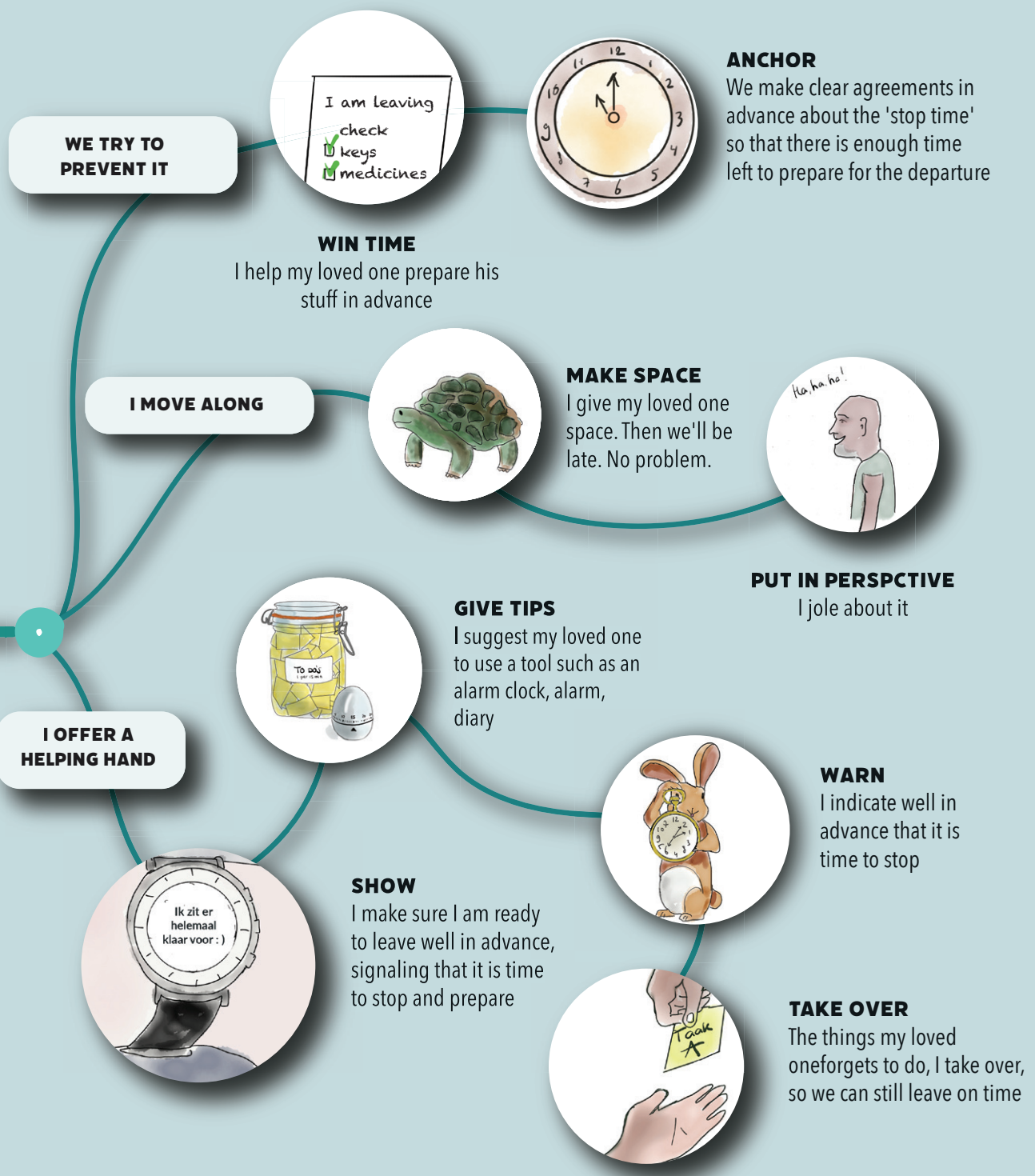
## A FALTERING SENSE OF TIME

Normally my neighbor was always ready to leave for an appointment well in advance. And now - if we have to leave at noon - she can decide that she still wants to shower at a quarter to 12 or that she still needs to pack all her things.

50 %

of the loved ones of people with Parkinson's from the COPIED study recognize this obstacle. The workaround they use most often is to take over tasks

### DETOURS





It is striking how much  
problems get solved if you  
let them rest for a while



3.

## Detour accelerators

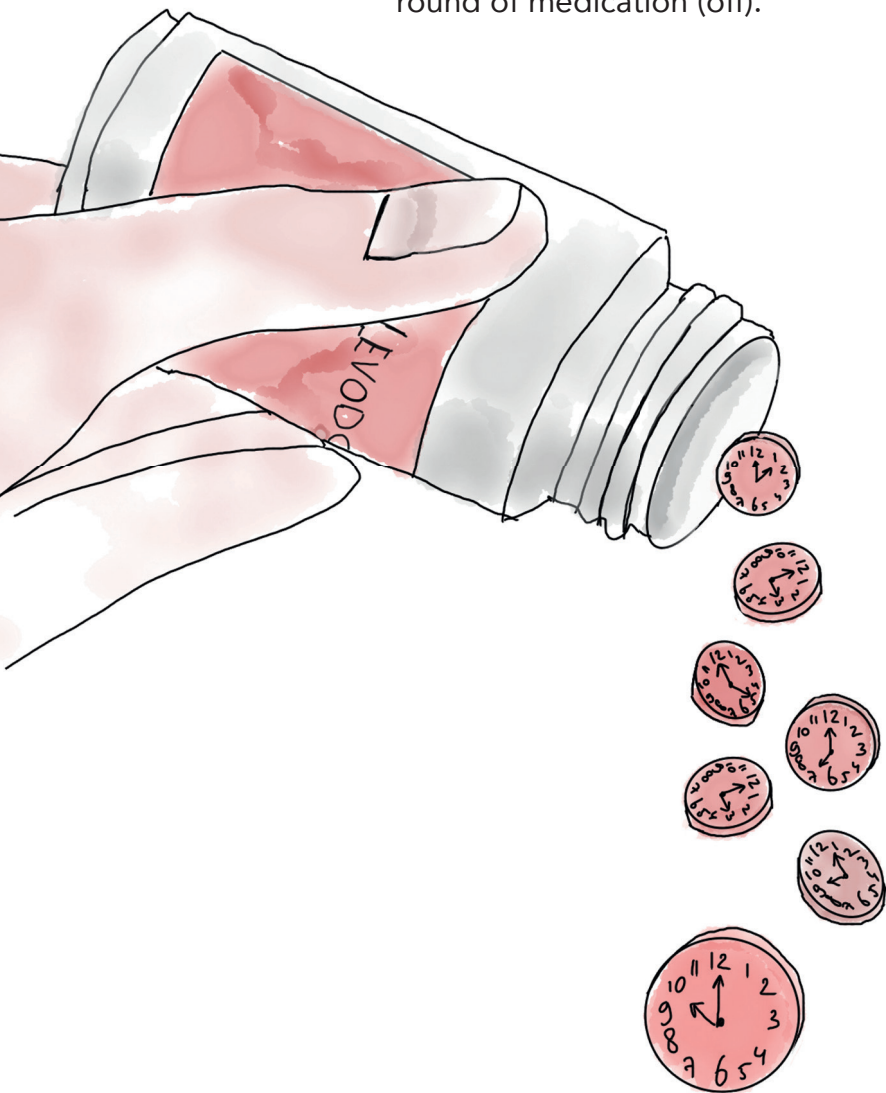


*It's easier to find detours when I'm well on the meds, slept well, don't have too much to do in one day and feel seen and supported.*

## The power of a good timing

We asked the COPIED participants what makes it easier for them to avoid obstacles or find detours. The question: "Is it a good time?" appears to be essential in this regard.

That starts with your medication. If your medication balance is fine (you're on), then some obstacles occur less than when you are almost ready for your next round of medication (off).



Both too much and too little medication can lead to lead to obstacles. Insight into the on-off moments, in your Parkinson's or that of your loved one, helps you to move along with the dopamine flow.



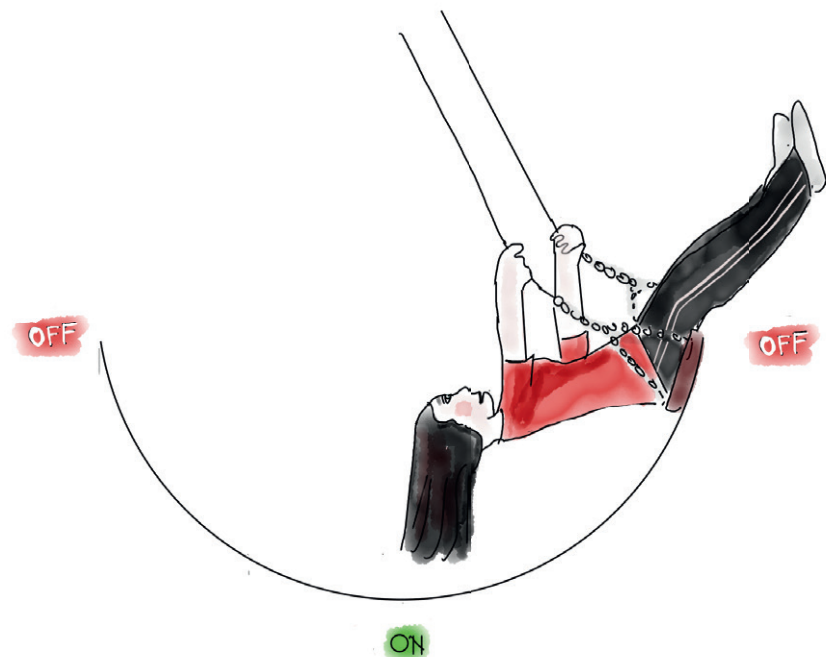
*I'll wait until the right time comes to talk about it.*



*I get an off period, my thinking skills deteriorate. I then keep calm and maybe withdraw for a while until things get better.*

## The stress paradox

With tension and stress you seem to be able to go two ways with Parkinson's. On the one hand, it can create obstacles. Your dopamine then is used up quickly and you are 'off' faster. For example, this type of stress can occur during emotional conversations, when things don't work out, when you don't feel understood or feel pressured. Then, the faster you have to go, the slower it goes. And the detour is slowing down. If you take more time, you'll finish faster.



When you are under stress, you produce adrenaline and you break down dopamine. Especially when people with Parkinson's are close to their medication moment, stress can hit them hard. The light can then suddenly go out. The unpredictability is difficult for many people with Parkinson's. After all, you can't prevent all stress around you.

On the other hand, there is such a thing as 'Kinesia paradoxa', that is "the sudden transient ability of a person with Parkinson's to perform a task that "he or she could not perform before". This is especially known for walking, where someone who cannot walk can run, for example. Or can't walk, but can if there is danger - also a form of stress. The detour actually makes the route faster than the 'normal' route that is defective in people

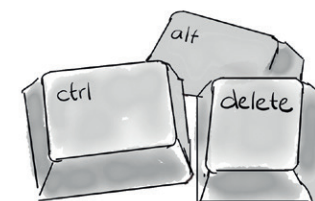
with Parkinson's. We also encountered examples of this in the COPIED data. A research participant who can no longer do his administration, but temporarily regains this skill after a burglary has taken place.



*Recently there was a break-in. Then things have to be arranged. Then he is also able to settle it well*

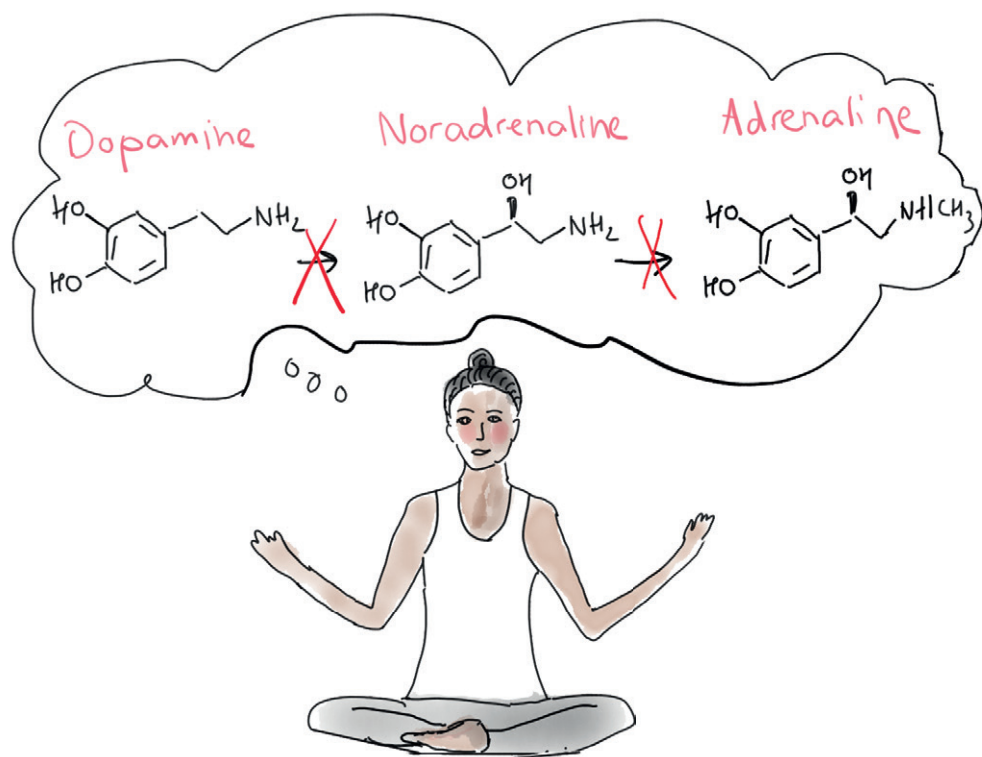
Or someone who can't concentrate but can when he hits himself and consciously 'resets' himself. Most of the COPIED participants use 'The art of resetting'. Only a small number indicate that they actually hit themselves. Instead they speak consciously to themselves. They give themselves a proverbial blow. And they 'just start over'.

