



PRRT

**Guide from Patient to Patient on Peptide
Receptor Radionuclide Therapy**

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PRRT – a Guide from Patient to Patient

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Please note:

This guide is primarily aimed at patients. But it can also be informative for the stakeholders of the healthcare system. The PRRT in particular requires good cooperation between service providers, payers, research, political actors, the media and patient associations.

The book was originally written in German. It is also based on many special features of the German healthcare system. In this respect, the English translation does not contain any adjustments to the content for comparable therapies in other countries: both in and outside Europe, many aspects of PRRT will only be comparable to the situation in Germany to a limited extent.

Links to articles in German should be translated using a translation software.

The guide can be downloaded here: www.prrt.info

The pictures published in this guide are private photos of the author.

Cover photo: Patient terrace of the Grosshadern nuclear station in October 2024 (Bavaria/Germany)

Introduction

This guide is intended for individuals facing PRRT: Peptide Receptor Radionuclide Therapy. It is primarily used to treat neuroendocrine tumors (NET) and their associated metastases. What makes this therapy unique is its foundation on "healing radioactivity." What makes this guide unique is that it is written by patients, for patients.

Readers of this guide are likely familiar with the challenges faced by many NET patients:

- First, the disease itself: How will it progress overall?
- Suddenly, PRRT is recommended: What are the chances and risks?
- Then, the multiple cycles, including isolation: What should you expect?

This PRRT guide aims to help answer these and similar questions. It is based on personal experiences as a PRRT patient and incorporates insights gained from conversations with other patients, doctors, nurses, and family members.

This guide does not provide medical information in the strict sense. Instead, it shares experiences and practical tips – ones that can help NET patients prepare for, undergo, and recover from PRRT as effectively as possible.

Although PRRT is only partially comparable to chemotherapy and is considered well-tolerated, it comes with its own challenges.

Above all, it requires one thing: Patience.

The goal of this guide is to use a combination of text, factual overviews, and real images to make the unique aspects of this therapy as tangible and relatable as possible:

- To break through the perceived abstraction of PRRT from the perspective of many patients and support the individual preparation and execution of the therapy cycles.
- And to foster trust that PRRT can significantly improve the health and quality of life of NET patients through "healing radioactivity."

I wish you great success with your PRRT!



Aschau (Bavaria, Germany), 12/20/2024

1



The NET Zebra: For good reason, the symbol of the “Encourager Award” by Netzwerk-NET

The individual NET Zebra

PRRT is typically used to treat neuroendocrine tumors (NET), which are rare but notably diverse. For this reason, the German patient organization Netzwerk-NET chose the zebra to symbolize the versatility of NET¹:

- Zebras may look similar at first glance, but each one has a unique pattern – no two zebras are identical!
- NET zebras are also masters of camouflage – they are often overlooked. Unfortunately, this means they are frequently diagnosed at a relatively late stage.

Anyone can develop a NET. Well-known cases include Steve Jobs² and Joseph Hanneschlaeger³. Younger individuals can also be affected, as demonstrated by rapper 'Fedez'⁴.

Each zebra, whether from these cases or any other NET patient, is unique!

The same applies to me. Let me sketch my NET zebra⁵ in advance to provide better context for the PRRT recommendations in this guide:

- For over 50 years, my visits to the doctor were almost exclusively for “minor issues”: migraines, the flu, or (sports-related) injuries.
- In 2017 and 2018, the first abdominal issues emerged. In 2019, diffuse cognitive disturbances followed. Among other things, I was diagnosed with a “psychological problem” because I experienced changes that didn’t seem to align with any “real” illness.
- In January 2020, a non-functional neuroendocrine pancreatic tumor measuring nearly 4 cm (G2) was discovered. It was successfully removed in March 2020.

In hindsight, it’s clear: my NET could have been identified and treated effectively as early as 2018. This realization is frustrating – especially when paired with the difficult-to-swallow claim that I had “imagined” my symptoms.

I have heard similar stories from other NET patients. Often, they are accompanied by statements like: “If my NET had been detected earlier, my condition would almost certainly have progressed much more favorably.”

But doctors are only human! For this reason, INCA, the International Neuroendocrine Cancer Alliance, launched an international awareness campaign in 2023⁶.