Giving yourself a certain form of stress (whether or not in your mind) can therefore serve as a detour accelerator.

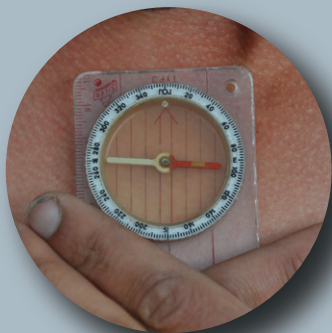


### More detour accelerators

In addition to the power of good timing and the art of resetting, the study participants mentioned other detour accelerators. We have put them side by side on pages 60-61.



# Detour accelerators



## SELF COMPASSION

“ You must also be kind to yourself. For example, you have to wait a long time, and yes, then you can also be impatient for a while.



## TIME AND SPACE

“ I have stopped working. My husband's Parkinson's was one of the reasons for that. Now I have more energy and space to fix what he cannot.



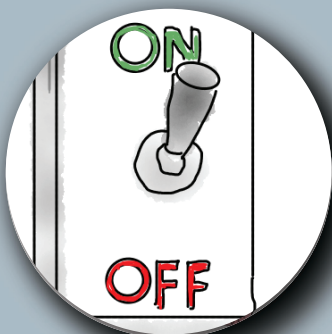
## MOTIVATION

“ I've learned to prioritize the things I must or definitely want to do when I'm functioning quite well.



## QUALITIES

“ The person diagnosed with Parkinson's goes through the same life in a different way with the same qualities. You can use those.



## MEDICATION

“ It is also really important that people record and describe their complaints very specifically, we now have other medication and he feels so much better now. I think that's underestimated.



## UNDERSTANDING

“ I am studying Parkinson's disease. That way I understand what is happening to me and I can explain it to others. Because of this I experience a lot of understanding from others.



## ENERGY

“ After an hour of exercise, my head functions better, my mood is better, my thinking is clearer, I am less sluggish, I respond faster in conversations, and so on.



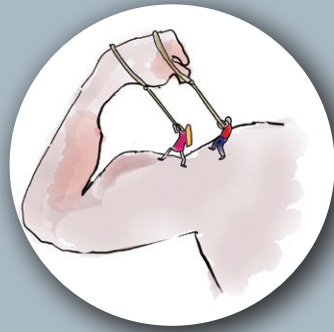
## SLEEP

“ I can only recharge during the night while sleeping.



### **SAFETY**

“ It's really about whether you feel safe enough. You can grow in that sense of security if it turns out that others appreciate your input despite your difficulty getting your points across.



### **ASSERTIVENESS**

“ You really have to stand up for yourself.



### **TIPS FROM PEERS**

“ Tips and tricks from fellow patients work 10x as well as tips and tricks from professionals. It's really different when someone who really knows what it's about gives you a tip or trick.



### **AUXILIARIES**

“ As thinking obstacles and the pressure on me increase, friends take turns taking my partner along for an afternoon. Friends happy that they can mean something, partner happy and so am I of course!



### **INSPIRATION**

“ When I have painted with a friend, I feel reborn for a moment. It give me energy.



### **SIMPLICITY**

“ With subjects that are more complex, I am much less able to keep everything "in order" than before.



### **AVOID**

“ I especially suffer from thinking obstacles when I am tired, or when sounds around me intrude. It's not continuous yet.



### **AVOID STRESS**

“ I especially can't switch gears when there is stress or emotion involved. Then I get stuck.



4.

## The road to understanding



*I long for advice on how to open up discussions to overcome obstacles in thinking with your family and environment, so that more understanding, support and recognition is possible and thinking obstacles can be taken into account.*



# Fairy tales and other metaphors

People with Parkinson's experience delays. They indicate that this makes them easily fall out of sync with their environment and it is difficult for them to explain how their clock keeps its own time.

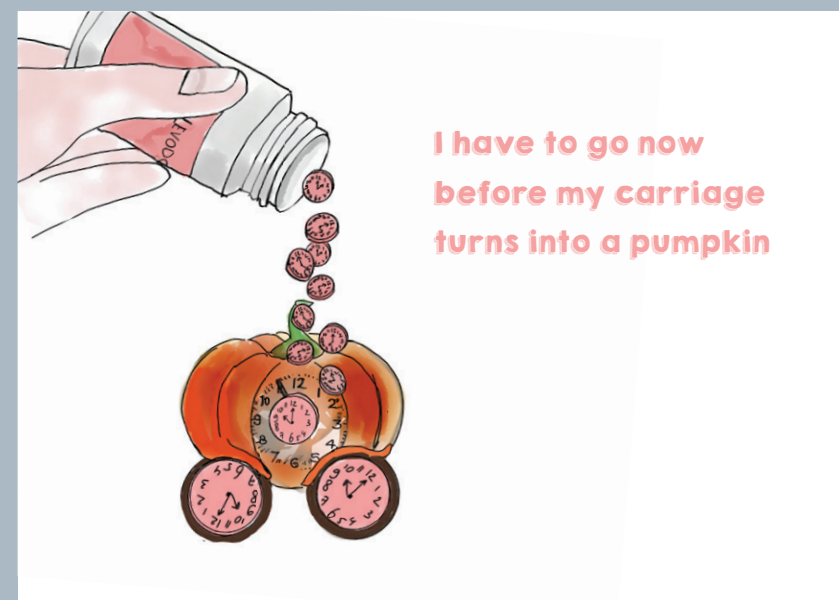
In the COPIED study, we asked whether people recognize this and if so, whether they could link a fairytale character to this image. Half of the research participants who answered this question said they did not believe in fairy tales, found the question strange, didn't know or recognize themselves in a fairy tale, were not yet bothered by time delays all too much, or because they found a detour. If you are one of them, then this page is not for you.

Of the people with Parkinson's who did see their situation reflected in a fairy tale, half recognized themselves in Alice in Wonderland, closely followed by Cinderella. Amongst the loved ones it was Alice who took the lead, closely followed by Sleeping Beauty (who has to be kissed before coming into action).

Other fairy tales in which people recognized themselves were Snow White and the Seven Dwarfs (I want harmony around me but secretly I put all dwarves to work to get everything done), Peter Pan (Like I'm floating above the meeting), Rumpelstiltskin (Nobody knows, nobody knows my name is Rumpelstiltskin), and the Princess and the pea.

People also gave other metaphors such as the sorcerer's apprentice, I'll Dolce Far Niente and the parallel universe in which a loved one has his or her own world "with hearing things and see which I perceive not."

It's not about the fairy tale, of course. It's about the metaphor that works for you. Maybe you have a movie in mind, a piece of music or something completely different with which you might give words to your thinking obstacles? Or maybe you don't feel that need at all and you can say very clearly what you need without fairies?



## The road to understanding

○ The question: “What would help you in handling thinking obstacles?” evoked the answer: understanding. Understanding the disease, yourself and that your surroundings understand you.



*I seek understanding, not help*

How can people with Parkinson’s and their loved ones explain to their surroundings what bothers them and what they need? How to start a conversation? The detours-cards in Chapter 2 may have supplied you enough food for discussions to start a talk at the kitchen table. This chapter mainly tackles how to get acknowledged in a larger circle and help re-write your “instructions”.

When you understand how your “user manual” changes it may make it easier to prevent obstacles off to choose more fitting solutions that provides your with some control. And when you know what you need, you can convey this to others. Sharing your user manual can lead to understanding.

How you gain this knowledge of yourself differs individually (person). And the time factor also plays its part. You also have to come to terms with your Parkinson’s. Acceptance time differs per person and is also a continue process as the disease progress.



*Reflection and planning together is not yet on the agenda. He finds awkward to admit... does not want to talk about it yet.*



*Only at a certain point, in retrospect, I realized that I had thinking obstacles. Despite thinking I knew a lot. If I had known this sooner, I would have tackled this earlier. So awareness is a central issue too.*



*It helps me: to gain knowledge of the disease, to follow the scientific research and to share this information.*

## Conversation starters

On the road to understanding you could use the conversation-pictures in this chapter. We will explain them on the next pages.



### **Conversation starter XV: First aid for group conversations**

As there are more factors at play that a person with Parkinson's has no influence on - such as traffic, parties and other activities that have their own pace and where things have to be done at the same time - the harder it can become to keep up with the pace. Adjusting your own pace is of course easier than changing the pace of the other. Losing the thread in group conversations may not be one of the most mentioned obstacles in people with Parkinson's and their loved ones for nothing.

We asked the research participants how their environment could help them if they lose their way in a conversation. In conversation starter XV we share the tips that the research participants have.

### **Conversation starter XVI: First aid upon misunderstanding**

People with Parkinson's and their loved ones indicate that it is sometimes difficult for their obstacles to be greeted with a "I have that too". That can be a way for your conversation partner to empathize with what it is like for you, but it doesn't always feel that way, according to the comments of the research participants. It may also feel like the other person is taking over or downplaying the issue. And in that way feels like a conversation stopper.

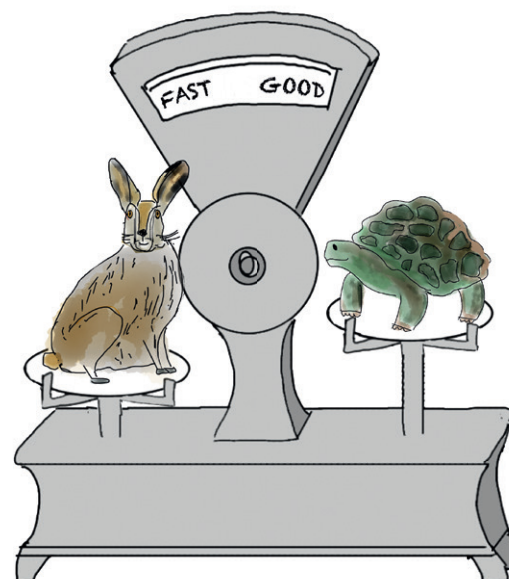
Conversation starter XVI gives a number of possible tips to increase understanding. For yourself and the other. These tips were distilled from the quotes by the principal investigator. It's her interpretation.

### **Conversation starter XVII: Parkinson's and the time benders**

Everyone has the same amount of time in a day, wouldn't you say? Yet for people with Parkinson's that may feel different. If an activity is not yet finished, their time is already up. Their time is, as it were, on receipt. To to get things done, they have to be creative with time. The image that emerged in the head of the principal investigator of the COPIED study was turned into a conversation starter in which people with Parkinson's are time benders. They always look for the balance between speed (the hare) and accuracy (the tortoise).

If they choose the tortoise, they spread out an activity over a longer period of time. This is easier if you can do an activity on your own and if things can be done one after the other. If they opt for the hare, they will go along with the other person's pace or that of the past. This can lead to errors that you can correct as a time bender. For example, by preparing the task, correcting things afterwards or coming back to something.

If this metaphor resonates with you, then conversation starter XVII may be a means for you on the way on the road to understanding.



### Conversation starter XVIII: Hand out your user manual

This conversation starter is the user by handing out the manual by means of the six cards that go with this book (the printed version, that is). It is a first modest elaboration of the wish that we have seen several times in different guises: Can you develop something that we can literally hand out to facilitate understanding?



*I would like to be able to give something to my environment so that they quickly, in a playful way, better understand what people with Parkinson's disease in general deal with and what I specifically run into myself. And that is also a reminder for myself.*



Got stuck in your train of thoughts?  
Cannot get started or cannot stop?

Recipe to unfreeze

Cognitively



A **llocate sufficient time. Plan ahead.**

B **reak down the task in smaller steps.**

C **oncentrate**

D **ual tasks? Avoid at all times**

E **xternal cues** (use an agenda, set an alarm, ask others to help,



## The road to understanding First aid for group discussions

### XV

#### CHALLENGES IN GROUP DISCUSSIONS

Having a fruitful group conversation when you have Parkinson's comes with a number of inter-related challenges.

A number of factors that may play a role are shown on the right.

#### VOICE

Parkinson's disease may soften the volume of your voice. You can also suffer from swallowing disorders. Of course, that does not promote good communication. If this is a challenge for you in group conversations, you may be referred to a speech therapist

#### BODY LANGUAGE

Less exuberant body language and facial expressions can prevent people with Parkinson's from drawing attention to themselves if they want to. It can also lead to difficulties in interpreting intentions for your conversation partner. If this comes into play, then you could delve into the power of mirroring.

#### THINKING OBSTACLES

Word finding problems and problems with structuring a conversation is what we mean by thinking obstacles that are central to the COPIED study. Difficulty finding a word can make conversations more difficult and exhausting

#### FATIGUE

Fatigue can be a major reason for not actively participating in social interaction and conversation. People make a personal decision as to whether they find it worthwhile to participate and otherwise consciously keep quiet

#### RELATIONSHIP TO ONE'S PARKINSON'S

How you think about your Parkinson's, how you think about yourself, partly determines what you allow yourself in a group conversation. Changes in your ability to express yourself affect your self-image. Your conversation partner usually only checks whether he understands you and does not see the possible underlying dent in your self-confidence if you do not tell them about it. The more comfortable you are with your illness, the better you will be able to share your instructions for use

#### RELATIONSHIP TO CONVERSATION PARTNER

In general, people with Parkinson's find it easier to have conversations with people they know and who are familiar with the consequences of the disease than with strangers

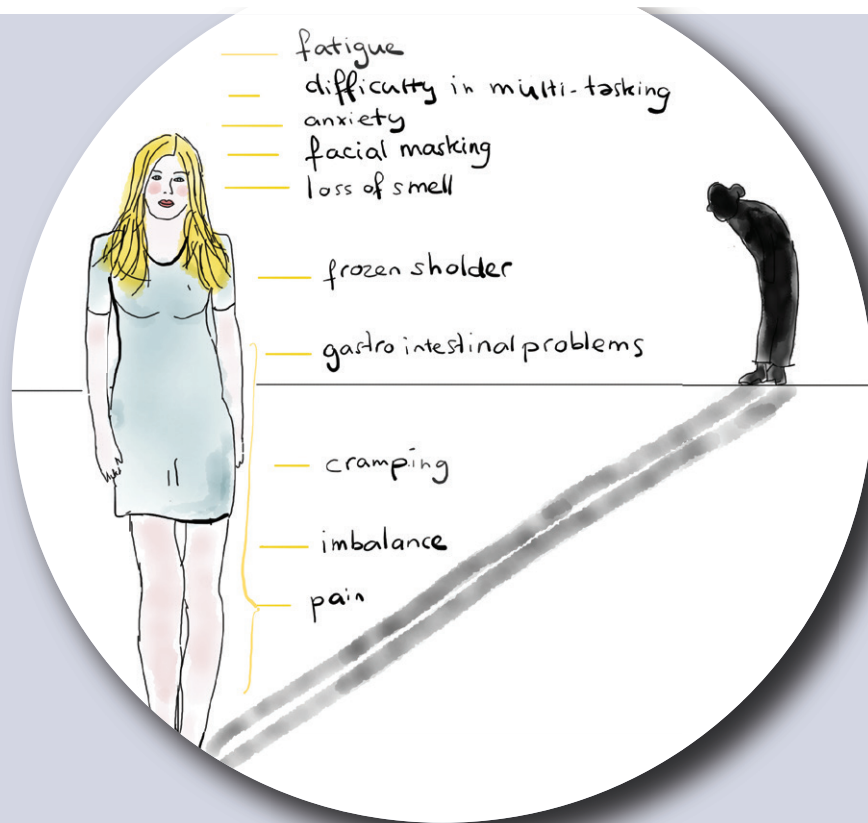
**Source** Johansson, I.-L., Samuelsson, C., & Müller, N. (2019). Patients' and communication partners' experiences of communicative changes in Parkinson's disease. *Disability and Rehabilitation*, 1-9. <https://doi.org/10.1080/09638288.2018.1539875> (Open Access).







Very often I am told: "Yes, I have that too, that is part of getting older". It is sometimes difficult to explain that it is really different. And at the same time to prevent those around you from thinking that you no longer have it all in order, that you become dumber.



\*The symptoms in the illustration are only exemplary.

## FACTORS THAT COMPLICATE UNDERSTANDING

### ■ INVISIBILITY

Parkinson's involves an unpredictable body with a multitude of varying symptoms. As a result, someone with Parkinson's has to deal with a changing self-image. The moment you pick out a symptom - a thinking obstacle - to talk about, you are actually also talking about the relationship of this obstacle to your Parkinson's. Another may also experience the thinking obstacle, but if he/she doesn't have Parkinson's, you're actually not talking about the same thing. An 'I have that too' then simply is not correct. This does not mean that you cannot still exchange detours together off course



What particularly bothers me is that - for the outside world, but also for loved ones close to me - many obstacles in thinking are often invisible and difficult to understand.

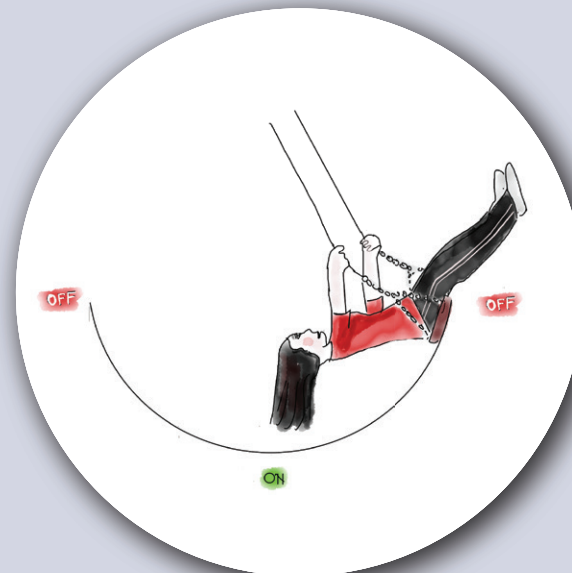


### ■ PROBLEMS SWITCHING

Switching problems can make it difficult to deal with misunderstanding or resistance during a conversation. By anticipating this, visualizing all the obstacles on the way to understanding, envisioning the conversation as best you can, you are more likely to get what you hope for



I can switch less quickly, and less quickly tell my story adequately. I find that frustrating.



### ■ UNPREDICTABILITY

People with Parkinson's have to constantly adapt, all the more so because the symptoms can change within minutes. Sometimes you can, sometimes you can't. By Parkinson's himself. And because of the interaction with the medication cycle. That can be confusing for people with Parkinson's themselves and certainly does not make it easier to understand



The symptoms vary a lot per day or subject and I never get used to that!



# The road to understanding Parkinson's and the timebenders



## XVII

Research participants indicate that the clock in their world has a different time. People with Parkinson's have to play with the time they have. Because on average it takes them longer to get things done, you could say that they have less time available per day compared to their healthy peers. If the activity isn't finished yet, their time is already consumed. Their time is, as it were, on receipt. In order to get things done, they are busy in all sorts of creative ways to bend time. This image led to this conversation starter in which people with Parkinson's are time benders.



### MAINTAIN SPEED

People choose to participate at the pace of the other. They choose speed over accuracy. To this end, they have to accept that they make mistakes, do not get everything and possibly lose the connection with others

#### PROCEED

If you're not fast enough, you can just proceed. For example, if you cannot find a word, but you want to keep up with the pace of the conversation, you replace word A for word B. Or you only listen to part of the question/assignment and then give a (wrong) answer, etc.

#### PRETEND

You think or pretend you can keep up with the other's pace



### BEND TIME

Space is made for the slowing pace, left, right and centoe, by timebending or less time input into the activity, by stripping/ lesseningβ reducing the activity. All for the purpose of performing the activity as its best.

#### FREEZE TIME

Take a moment to do something right away and give it your undivided attention

#### BORROW TIME

Borrow time you don't have and pay it back later with interest (a payback day)

#### SPREAD TIME

Take more time to do something (e.g. repeating yourself to remember something)

#### MOVE TIME

Ask for a postponement or take a time-out

#### STRIP

Omit certain aspects from an activity. For example, company, but not many people or less long, without the music. Etc.

#### HOARD TIME

Prepare, structure, cut into pieces, visualize or create mnemonics for the task in advance in such a way that you are/seem less affected by the delay during the activity itself

#### ESCAPE

Here it is no longer possible to participate and/or someone does not think it is worth it (any longer) and drops out

#### ADJUST

Adjust your input to the activity, for example by listening only or asking questions instead of talking

#### PRIORITISE

Exchanging one activity for something completely different where the delay (at that time) occurs less or where someone doesn't mind slowing down less

#### POSTPONE

Doing things you didn't have time for during the activity after the activity (checking spelling for example)



It is also interesting that a kind of 'no longer coinciding with time' occurs. There is a problem and you have to go back to the past to solve it or plan for your future self not to get into trouble. As a person with Parkinson's, you end up in a parallel universe, in which your time does not coincide with the time of the people around you | Marina Noordegraaf, in the notes to the data analysis



**EXPAND TIME**

In order to not have to choose between fast or good, someone 'delegates' (part of) his/her delay to the other or to a device such as an alarm.



**USE A DETOUR SWITCHER**

The so-called detour switchers make it possible to try out a new detour where time is on your side more



**SAVE TIME**

People deposit into the time savings account and extend the time that they can be actively involved with something after or before

**DEPLOY**

Outsource part of the task to a tool, e.g. an alarm to remember medication

**GIVE SUBTITLES**

Explain how cognitive obstacles work in Parkinson's, explain the rules of the game and thus give others the opportunity to slow down

**OUTSOURCE**

Have someone else do the task

**ASK FOR HELP**

Ask someone's help to assist with (part of) the task

**RECOGNISE**

Recognising and acknowledging what is, creates space for the delay exactly as it is

**RESET**

Reset yourself, for example by physically slapping yourself or speaking to yourself

**REFLECT**

Pause and then see what happens to find new detours

**GET TO KNOW YOUR DISEASE**

Getting to know your disease makes it possible to take new detours that actually work

**LEARNING FROM OTHERS**

Discovering new detours through the feedback from others

**MOVE**

Exercising, dancing, being physically active helps to ease the delay

**MEDICATION**

Taking the medicines on time ensures that you avoid time shrinkage

**LOOK AT THE BRIGHT SIDE**

For example, if you manage to enjoy the things that do work and if you manage not to be so hard on yourself, you add time into the time savings account

**SELFCARE AND STRUCTURE**

Sleeping and eating well, not too much stimuli and a fixed structure keeps the delay in check

**GOOD COMPANY**

Feeling understood relaxes and leads to the production of dopamine. Time slows down

**TO BE IN DEBTS**

Consciously using time benders becomes more difficult the more your time savings account is 'in the red'. The following aspects are associated with a rapidly depleting time savings account and are often the counterpart of time savings



**FATIGUE**

Fatigue from poor sleep or energy-guzzling activities

**BAD SELFCARE**

Not taking medicine on time, eating poorly, not exercising, etc

**UNKNOWN TERRITORY**

Getting stuck due to unexpected and new situations and environments

**EXTERNAL STRESS**

Being distracted and stressed by stimuli in the environment, by multiple things happening at the same time, people talking at the same time, time pressure, etc.

**COMPLEXITY**

Difficult tasks that consist of many sub-steps or where several things have to be done at the same time

**INTERNAL STRESS**

Delay due to one's own emotional response (fear, feeling guilty, etc.), strict norms and values about how it should be and/or incomprehension from the environment

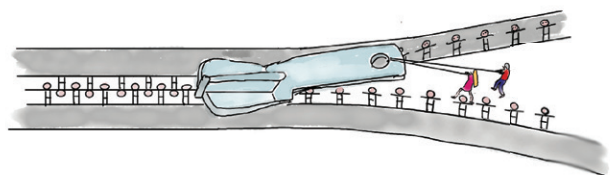


## The road to understanding Hand out your user manual

XVIII

The cards you receive with this book are a first modest elaboration of the wish that we saw several times: Can you develop something that I can give to my environment to facilitate understanding? The six cards combine an image with an explanation and/or request. Below you can see two examples. Have you handed them all out? You can download and print them from [www.copiedstudie.nl/cards](http://www.copiedstudie.nl/cards) or reorder the printed cards from <https://detours-parkinsonian-brain.com>

### Could you, please, slow down with me?



### Could you, please, slow down with me?

I have Parkinson's disease. I miss more than 70% of the brain cells that produce dopamine. This slows down my speed of thought and actions.

It means I sometimes cannot keep up with you. Before you know we are drifting apart and we talk past each other.

When this occurs could you please slow down with me till we are back to a joining point and pick up from that point?