¹ www.netzwerk-net.de

² https://www.focus.de/gesundheit/ratgeber/krebs/news/sein-kampf-gegen-den-krebs-steve-jobs_id_2534664.html

³ A famous German actor: <https://www.faz.net/aktuell/feuilleton/medien/rosenheim-cop-schauspieler-joseph-hanneschlaeger-ist-tot-16591136.html>

⁴ <https://www.gala.de/stars/news/chiara-ferragni--ehemann-fedez-leidet-an-bauchspeicheldruesenkrebs-22623940.html>

⁵ The whole story here as a video: <https://www.mynetjourney.com/de/ressourcen-fuer-patient-innen/erfahrungsbericht-oliver-merx>

⁶ <https://incalliance.org/stories/oliver-germany/>



Corinne (France)

My name is Corinne, I am a 61 year-old GP, married to an A & E doctor, I have two children - a...

[Read Story](#)



Sergio (Chile)

My name is Sergio Alvarado, I am from Chile, 53 years old. I am Professor of Mathematics and a veterinary doctor. I have...

[Read Story](#)



Britta (Denmark)

My name is Britta, I am 73 years old and live in Denmark. I live in a flat with my dog. My current...

[Read Story](#)



Bill (USA)

My name is Bill Thach, I am a 38 year-old living in the United States in the state of Texas. I am married...

[Read Story](#)



Nicholas (Kenya)

My name is Nicholas Rotich. I am a Kenyan. 47 years old. Hobbies: Farming and environmental conservation. How were you diagnosed and how...

[Read Story](#)



Angela (Brazil)

My name is Ângela Maria Rocha, I'm 54 years old, I'm from Brazil and I live in Minas Gerais, in the city of...

[Read Story](#)



Oliver (Germany)

My name is Oliver. I live in Germany, I am 59 years old, I have been married for 35 years, I have 2 children, 4 grandchildren...

[Read Story](#)



Yu Qi (Taiwan)

Age: 51 years old Name: Yu Qi Country: Taiwan Hobbies: travelling, making new friends, learning new things. How were you diagnosed and how...

[Read Story](#)



Luciano (Italy)

I'm Luciano. I was born in Milan in 1949. I am married and I have one daughter. I currently live in Monza...

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INCA Campaign on NET: They are often overlooked!

The numerous examples in the campaign highlight how often the pattern of "overlooking NET" occurs – everywhere in the world, not just in Germany. The diagnosis of "imaginary illness" also seems to be widespread among NET patients. Both are rooted in a common and reasonable medical rule⁷:

"Common things are common, and rare things are rare."

This rule of thumb leads to another significance of the zebra: among medical professionals, it serves as a general synonym for misdiagnoses. The reasoning behind this is the German saying:

"When you hear beats, think horses, not zebras."

But NETs are zebras! The "hoofbeats" of those affected are often misinterpreted.

People who experience diffuse changes due to an undiagnosed NET may, sooner or later, develop actual psychological problems as a result of the misdiagnosis of "somatic depression"⁸ – a self-fulfilling prophecy.

This happens because they don't feel taken seriously, because they are forced to pit the reality of their internal experiences against a medical assessment, because they must dare to contradict. And as their "hoofbeats" get louder and louder, they risk being even more likely to be labeled as troublemakers, malingerers, or mentally ill. A vicious cycle.

I also intensified my "hoofbeats":

- First, because I come from a family of doctors. I was always aware of how often my parents spoke about misdiagnoses at home – but only there.
- Second, because my wife's MS was "overlooked" for an extended period. She was repeatedly diagnosed with "psychological issues" until one day she collapsed at work with a suspected stroke. In hindsight, it became clear that the MS could have been diagnosed relatively easily at least six years earlier – among other things, the contrast agent for a neurological examination had been "forgotten."
- Third, and most importantly for me: despite massive doubts, I was convinced that something in me had changed drastically. I even argued with two doctors about my conviction, saying something along the lines of: "If no cause is found, that doesn't mean I'm imagining things or have psychological problems!" Therefore, I refused to take medications for an assumed depression.

Such backstories are common among NET patients and can be relevant when considering the prospect of an upcoming PRRT. The therapy intensifies a challenge that often accompanies NET: the need for psychological stability in the face of numerous short-, medium-, and long-term uncertainties.