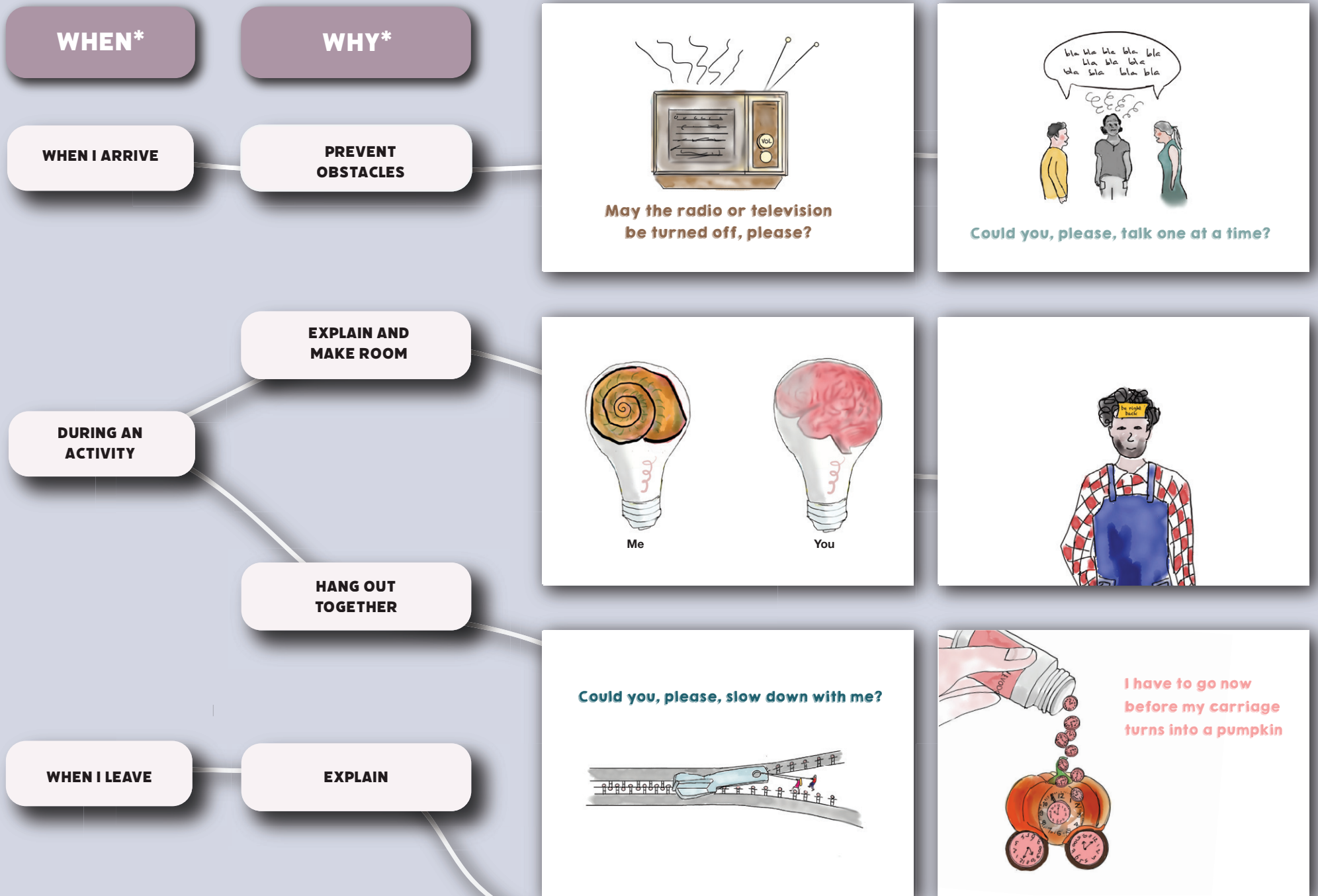
Running out of cards? Download them from [www.copiedstudie.nl/cards](http://www.copiedstudie.nl/cards) or reorder the printed cards from [detours-parkinsonian-brain.com](http://detours-parkinsonian-brain.com)



### Back in a Jiffy

Please be patient. I have Parkinson's disease. I am missing over 70% of the braincells that make dopamine. This causes obstacles in my thinking, like now. I need some space/ time to be able to reconnect.

Running out of cards? Download them from [www.copiedstudie.nl/cards](http://www.copiedstudie.nl/cards) or reorder the printed cards from [detours-parkinsonian-brain.com](http://detours-parkinsonian-brain.com)



\* Which card do you hand out when? Here you are given an idea.



# 5.

## Q&A

In this chapter Odile van den Heuvel, Annelien Duits, Rick Helmich, Ingrid Sturkenboom and Jorik Nonnekes answer a number of questions from research participants of the COPIED study.

## Q&A with the neuropsychiatrist **ODILE VAN DEN HEUVEL**



*Prof. dr. Dr. Odile van den Heuvel is a psychiatrist and professor of Neuropsychiatry at the Vrije Universiteit and Amsterdam UMC in the Netherlands. In 2010, she founded the Center for Neuropsychiatry, where people with Parkinson's and psychiatric complaints are treated.*

### **What does a neuropsychiatrist do?**

As a psychiatrist, I try to bridge the gap between the patients' daily experiences on the one hand and neurobiological research on the other. I look at my patients' problems, which are often complex in nature, from different points of view: the individual experience, the social context, the physical possibilities and limitations, the possible neurobiological explanations from the brain research, and thus try to work with the patient and other involved practitioners to come up with a treatment plan.

### **Are obstacles in thinking part of Parkinson's?**

Problems with thinking are already present in about a quarter of people with Parkinson's at the time of diagnosis. Then the problems are usually still subtle, but as the disease progresses, they can lead to obstacles that are measurable in a neuropsychological test.

### **Which thinking obstacles are common?**

The cognitive problems in Parkinson's are mainly associated with the so-called executive functions, especially in the early stages of the disease. Executive functions include planning, working memory, flexibility and the ability to suppress impulses. In addition, it often happens that people with Parkinson's have problems with processing speed, attention, memory and maintaining overview.

What obstacles someone experiences differs greatly from person to person. The transition from mild cognitive impairment to dementia is characterized by such severity of the obstacles that they severely impair a person's daily activities.

### **When is it Parkinson's and when is it age?**

Cognitive problems are not always a direct result of Parkinson's disease. First of all, with age, thinking slows down in almost everyone and the ability to learn and memory decreases.

If you have thinking problems related to Parkinson's, the decline is greater than would be expected based on your age and education level.

### **Will I get Parkinson's disease dementia?**

The honest answer is: We don't know. No one can see into the future. However, studies on the long-term course of



the disease have shown that about 80% of people with Parkinson's develop dementia after ten to twenty years. This also applies to people who do not yet experience any thinking problems at the time of diagnosis.

### **Could obstacles in thinking also be caused by something else than Parkinson's?**

Yes absolutely. It is very important to identify possible treatable causes. If you suffer from depression, anxiety or other psychiatric symptoms, this can also lead to problems with attention, memory or thinking speed. After treatment, the thinking functions may also recover.

Your Parkinson's drugs and any sleeping pills can also lead to reduced mental clarity and problems with thinking.

### **Is Parkinson's disease dementia (PDD) the same as Lewy Body dementia (LBD)?**

No. In both diseases researchers do find so-called Lewy bodies in the nerve cells of the brain during autopsy. These are protein deposits. The difference between the

two is mainly in the course of the disease. When you develop dementia symptoms before or within one year after you developed the motor symptoms, it is called Lewy Body dementia. If you only get symptoms of dementia later in the course of Parkinson's disease, at least 1 year after the onset of the motor complaints, this is called Parkinson's disease dementia. The diagnosis is therefore currently mainly based on the sequence and timing in which you develop certain symptoms. Whether the 1-year rule is also a biologically valid distinction or whether there are subtypes on a continuum of Lewy Body disorders is the subject of research.

### **Can I also get Alzheimer's disease?**

Unfortunately, people with Parkinson's disease are not protected against developing other diseases, and apart from Parkinson's disease, there can also be another type of dementia, for example due to vascular damage (this is called vascular dementia) or Alzheimer's disease.

The profile (as measured by neuropsychological examination) and the course over time can often make clear what type of dementia it is. Colleague Dr. Annelien Duits tells more about this on the following pages.

#### **More info**

Weil, R. S., Costantini, A. A., & Schrag, A. E. (2018). Mild Cognitive Impairment in Parkinson's Disease-What Is It?. *Current neurology and neuroscience reports*, 18(4), 17. <https://doi.org/10.1007/s11910-018-0823-9> (Open Access).

Aarsland, D., Batzu, L., Halliday, G.M. et al. (2021). Parkinson disease-associated cognitive impairment. *Nat Rev Dis Primers* 7, 47 <https://doi.org/10.1038/s41572-021-00280-3> (Open Access).





## Q&A with the clinical neuropsychologist **ANNELIEN DUIITS**

*Dr. Annelien Duits works as a clinical neuropsychologist and UHD (associate professor) at the Departments of Medical Psychology at Maastricht UMC+ and Radboud university medical center in Nijmegen in the Netherlands. She combines patient care and research within both institutions. Themes in her scientific research are behavior and cognition on the one hand and psychosocial interventions on the other hand of patients with movement disorders and in particular people with Parkinson's disease.*

### **What does a clinical neuropsychologist do?**

A clinical neuropsychologist is concerned with the cognitive, emotional and behavioral consequences of brain disorders. He or she combines a role as practitioner with that of conducting research and developing and disseminating new knowledge and policy.

### **Are thinking obstacles measurable?**

Obstacles in thinking are known as “subjective” cognitive problems. It is about the hindrance that a person him- or herself experiences.

Objective cognitive problems are obstacles in thinking that are measured on a neuropsychological examination. With objective problems, your test scores deviate from performance of healthy peers with similar education. We then call this a cognitive impairment.

Subjective problems in thinking can also be measured. This is then done, for example, through self-reporting. But it is still about the problems that someone indicates themselves, as in the COPIED study.

### **What is the relationship between obstacles in thinking and cognitive impairment?**

There is much debate in the scientific literature about the relationship between subjective thinking obstacles and objective cognitive impairment. It is not self-evident that what is measured corresponds to what people themselves experience and vice versa. Yet there is indeed a relationship between the two.

If a neuropsychological examination shows that there is a problem with remembering, this appears to have a predictive value for experiencing obstacles in thinking. This is much less the case with objectively observable impairments in planning, starting, stopping and spatial orientation.

Conversely, there are studies that show that having subjective symptoms predicts a transition to cognitive impairment, but there are also studies that do not. It has also often been shown that thinking obstacles are actually associated with psychiatric symptoms such as anxiety and depression.

That thinking obstacles are common in Parkinson's disease, even in the early phase, is not in dispute, but they do not necessarily accompany or transition into cognitive impairment!

### **What is the added value of a neuropsychological examination?**

To give people with obstacles in thinking insight into the nature of their symptoms, a neuropsychological examination can be helpful.



With a neuropsychological examination you map out different cognitive functions. These include memory, concentration, work pace, language, visual-spatial understanding and so-called executive functions such as planning and problem solving. You carry out assignments, the test part, and you fill in a number of lists that ask about your mood and the impact of the the obstacles on your daily life.

The results of the test indicate whether there are any cognitive impairments and provide insight into a person's strengths and weaknesses. With that information, neuropsychologists provide tailored advice such as cognitive training, a tailored detour or, on the contrary, treatment aimed at anxiety symptoms.

Often the insight obtained is sufficient and - with appropriate advice and (restored) confidence in their cognitive functioning - people can move on.

### **Can neuropsychological testing help distinguish Parkinson's disease dementia (PDD) from Lewy Body Dementia (LBD)?**

The difference between a Parkinson's disease dementia and Lewy Body Dementia cannot really be made on the basis of a neuropsychological examination. However, the neuropsychological examination is necessary to make the

diagnosis of dementia. The distinction between mild cognitive impairment (MCI) and dementia is mainly about the severity of the obstacles in thinking and their impact on daily life. If there are cognitive disturbances in multiple areas and a person can no longer function safely and independently we speak of a dementia.

The distinction between LBD and PDD is currently made on the basis of the disease course. If there is evidence of dementia early in the course of the disease (within one year after the diagnosis of parkinsonism) we speak of LBD. Severe visual hallucinations and strong fluctuations in vision support the diagnosis of LBD.

### **When and to whom do you refer?**

If the disorders are so severe that it could fit a dementia we refer to the neurologist or psychiatrist. For severe mood symptoms we refer to the psychiatrist. For additional advice in the home situation, applying structure such as making a daily schedule, using tools and learning cognitive strategies, we often refer to occupational therapy. Especially when assessing whether someone can function safely at home, we cannot do without an assessment by the occupational therapist.

#### **More info**

Pan C, Ren J, Hua P, Yan L, Yu M, Wang Y, Zhou G, Zhang R, Chen J and Liu W. Subjective Cognitive Complaints in Newly-Diagnosed Parkinson's Disease With and Without Mild Cognitive Impairment. *Front. Neurosci* (2021) 15:761817. <https://doi.org/10.3389/fnins.2021.761817> (Open access)

## Q&A with the neurologist **RICK HELMICH**



*Dr. Rick Helmich is a neurologist at Radboudumc in Nijmegen and a researcher at Donders Institute for Brain, Cognition and Behaviour in Nijmegen in the Netherlands. There he is researching, among other things, the effect of psychological stress on parkinsonian symptoms such as tremor, involuntary movements and the 'freezing of gait'. He investigates at the brain level which mechanisms are involved.*

**You are doing research on stress\* and parkinsonism. The research participants of the COPIED study indicate that stress is a huge trigger of thinking obstacles. Can you explain that?**

Increased stress sensitivity is largely due to Parkinson's disease itself, probably because the lack of dopamine and perhaps serotonin which makes it harder to control a situation properly and quickly. Things don't happen as you want or expect, and that can lead to stress and an increase in Parkinson's symptoms. This is almost immediate: for example, tremor is a visible barometer for stressful situations for many people.

The annoying thing is that an increase in parkinsonian symptoms can also lead to an increase in stress again. In this book, that's called obstacle domino. It can then help to become aware of this stress response. Relaxation exercises and mindfulness can be ways to stand next to those dominoes and reduce stress. Another detour that comes up a lot in this book is a time-out: starting all over again after hitting the stop button.

*\*Stress is a reaction in the body associated with mental tension and physical sensations, such as increased heart rate, sweating, restlessness.*

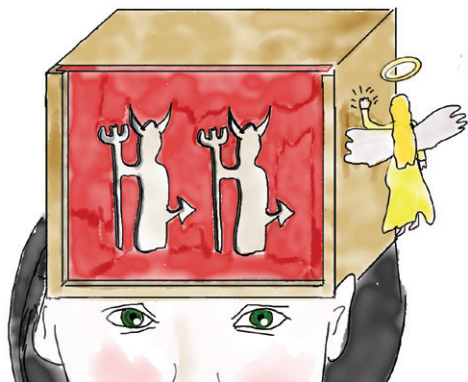
**Being understood seems extra important for people with Parkinson's. Could that be because dopamine is released when you feel understood?**

To my knowledge, this has never been studied directly. What is known is that rewarding circumstances produce a dopamine spike, while disappointing or punishing circumstances produce a dopamine dip. This also applies to people with Parkinson's disease, who have less dopamine. In addition, what is known is that "rewarding circumstances" can be very broad. So social interactions can also have an impact on the dopamine system. In other words, not only things like good food or sex are rewarding, but also a good conversation, a hug, or feeling understood. If people with parkinson's don't feel understood, I can imagine that this feels like a "punishment," which is accompanied by a dip in dopamine.

**People with Parkinson's are more sensitive to learning from punishment than from reward. Why is this?**

For learning new behaviors, or new skills, both forms of learning (from reward and from punishment) are important. Being told that you are doing something right (reward) can be an incentive to do it that way again next time, but being told that you are doing something wrong (punishment) can also be an incentive to do it differently next time or to avoid doing it.

That people with Parkinson's learn more easily from punishment than from reward is because the dopamine deficiency in the brain makes it more difficult to make a dopamine spike, which is necessary to learn from reward. Incidentally, this learning process is influenced by medication.



### **Could this explain why being understood is so important for people with Parkinson's? Once they have a negative experience, are they less likely to try again?**

Yes, that's possible. If people with Parkinson's get a "sense of punishment" when they are not understood, there is a chance they will drop out of a conversation next time. Moreover, lack of understanding can also lead to stress, which makes the symptoms worse. We are currently doing research into resilience: how we can strengthen it in people with Parkinson's disease. It appears that an optimistic attitude to life plays a role. What meaning do you give to a negative or stressful event?

It might help to be aware of the effect of being misunderstood, but not to let it get you down. Positive social interactions can be extremely rewarding, and contribute to a better quality of life and fewer Parkinson's symptoms. A negative experience does not mean that things will go the same way next time.

Sometimes it helps to say things out loud. Stiff muscles in the face, for example, can make it harder for others to read emotions from the face of someone with Parkinson's disease. If people don't know that, they may interpret the facial expression of someone with Parkinson's as indifferent or even angry.

In addition, perhaps being understood begins with understanding yourself. It is important to realize that thinking obstacles are not "between the ears". The distinction between "mental" and "physical" symptoms is actually hard to make in Parkinson's disease. Ultimately, they are all brain processes that are influenced by substances such as dopamine.

### **Motivation gets people moving. Can you explain that?**

Motivation, and the "flow" feeling, is a special combination of liking something and having the concentration to be completely absorbed in it. Among other things, dopamine is released in the process. In a very large study, we asked 5000 people with Parkinson's what kind of circumstances influence their symptoms. The result is that things like stress worsen Parkinson's symptoms considerably, but that doing things you enjoy can improve the symptoms. What kind of things those are is different for everyone.

My advice is to look for things that make you feel "on", which put you in a flow. Then the Parkinson's symptoms will also be less! It also helps to avoid things that cause stress. This is beautifully illustrated in a film by René van Helsdingen, who has Parkinson's himself. Zie <https://www.youtube.com/watch?v=TqRNsE7v72Y>.

#### **More info**

Van der Heide, A., Meinders, M. J., Speckens, A., Peerbolte, T. F., Bloem, B. R., & Helmich, R. C. (2021). Stress and Mindfulness in Parkinson's Disease: Clinical Effects and Potential Underlying Mechanisms. *Movement disorders : official journal of the Movement Disorder Society*, 36(1), 64–70. <https://doi.org/10.1002/mds.28345>

Van der Heide, A., Speckens, A.E.M., Meinders, M.J. et al. Stress and mindfulness in Parkinson's disease – a survey in 5000 patients. *npj Parkinsons Dis.* 7, 7 (2021). <https://doi.org/10.1038/s41531-020-00152-9>



## Q&A with the occupational therapist **INGRID STURKENBOOM**

*Dr Ingrid Sturkenboom works as an occupational therapist and researcher at the Radboud university medical center in Nijmegen in the Netherlands. Her expertise lies in the field of allied health care in Parkinson's disease. In her work she combines research, quality improvement projects, teaching and patient care.*

### **What does an occupational therapist do?**

In Parkinson's, problems with movement, cognition (thinking) and/or fatigue can hinder the performance of activities. An occupational therapist helps people to increase their own capabilities so they can perform their daily activities more easily or more independently. Here, you can think of organizing your household, traveling by bus, doing work tasks and cooking a meal.

Based on conversation and observation, the occupational therapist will determine where the problems and possibilities lie, what the underlying factors are that influence this and what the wishes and possibilities are for improvement. The occupational therapist will then use coaching, advice and training to work with you practically, usually in your own living or working environment. This professional can also advise your loved ones on how they can practically deal with the obstacles experienced, for you and for themselves.

### **Can you give an example of how an occupational therapist helps alleviate an obstacle in thinking?**

Absolutely. I like to do that using a concrete situation. Karel has difficulty cooking a hot meal. The obstacle in thinking that occur when Karel cooks a meal is

difficulty in keeping an overview of the various tasks that need to be done. As a result, cooking takes a long time, something sometimes burns and dishes are not ready at the same time. The occupational therapist helps Karel to break down the entire cooking activity into steps. Together they then look at what the handy sequence is and how he can prevent tasks from having to be done at the same time. For example, by separating the cold preparation from the cooking itself and first getting everything ready that is needed. The use of the step-by-step plan is trained and Karel also learns to include regular moments of check during the cooking process.

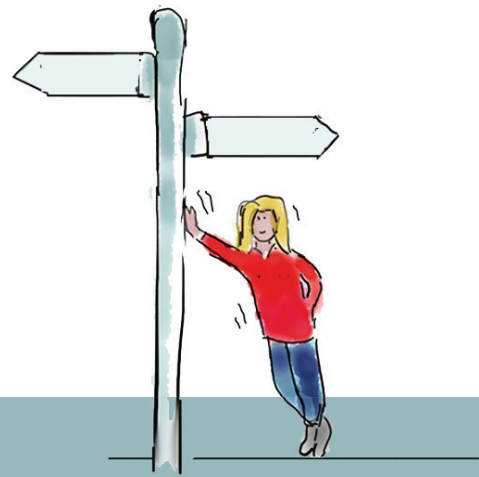
### **Can I avoid obstacles in thinking?**

There are no known ways yet to prevent decline in thinking in Parkinson's. What is known is that sufficient exercise and staying socially and mentally active are good for the brain and thinking. Possibly this can slow down decline.

You can, however, alleviate the perceived thinking obstacles. That's what the detours in this book are for. Further, it appears to be easier to avoid obstacles or make up detours when you are well medicated, rested, and when you feel understood by others. You'll find more information about that in Chapter 3 of this book.

### **Who do I report to when I experience thinking obstacles?**

The moment you experience changes in your thinking in your daily activities, or are worried about it, it is good to report this to your neurologist. Parkinsonin's nurse etc. Together with you and your loved one, they can determine whether these symptoms are consistent with Parkinsonism and whether adjustment of medication may be advisable.



They also have a good overview of the other healthcare professionals you can turn to for even better identification and relief of thinking obstacles.

### **To whom does the neurologist or Parkinson's nurse refer when?**

In the Netherlands: The speech therapist comes into the picture when obstacles in thinking affect speech. Psychology and social work can also offer support in dealing with the consequences of Parkinson's disease. A neuropsychologist can objectify the obstacles in thinking that you experience with a neuropsychological test. Dr. Annelien Duits already told us about this. The neuropsychiatrist can advise if there is an underlying depression or anxiety symptoms. The occupational therapist helps to further identify the obstacles in thinking that you experience in your activities and the detours that are most appropriate for your personal situation.

Care providers affiliated with ParkinsonNet are specifically trained in the field of parkinsonism.

### **I see nice detours in this book but when it comes down to it, I don't manage to apply them. Now what?**

A different approach often means doing things differently than you are used to. Breaking habits and doing things

differently is not always easy. Nor is it always clear exactly which approach fits you and your situation.

Not being able to get started (even with a detour) is, of course, one of the obstacles in Parkinson's. If that's where you could use some support in devising and applying detours in your daily life, you can consult the occupational therapist.

## Q&A with the rehabilitation physician **JORIK NONNEKES**



*Jorik Nonnekes is rehabilitation physician at the Radboud university medical center and in the Sint Maartenskliniek in Nijmegen in the Netherlands.*

### **What is the relationship between freezing of gait\* and thinking obstacles?**

This is a very interesting question that can be answered in several ways.

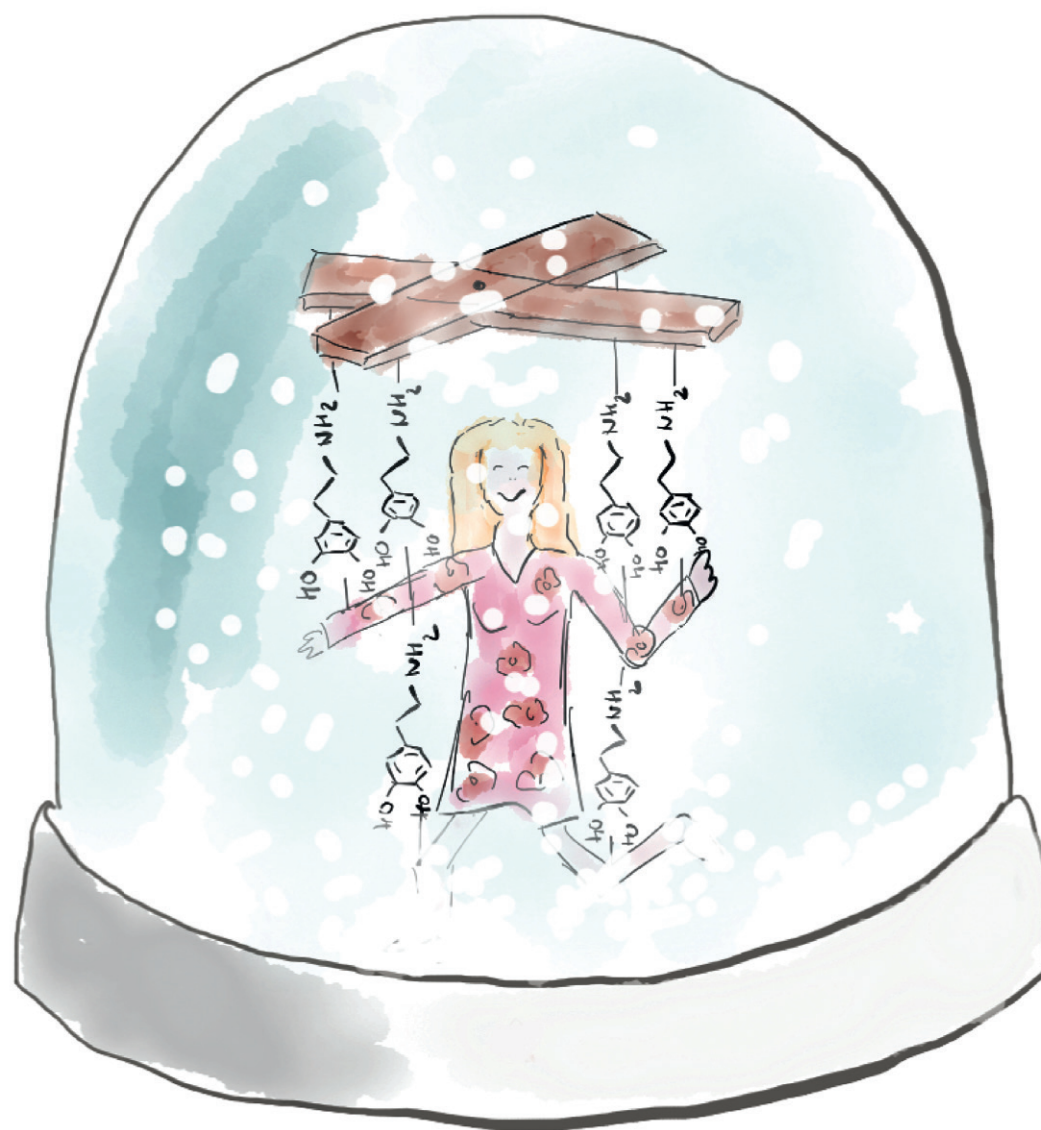
We know that thinking and moving are very much intertwined; people with severe cognitive problems walk differently, for example, than people without problems in thinking. People with Parkinson's who have difficulty to switch gears - one of the obstacles that people mention a lot in the COPIED survey - are more likely to suffer from freezing of gait. And finally, people with Parkinson's often apply cognitive strategies - detours - to walk better (e.g., thinking of a pleasant situation such as a sunny beach or avoiding a cognitive double-task).