⁷ At least used in Germany <https://flexikon.doccheck.com/de/Zebra>

⁸ <https://www.psychiatry.org/patients-families/somatic-symptom-disorder/what-is-somatic-symptom-disorder>

In my experience, PRRT is not solely about the medical treatment of the primary tumor or metastases. Due to its unique characteristics, PRRT also involves successfully addressing accompanying psychological aspects in many ways.

In this guide, I will repeatedly touch upon the topic of mental health, particularly because the psychological challenges associated with PRRT can be quite diffuse. For me, the uncertainties tied to PRRT developed a dynamic that was difficult to foresee in advance.

Specifically, the delayed side effects of PRRT repeatedly challenged me to process an unexpected paradox. I felt a perceived contradiction that, over the course of PRRT, occasionally became more pronounced:

- On the one hand, the PRRT appeared to work remarkably well in combating the metastases.
- On the other hand, I felt (at times) increasingly worse mentally.

This divergence between objective and subjective factors, I believe, can largely be attributed to the unique nature of PRRT. I emphasize this because there is a high likelihood that a critical factor contributing to the therapy's ultimate success is also present in PRRT – one that cannot always be directly controlled:

The activation of self-healing powers and the maintenance of a stable psyche!

Against this backdrop, let me return to describing my NET zebra and the associated psychological challenges and coping strategies.

Although my NET was diagnosed relatively late, I was considered cured for some time following a successful R0 left-sided pancreatic resection. And indeed, after the extensive surgery and subsequent psychological counseling, I sometimes felt fitter and better than ever before. I decided to accept the situation as it was and look ahead. Additionally, I began taking up a new hobby step by step: e-biking.

To this day, the e-bike serves as a kind of "motorized doctor" for me, helping me repeatedly achieve and improve small successes – both physical and mental. Equally important to me is writing about my many e-bike tours⁹. This guide includes some photos of tours that seemed particularly fitting in the context of my experiences, challenges, and insights during PRRT.

Both the tumor diagnosis and e-biking have made me, in a special way, more fearless and determined. I still love tackling steep climbs of over 50% with the e-bike. The experience I have during these climbs:

It's uphill from here!

⁹ www.doktor-ebike.de



55% incline
with an e-bike

My favorite e-bike incline on a ski slope above Aschau (Bavaria, Germany)

But even I have experienced, and continue to experience, occasional mood swings – largely due to a constant underlying sense of unease:

- How long will the relatively positive progression of the disease last?
- When will the next setback come – and what exactly will it look like?
- How well will I be able to handle the next setback?

And setbacks did come for me, as they do for many others:

- Just a few weeks after the tumor resection, I developed large postoperative fistulas twice in quick succession. These carried the risk of sepsis, which was narrowly averted the first time.
- In 2021, I underwent hernia surgery. I narrowly escaped a critical outcome due to a double deep vein thrombosis with a double massive pulmonary embolism that went undiagnosed for days¹⁰.
- At the beginning of 2023, the first tiny metastases appeared, almost certainly present since the initial pancreatic resection. I was not amused.
- Finally, in April 2024, PRRT was recommended. The prior Somatuline therapy¹¹ was no longer sufficient. This was unfortunate because, with this therapy alone, I could have continued indefinitely without PRRT.

Against this backdrop, I've divided my "health life" into three phases:

1. Life without a diagnosed tumor (approximately 55 years)
2. Life after the tumor, but without diagnosed metastases (about three years)
3. Life with diagnosed metastases (for about 1.5 years and counting)

Even in phases two and three, my life was relatively normal – both privately and professionally. At times, I had to remind myself that I had even undergone tumor surgery. It was the same with the metastases: you know they exist, but you don't feel them!

It was precisely this reason that the necessity of PRRT brought renewed, at times significant, uncertainties.

Now, as I write this guide from one patient to another, one thing seems clear:

- PRRT has worked wonderfully in terms of reducing my metastases.
- At the same time, the accompanying factors of PRRT have shaken me up internally!

Because of the diffuse dual nature of this experience, I decided to share my uncertainties, experiences, and coping strategies here as openly as possible.

For anyone going through something similar, you might think: "Good to know it's not just me!"