For both 'cognitive freezing' and freezing of gait, we do not yet know exactly what goes wrong in the brain. What we do know is that both thinking and walking are not controlled from one place; an entire brain circuit is involved. To make it even more complex, you can control walking from multiple brain circuits, and probably this is the same for thinking. I expect compensation strategies (or detours) to take advantage of these variations. At brain level, a detour is literally chosen!

*\* Freezing of gait is the feeling that your feet are glued to the ground.*

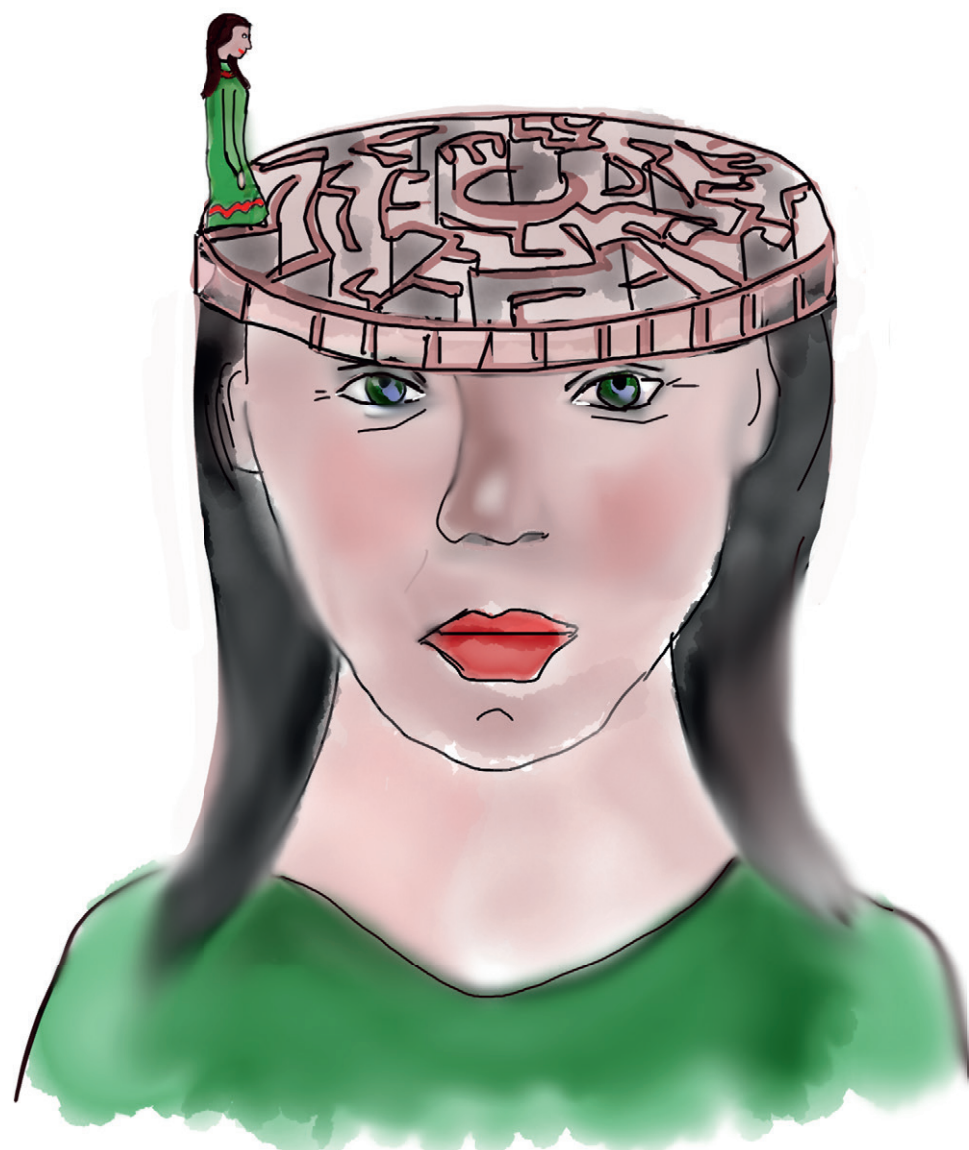
### **Sources**

*Morris, R., Smulders, K., Peterson, D.S. et al. (2020). Cognitive function in people with and without freezing of gait in Parkinson's disease. npj Parkinsons Dis. 6, 9. <https://doi.org/10.1038/s41531-020-0111-7> (Open Access);*





**What would really help me is  
an ability to open the closed doors  
in my mind whenever I want to**



6.

## Darling detours



*Every obstacle and detour does bring about a conversation. Conversations about the view on the quality of life , and what really matters. These conversations help to bring love.*

## Darling detours

“What is your favorite detour?” we asked the COPIED research participants as one of the final concluding questions of our questionnaire survey. 287 people with parkinson’s and 80 relatives sent in their darling detours.

The question about a person’s favorite detour was not linked to a particular thinking obstacle. Instead, it was about harvesting those detour that comes to mind first. That are on the tip of the tongue. Close to the heart.

### The cherries on top of the cake

In this chapter we have compiled quite a few of the submitted favorite detours.



Three pages full of those from loved ones and six pages full of those from people with Parkinson’s. It is striking that many favorite detours are about seeking connection. With yourself, with each other, with the disease, with peers. For us, these are the cherries on top of the cake.

If you look at the favorite detours, you may see your own amongst them. Or maybe you will see one that could have been yours. And who knows, maybe the detours of your peers will inspire you. Or they may lead to a nice conversation.

### Closing the loop

It is far from self-evident that research participants get feedback on the input they have provided to a scientific study. Quite wrongly, of course!

With this chapter, we hope to give back what our research participants gave us. In a different form. By literally, openly and anonymously sharing what people wanted to share. In the vernacular in which the favorite detours rolled into our database.

As a thank you for your time and candor.

**Inspiration** Lewis, M.A.(2021). Return of Results to Patients: A Gesture of Respect and Responsibility. Journal of Immunotherapy and Precision oncology. <https://doi.org/10.36401/JIPO-21-X7>

## DARLING DETOURS

for and by the loved ones of people with Parkinson's

### LOVINGLY NEGLECT

Adjust the pace of daily life if desired, but do not take over everything. Loving neglect can help.

### MONITOR AND GUARD YOUR ENERGY

Taking care of myself so that my energy level remains at the right level.

### OUTSOURCE TASKS

More time for myself by finally taking that step to call in more (household) help, so that there is more time for doing things together at his pace and within his energy.

I arranged help and have them come while I leave to do something for myself.

### 'WISH DETOURS'

I would like every Parkinson's patient and their relatives to have regular contact with a psychologist. It is no small thing to notice changes, to accept them and to be able to discuss them.

Better cooperation between different parties around a person with Parkinson's and clarity and support for the caregiver. In addition to care, there is often a lot of red tape and uncertainties

What would help me is to work with a permanent nurse able to talk every now and then about how to continue. A confidant.

Network for children of people with Parkinson's

That the doctors (especially the neurologist) pay more attention to the cognitive obstacles in Parkinson's. Less emphasis on medication and more on how do you deal with it.

There should be more peer groups for informal carers

### REMOVE OBSTACLES



Removing obstacles is also making it easy for him, for example with a drink from his network club. Primarily he says "no, I'm not going". But I suggest that he ask a friend to pick him up and that he can call me anytime he wants to go home. Or encourage him to go for an hour. That helps.

### USE THE OFFER

We have followed the PPEP4a11 (self-management program for the chronically ill and their partner), from which a friendship has arisen and is very valuable

Ad Nouws' books have been of great help to me.

In 2018 I did the course 'Keep your attention' of the Parkinson Association, given by another occupational therapist. I learned a lot from that. As a result, you automatically start thinking further.

### SHARE TIPS AND FIND RECOGNITION

Reading or seeing tips from each other (video, drawings, etc.) will help to deal with obstacles. That gives you inspiration and makes you flexible in the possibilities. In addition, recognizability is often comforting.

What I saw on Parkinson TV was that an occupational therapist had made a booklet with photos, one per step and page, of the coffee making. I also told this to my mother. Maybe we can make something like this for my father, like the oven.

## DARLING DETOURS

for and by the loved ones of people with Parkinson's

### FOCUSING ON WHAT'S REALLY IMPORTANT

Together we calmly discuss what is going to happen or how we are going to tackle it. It helps me focus on what really matters.

### TRUST

We always invent a way that is convenient in the situation as it arises. This way we always solve it and we can be very satisfied with that. It also gives us confidence that with what is yet to come, that we will succeed.

### MOURNING and DEEPENING RELATIONS

Make time for grieving. We cry together for what we miss so much now. That gives air and relaxation.

Every obstacle sparks conversation. Conversations about the view on life, the view on the quality of your life, and what is really important. It brings love to share things with each other.

Keep calm and accept that life is unjust and make do with fate. I give my loved one the confidence that I will always be there for him.

### GO OUT

If we can go out together in nature (or somewhere else) and he can just do his thing..... wonderfully with just the two of us, then he has no stress or worries and therefore suffers the least from complaints...

Do fun things more often, especially getting outside and out.

Discover new things that you can do.

### GRATITUDE and JOY

Although gradually more and more things are no longer possible, still keep seeing that a lot is still possible.

Enjoying what is still possible and staying in the here and now. Gratitude for what is there is extremely important

I know that love always wins.

Laughing together, putting things into perspective.

It is important to look back on experiences we have had together. We need to keep in touch with each other and talk about our mutual interests and feelings. Sharing intimacy ensures more equality, even when there is inability.

### GETTING SOMETHING BACK

Feeling what is needed or not and then getting a grateful look. We are a good team.

It is nice to see how my loved one appreciates the attention and the delay.



### DELAY and TUNE-IN

Checking in and asking: what's going on in your head right now? How can I help you?

In a discussion, pay close attention to whether he/ she is still in the game. Otherwise, take a break or go with the flow so that he/ she can reconnect. So slow down together.

Become calmer and more patient yourself.

Taking a deep breath, not being in a hurry and deciding to take all the time he/she needs works best.

## DARLING DETOURS

for and by the loved ones of people with Parkinson's

### ENCOURAGE AUTONOMY

I let my partner do his own thing as much as possible.  
And I leave the things that he can still do well to him.

### USE REGIONAL LANGUAGE

Use your ordinary familiar language. This may be easier if spoken from the heart.



### NAME PINK ELEPHANTS

Openly discussing what we encounter, so you can tackle the problem. Silence can become a real problem,

Naming difficult things in the disease process, for instance during a walk together.

### PICK THE RIGHT MOMENT

Talk about it and try to keep it light hearted.  
Don't push is, but wait for the right moment,  
Don't tell him activities too long in advance,  
so that he doesn't have to remember that as long!

Start earlier with the preparation of activities, take that into account. Does something really have to be done now, even when the energy is gone or can it also be done later?

### ME-TIME

Especially doing things for me. That gives me space in my head and that benefits everyone.

Now that the thinking diminishes and the pressure on me increases, friends take turns taking my partner for an afternoon, with the result that he always has a nice afternoon, doing something different with each friend and I have some me-time. Friends are happy to help in a meaning full way. This makes me happy too!!

Park my wife for a while with a book, newspaper or an activity.

### UNDERSTAND PARKINSON'S

Read a lot about Parkinson's! Knowing a lot makes understanding much better!

Understanding the disease in a broad sense is central to me.

Gaining insight into the disease, which leads to understanding, insight and acceptance of the disease and also connection with each other.

Get proper guidance from experts.

### MOBILISE HELP and UNDERSTANDING

Explain to friends.

Get help from the grandkids.

Understanding of friends & children.

### TAKE OVER

Getting rid of tricky or complex tasks, like cooking. releases us and we enjoy a good meal! eater.

## DARLING DETOURS

for and by people with Parkinson's

### TELL IT LIKE IT IS

Just tell them you went down a side road and lost the main route for a while. I will get back to the main road again, whether or not I get help.

### PATIENCE, PLEASE

Asking to be patient and saying I need a little more time to.....



### INDIVIDUAL CONTACT

Withdrawing from a group conversation and making individual contact.

Have one-on-one conversations. I notice that because I am calmer and focus better, the quality of my conversations has increased greatly. This is also recognized by others: someone even said that I calmed him down!

### UNTANGLE THE CHAOS

Bite-sized chunks: break down activities into manageable chunks. For example, when cleaning: not the whole house at once, but per room/floor. Untangle the chaos!

### LANGUAGE SWITCH

If I cannot find a word, I switch to a different language.

### WRITE

Write about my experiences and have them read by people I trust.

### A FIXED DAILY SCHEDULE

What helps me is a day with a fixed structure! Get up at a fixed time (6.30 am) and go to bed at a fixed time (23.00). Good fiber-rich food every day (for intestines), 1 hour of sports/exercise, drinking 2 liters of water/day, the thinking activity in the morning (work) because then I am fit and exercise at the end of the day. Finally in the evening some Sudoku to stimulate my brain.

### BE ASSERTIVE

Simply stand up for myself.

### EARLY RETIREMENT

Quitting work on time was a very good decision.

### ACCEPTANCE

Acceptance of the fact that I have to say goodbye to pieces of myself more and more often.

## DARLING DETOURS

for and by people with Parkinson's

### GIVE PATIENCE

Not only ask for patience. Also give patience.

### PROCRASTINATE

Procrastinate, it is striking how many problems are solved if you let them rest for a while.

### UNDERSTAND OTHERS

It's not really a detour, but it does make life more beautiful. I have more understanding for my child with Asperger's. Through my own experience I now really understand better what it is like for him in this busy world.

### ASSOCIATE

I always had a hard time remembering Julia Roberts' name. Because of the combination J.R, which are my own initials, I don't forget that anymore.

### SLEEP

The best 'detour' is a GOOD night's sleep, then the day will run much smoother.

### SLOW BEING AN OPPORTUNITY

Recognizing the added value of speaking slower.

### ALLOW YOURSELF TO BE WHO YOU ARE

The funny thing is that, for example, I find sitting on a terrace much more enjoyable than before, there is no cognitive purpose in it. I experience a lot of support from my environment to be able to close my eyes now and then because they fall shut.

A lot also depends on your environment, how they react to it. Do they draw attention to it or allow you your 'shortcomings'. It is also nice if they help you on your way discreetly or unobtrusively.

My favorite detour is when my buddy (wife) helps me with understanding in my ABC trick to find the word I've lost for a while.

### PLAN and PREPARE

Preparing planned activities makes me calmer.

Make a plan.

### TRAIN THE MULTITASKER IN YOURSELF

I consciously try to do two things at once. I listen to music while I work, I talk while walking. Things like that.

### FORCE MYSELF

To get myself moving, I've asked friends to come over and go for a walk with me. Two friends came because of it and enjoy it too!





## DARLING DETOURS

for and by people with Parkinson's

### TRUST YOURSELF

Trust yourself, sometimes it takes a little longer but it's still there. The knowledge, skill or whatever.

### LIVE!

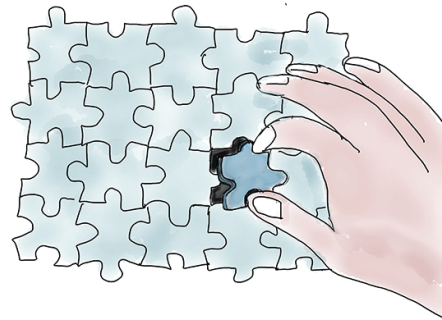
Living from philosophy that everything is possible as long as it turns out that it is not possible.

### SMALL TARGETS

Do one thing well every day instead of a few mediocre things. Then I can check something off every day. And be satisfied with that.

### NOT EVERYTHING IS PARKINSON'S

Keep thinking, searching, practicing is important in my opinion. And this not with exercises especially for this target group, there is a lot in the ordinary trade.... sudoku, crossword, puzzles, ....



### DON'T KEEP UP APPEARANCES

What helps is to know that you are not alone with your problems. The examples are very recognizable and that is already very nice. Also the fact that so many people are so driven to make Parkinson's more bearable is great. The Parkinson Association does a great job with very few people. Parkinson's is getting more and more on the map and that helps people to understand what we suffer from. I can still cope but no one should tell me it won't be so bad. It's hard work. 24/7. It's important that people are starting to understand that.

### DO IT FOR SOMEONE ELSE

Motivation makes you more likely to undertake something, so you can enjoy it for a long time. Even if it takes a lot of strength. I want to keep the promises I make to my children. They are also my motivators to exercise.

### USE MORE TOOLS

Use more tools like an iPhone or iPad to take notes, organize work. Make to do list and actually cross it off, turn on alarm clock on watch.

I write everything down in my things to do book.

Writing things down in my phone.

Use Evernote. but then I have to remember how I saved it.

### HUMOR

Looking at obstacles from the humorous side.

Put in perspective. Humor.

Making jokes to keep yourself alert.



## DARLING DETOURS

for and by people with Parkinson's

### HOVER

Evaluate (helicopter, hover above the situation), restructure and focus.

### BEND

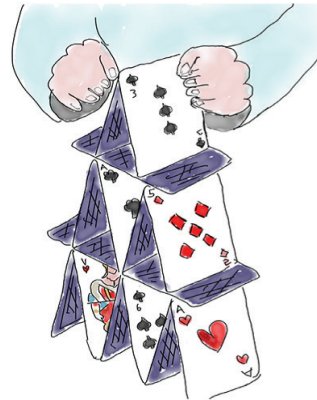
Bend like bamboo. Doesn't always work, but it gives me the most peace of mind.

### PLAY OPEN CARD

My best course is: be open about it and say what's going on.

Explain that something may not work because of the Parkinson's. Be neutral about it, don't make it a problem.

Openness about Parkinson's and being able to share this with my children.



### PEER 2 PEER CONTACT, SUPPORT (GROUPS)

Fellow patients who have Parkinson's for a longer period of time and who are relatively "good" taxable persons. Who are creative in solutions. They can be inspiring.

A supportive environment, understanding my partner.

Social contact with positive friends who help me.

Exchange tips with fellow sufferers.

Colleagues and my husband are the support points who understand me and accept me as I am.

Engaging my wife: she knows everything, she understands, she prevents me from blundering or falling.

Calling someone who understands that I want to let off steam (indistinctly).

Sometimes I experience encounters with fellow patients less positively than doing pleasant things with others.

Experiencing understanding from the environment and feeling safe.

### UNDERSTAND THAT SOMEONE DOESN'T GET PARKINSON'S

Ask what I have not understood; explain and tell that I have Parkinson's disease and thank the other person for pointing out what I have overlooked. If people react visibly annoyed to me, I try to kindly explain why I do the way I do. If then everyone continues his or her way with kind regards, I am happy.

### BE MILD

Adjust your judgment of yourself. Don't feel like you're wasting your time.

My biggest favorite: "I'll dolce far niente" because that doesn't seem to be possible in the Netherlands, where we have to fill every second usefully.

### ONE STEP AT A TIME

My approach is that I do things at my own pace and work in groups as little as possible. If I work in a larger group, I have to participate in too high a gear and I will eventually drop out.

By taking more time for planned things, among other things, there is more peace and space for more meaningful conversations.

### ONE GEAR LOWER

No longer everything at once for the Parkinson's.

Don't let myself get upset. Keep my own pace, wait a while and ask for understanding.

## DARLING DETOURS

for and by people with Parkinson's

### ENJOY

It's the little things like relaxing on the grass in the sun...

Experience gratitude and write it down.

### CRTL-ALT-DEL

Back to the basics/beginning and build up slowly, step by step.

Reset. Rethinking is sometimes nothing more than stopping thinking.

### TAKE FIVE

When my head is full I sometimes do yoga/stretch exercises.

Build in a time-out or rest.

Playing a game, daydreaming, picking up a hobby. Listening to beautiful music, working in the garden, breathing exercises, etc. Actually make sure I relax, get rid of the stress. Without stress I am happier and everything goes better.

Meditate.

Doing everything with great care and attention, feeling that I am doing something good with it - even if it is slower - ('the journey is the destination') instead of sticking to an rather pace, and then feeling I fall short.

### REDUCE NOISE

Turn off radio. Incorporate unexciting moments.

Headphones or earplugs with noise canceling: Shopping was no longer really an option. But with headphones on it is.

Putting earplugs in during a meeting helps me conserve energy for what it is needed for. Then I have to listen very consciously and force myself to focus.

### FORCE MYSELF

Forcing myself to procrastinate as little as possible.

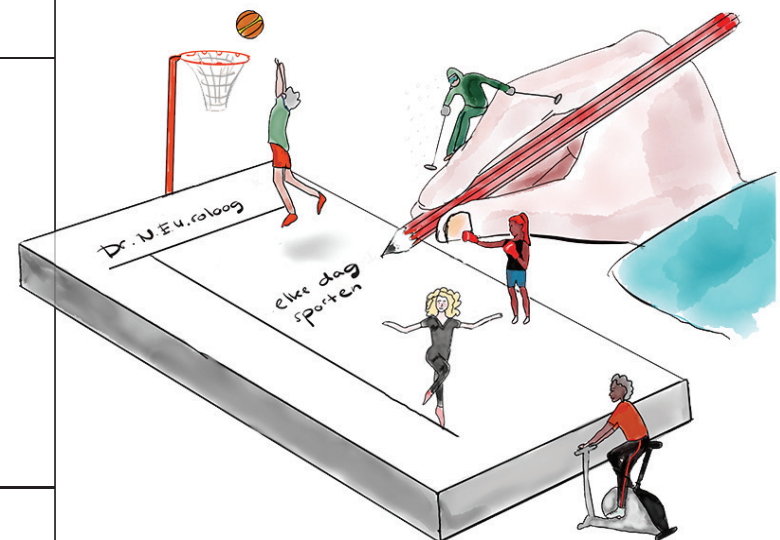
### BE CREATIVE

I am creative with paper, paint, mixed media and make small paintings and cards. Then the focus improves afterwards. In fact, you remove all incentives for a while.

Find peace in the Mandala design, drawing and coloring.

### COGNITIVE TRAINING

Cognitive exercises such as calculating and memory training from MAX.



### MOVE IT

Walking, exercising or cycling, running or working outside in the garden.

Listening to salsa music and moving to music.

I regularly dance, turn on the music and get out of my head, move, that's how I get out of being mentally and physically off.

## DARLING DETOURS

for and by people with Parkinson's

### ALTERNATE

When I can't type anymore, I'm going to pull weeds in the garden. There is always something that can be done, just not always what you thought or hoped for.



### FOLLOW YOUR PASSION

Motivation: If I am driven and enthusiastic I can still move mountains and there seems to be little P.

### CHOOSE FOR WHAT GIVES YOU ENERGY

Put everything on the scales. When the negative of something outweighs the positive, it's time to move on. Being happy and positive in everything you do is half the medicine. This, of course, does not apply to everything. Then the choice isn't to do too many negative things on the same day, but to spread them over several days if possible.

### PUSH YOUR BOUNDARIES

It strikes me that since I was diagnosed with Parkinson's, I push my limits more often than before. And that motivates me. Now it is still possible. I often turn out to be able to do it and that encourages me. But perhaps that is not a detour, but simply daring. It feels good (especially when it works).

If it doesn't work, then try if it works the other way, or my practical ability to solve problems, still takes me very far.

Learning new things i.e. a new language.

Doing things to see where the limits lie.

If you are under stress, go to a party and meet interesting people, then I come home recharged.

### DOSE

Don't push yourself too much now and then build in a rest between activities. A regular life is also very important, tensions and stress don't work for me....!

### MICROPAUSE

At first I couldn't attend a group meeting for long. Now I withdraw for a while and then rejoin (while I am still sitting at the table). It changes your role, but that also makes it interesting.

Give myself time and, for example, take a small break from my work.

### DO NICE THINGS

Do fun things with a buddy. Attend a concert, have a drink, light a cigar, do nothing.

### UNDERSTAND PARKINSON'S

I immerse myself in: what is Parkinson's disease. That way I understand what is happening to me and I can explain it to others. Because of this I experience a lot of understanding from others.

The information from Parkinson TV and the books by Ad Nouws have been of great help to me.

### PREPARE

Making coffee: before someone else is in the kitchen I count and put the 8 scoops of coffee in the filter and the coffee machine is ready for the moment a visitor or my wife joins. It is impossible to remember the number of scoops and pay attention at the same time.

### SWITCH ROLES

At least when I grind my own coffee, people won't talk through it (especially if I've turned my face away and just don't respond).

**Do not dismiss my detour,  
not even if my detour according to  
your detour is a detour**

*To paraphrase Bruno Paul de Roeck*



**Once upon an idea**

# Once upon an idea ..



*It is my hope that - by giving an example of how to make science relevant and useful -  
I will inspire parkinsonian researchers not to unintentionally overlook the people their research is aimed at*

*Marina Noordegraaf*

## **Once upon an idea**

It is September 19, 2019. At a meeting of the Patient Researchers Working Group of the Dutch Parkinson Vereniging, I shared my version of the following article:

*Nonnekes J, Růžička E, Nieuwboer A, Hallett M, Fasano A, Bloem BR (March 25, 2019). Compensation Strategies for Gait Impairments in Parkinson Disease: A Review. JAMA Neurol. <https://doi.org/10.1001/jamaneurol.2019.0033>*

I made drawings of the detours collected by the authors that people with Parkinson's use to avoid 'freezing of gait' - freezing while walking. The accompanying poster is entitled '55 detours that Parkinson's patients use to circumvent freezing'.

The poster can be downloaded by anyone on an openly accessible repository for research results. It is available in Dutch, English and - on request - also in Czech. Since its publication, the poster has been downloaded more than two thousand times. In addition, the poster has found its way to fellow patients and also

physiotherapists are ordering the poster. After all, a poster is easier to hang on your wall than a journal article.

## **Usable science**

I made the poster as an example of usable science. I wanted to show that making scientific research accessible and usable for the people it is intended for makes sense. The form matters.

Usable science starts with researching what matters to people with Parkinson's and their loved ones. When Edwin Barentsen, my fellow patient researcher, gets his hands on the poster, he looks at me tellingly. Almost at the same time we say, "Shall we also make such a poster for obstacles in thinking in Parkinson's?"

Both Edwin and I suffer more from our thinking obstacles than from those in movement. When you are in the midst of your working life when you are diagnosed with Parkinson's, obstacles such as problems in multitasking, switching and filtering require a real adjustment. Especially when these symptoms are still only sparsely recognized.

# 55 DETOURS WITH WHICH PARKINSON PATIENTS BYPASS FREEZING

## 7 CATEGORIES



## 55 DETOURS



Adapted and visualised from Nonnekes J., Ruzicka E., Nieuwboer A., Hallett M., Fasano A., Bloem BR (March 25, 2019). Compensation Strategies for Gait Impairments in Parkinson Disease: A Review. *JAMA Neurol.* Retrieved from doi:10.1001/jamaneurol.2019.0033

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See Noordegraaf, Marina, & Nonnekes, Jorik. (2019). 55 Detours with which Parkinson patients bypass freezing (Poster) (1.0). Zenodo. <https://doi.org/10.5281/zenodo.3293107>



We know we're not the only ones and wonder if we could collect, aggregate, and redistribute the detours that people with Parkinson's find around their thinking obstacles. A kind of peer-to-peer contact via a self-help tool. And then do it in a scientifically substantiated way so that the results find its way to the neurologist, etc. It is November 15, 2019. Our enthusiasm has translated into research questions. With these questions in our pockets, we look for scientific reinforcement.

Dr. Ingrid Sturkenboom, expert in occupational therapy in Parkinson's disease at Radboud university medical centre Nijmegen in the Netherlands, responds enthusiastically and brings in Dr. Esther Steultjens, expert in daily living, cognition and cognitive strategy training, from the HAN University of Applied.

Sciences. As a foursome, we put together a grant application for the Dutch Parkinson association. We are keeping our fingers crossed until judgement day: June 22, 2020. We are one of the honored projects in the 2020 grant round!

Then comes the preparation. Since the start of the COPIED study on October 1, 2020, I have been coached by Ingrid and Esther to actually conduct the study myself. I get my BROK certificate, take online courses in qualitative data analysis, draft my first application for the Medical Ethics Review Committee, recruit research participants, learn to separate personal data from the rest of the data, draft a questionnaire, and translate the results into this book.

## **The journey**

It was and is quite a journey to create this book, against my own thinking obstacles. I absolutely see the benefits of being both the researcher and a person with Parkinson's with thinking obstacles. This allowed me to put this still underexposed topic on the (research) agenda for many people with Parkinson's. Also, my experiential expertise had the advantage that - especially in the 1:1 interviews - I could stay close to the experiences of people themselves. If you know a problem from the inside, you simply ask different questions.

On the other hand, my head regularly frustrated the progress of the project and for days I couldn't get anything down on paper, I lost the overview and doubted whether I should be the one to show others the way. And the fact that I can no longer write and spell correctly at the same time became intrusive.

## **Pippi Longstocking**

Still it is up to us to show what patient empowerment can look like. It's up to us to make sure that people don't talk about us, but with us. It's up to us to show ourselves.

According to my belief, there is only one way to change the world: by living the change you want to see. Walk your talk. Now that's exactly what we set out to do with the COPIED study. Science is often communicated with delay in a form that is not useful to the people for whom the research is done. That's not Okay. We wanted to set an example of science that is both tangible and useful.

The journey is far from over, but I continue to feel like Pippi Longstocking, who has never done it before and thinks that she can therefore do it. Even after a Parkinson's diagnosis.

### **Words of thanks**

I am grateful for the wonderful people who have made it possible for this book to see the light.

Thank you, Parkinson's colleague Edwin Barentsen, for the nod at the meeting of the patient researchers that set everything in motion. And for the careful fine-tuning along the way. Without you, this book would not have been here. We are living proof that you can open new doors after a Parkinson's diagnosis. Anyone who - after our adventure full of proactive twists and turns - dares to say that the defining characteristic of Parkinson's is inertia again, should have a look at what can actually be still done. Despite or maybe even in spite of Parkinson's.

Thank you Ingrid Sturkenboom for saying a resounding YES when I asked you for scientific reinforcement. I have rarely met a researcher who is so open to the talents of the patient. Thank you for your encouragement, your tips, your feedback, for showing me the way. That is patient empowerment in practice. Thank you also, Ingrid, for getting Esther Steultjens on board. It saddens me greatly that during the duration of our research she passed away on October 11, 2021 at the age of 58. Thank you, Esther, for taking me extremely seriously. I carry this experience with me full of gratitude. You provided the equality in which true co-creation could occur. Jolanda van Omme was also indispensable. She was my extra pair of eyes and co-analyzed the interview data with me.

Dear friends Jacqueline van Lieshout and Nicoline Mulder: Thank you that during the focus group interviews you wanted to be my detour. Jobien Wind, thank you so much for being an observer and for flipping through the concept of this book in detail. The latter also applies to Suzanne van Horssen. The three of us form a peer review group called MP3 (The Three Fellow Parkies) about combining Parkinson's with work. An important support point to fall back on during this research. And Tom Gerats, thanks for being a Parkinson's colleague under one roof and guiding me along the way. How beautifully you can tell about your thinking obstacles!

Irma Jansen and Ad Nouws, many thanks for suggesting candidates for the focus groups.

I thank the members of the advisory board Peter van den Berg, Simone Rensen, Bas Bloem, Odile van den Heuvel, Jorik Nonnekes, Annelien Duits and Ad Nouws for their support and valuable feedback along the way.

Anoek van Rijn of ParkinsonNEXT went out of her way to build the questionnaire the way I asked. Wonderful. Marieke Lindenschot and Remco Klopper, thank you for teaching me the PRPP model and adjusting my drawings. And Rick Helmich for thinking along about what is and isn't between the ears in Parkinson's.

Sanne van den Berg, my partner-in-inspirational-strolls through the Ooij. Your feedback has made this book more personal and clear. If you don't want people with Parkinson's to be overlooked, you also shouldn't make yourself smaller than necessary. Wonderful lesson.

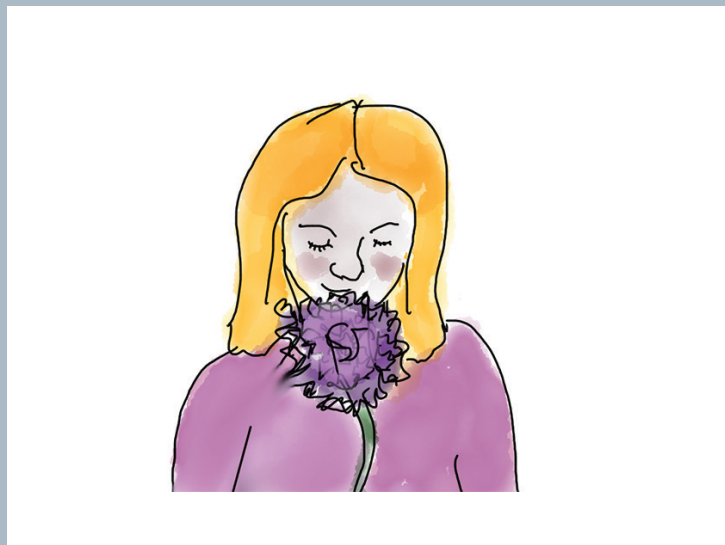
Ria van Hoewijk and Jan Arend Brands, dear parents-in-law. So nice how you want to learn the new habits to make our life with Parkinson's as pleasant as possible. Thank you for being my spelling check. It took me a while, but the manual we were looking is now available in book form! And thank you darling Tommi, and dear sons Pim and Pepijn, for the unconditional support on our new path of life.

Bas Bloem and Marjan Overdiep: thanks for writing the foreword. I am still blushing ..

My thanks to all research participants is enormous. It is unbelievable how much data you have provided in spite of the thinking obstacles you encountered while completing the questionnaire. I have tried many of your detours by now. So nice! It was a feast of recognition. I sincerely hope that you will experience it the same way.

Finally, many thanks to the people at de Parkinson Vereniging and ParkinsonNL who gave me the confidence and the funds to make this project possible.

### In memoriam



Very sadly, 6 months after the publication of the first Dutch edition of this book, Marina Noordegraaf passed away (October 14, 2022, age 53). Since being diagnosed with Parkinson's in 2018, Marina dedicated her time, skills and work to making fruitful connections between scientists, healthcare professionals and the community of

people with Parkinson's. She did this to ensure that the work done by professionals would truly benefit and be meaningful to people with Parkinson's.

While certainly not her only work, this book is her masterpiece. It illustrates her unique talent for explaining and visualizing complex issues in an understandable and meaningful way. In the Netherlands, the COPIED study and the book has helped many people with Parkinson's, their loved ones to recognize and handle the often invisible thinking obstacles in everyday life. This was evident from the many personal messages she received. With this English edition we fulfill Marina's wish to reach and benefit the wider international Parkinson community as well.

We hope it will inspire many!

*Edwin Barentsen and Ingrid Sturkenboom*



## **MIRROR, MIRROR ON THE WALL**

*You know it too, rigidity,  
The on and off, anxiety  
The difficulty to undress  
The pain, the cramp, the loneliness*

*Dishes that don't cooperate  
The arm you cannot activate  
The parties you decide to skip  
The abyss at your fingertip*

*Your stress resistance gone awry  
A future that has passed you by  
Your self-image, all shaken up  
No cure to make this damn thing stop*

*The rusty brains, low energy  
The hiccups in your memory  
Your multitasking days long gone  
A voice inside which shouts: "Hold on!"*

*It's Parkinson's, time to connect  
The old and new will intersect".  
I thank you, mirrors on my wall  
For making me feel far less small*

*Because you mirror my existence  
It reduces my resistance  
to the things I cannot change  
And acceptance is in range*

*Eager to open up*

**MARINA**





ParkinsonNL



PARKINSONISME  
VERENIGING

## DETOURS THROUGH THE PARKINSONIAN BRAIN

This is a self-help book for and by people with Parkinson's and their loved ones. With this book we want to:

- Enable people to identify the thinking obstacles that stand in their way the most;
- Facilitate discussions on a relatively invisible topic;
- Inspire people to try out the detours of their peers;
- Inform and stimulate awareness.

The thinking obstacles and detours were retrieved as part of a scientific study:  
The COPIED study. COPIED symbolizes learning from each other by copying each other.

This book is meant to be flipped through at your leisure, to be left open on a page that appeals to you, to discuss with the people you love, to take to your caregiver, to leave it lying around on the kitchen table and then see what happens when others see it lying around. Above all, it is intended to make thinking obstacles in Parkinson's so visible that its invisibility is no longer an obstacle in itself.

The COPIED study was made possible with a grant from the Dutch Parkinson's Association (Parkinson Vereniging) and ParkinsonNL.