¹⁰ <https://www.apotheken.de/krankheiten/4283-lungenembolie>

¹¹ <https://www.uksh.de/uccsh/Das+UCCSH/Spezialisierte+Krebszentren/Krebszentren+Campus+Kiel/Zentrum+f%C3%BCr+Neuroendokrine+Neoplasien+Campus+Kiel/Systemische+Tumorthherapie.html>

Recommendations from patient to patient regarding your individual NET Zebra:

- Engage as openly as possible with your individual NET Zebra: What has gone well or even better than expected despite all the disappointments?
- Do this primarily for yourself (and your close family members). Take the time you need for this – it is time well invested!
- A thorough understanding of your own NET Zebra is – as will become evident – a significant aid in managing the unique aspects of PRRT in many cases.
- Keep in mind: Once PRRT cycles begin, you will (at least temporarily) be isolated, sometimes alone, and in many ways left to your own devices.
- The clearer and earlier you can visualize the entire course of your illness, the better your self-healing powers can support the PRRT.
- If necessary, consider seeking psychotherapeutic support even before starting PRRT. Openly discussing situational uncertainties can help you view PRRT primarily as an opportunity from the very beginning.
- The earlier you start psychotherapeutic support, the more helpful it can be between or after individual PRRT cycles.

2



**A dense, long-lasting autumn fog:
It has quite a bit in common with PRRT ...**

Decision for the PRRT

The decision to proceed with PRRT must be made collectively by multiple stakeholders. It doesn't simply fall from the sky – or does it? The first indications for me came in mid-April 2024. On a Friday morning, I received an unexpected call from the hospital: they wanted me to come in the following Monday. There was a new finding from the latest MRI. Additional details would be provided by the attending physician on-site.

After such a phone call, all you can do is wait ... two and a half days.

My takeaway from this experience: the magic word in the context of PRRT, from the very first moment, was "patience." The following overview explains why this is the case. The typical "patience aspects" of PRRT are highlighted in comparison to chemotherapy:

	PRRT (Peptid-Rezeptor-Radionuklid-Therapy)	Chemotherapy
Illness	Mostly neuroendocrine tumors (NET) with specific receptors	Different types of cancer
Duration of treatment	Several months , in several cycles with week-long breaks in between	Varies: weeks to months, usually in regular cycles
Medicinal substance	Radiolabeled peptides that bind to tumor receptors	Use of cytotoxic drugs that attack rapidly dividing cells
Mechanism of action	Radiation is delivered specifically to tumor cells	Damage to all rapidly dividing cells, including healthy cells
Typical side effects	Fatigue, nausea, reduced blood values, delayed radiation effect	Nausea, hair loss, reduced blood values, risk of infection
Administration	Intravenous, multiple inpatient treatment required	Intravenous or oral, partly inpatient, partly outpatient
Isolation required	for a few days after injection due to radioactivity	Usually not
Aftercare	Continuous checks in the middle and at the end of cycles (e.g. blood tests, PET-CT)	Regular check-ups (blood tests, imaging if necessary)
Specific restrictions	Avoidance of close contact after treatment (especially pregnant women, children)	No specific social distancing rules required
Use in case of recurrences	Suitable for certain recurrences of neuroendocrine tumors	Can be used for various tumors, even in the case of recurrences

Even though the table comparison is only a rough overview, it gives a sense of the particular challenge posed by PRRT:

As a PRRT patient, you need patience, patience, and more patience.

There's a lot of hope, but no quick clarity! For this reason, the most fitting metaphor is a thick, persistent fog that takes a long time to dissipate. You don't have good visibility up close, let alone in the distance. The sun isn't shining and it's not raining cats and dogs. In many respects, the environment appears vague and blurred. Much can only be guessed at.

The first hint of this approaching fog started with the mentioned phone call – even though, at that moment, I didn't yet know PRRT was ahead of me:

- During the call, my adaptive subconscious began sketching short-, medium-, and long-term scenarios of the possible progression of my illness.
- These included a potential best case, a worst case, and something in between.

This might not seem like the best possible reaction for everyone, but during the call, I started preparing myself for the less favorable outcomes, such as massive growth of known metastases, many new metastases, or the need for chemotherapy:

- The downside: This approach can lead to "unpleasant fantasies" that, in hindsight, may turn out to be incorrect.
- The upside: You are prepared for bad news and may even be positively surprised if the actual news turns out to be less severe.
- In my opinion, trying to estimate probabilities without concrete diagnostic information is not helpful. The key is finding a personal coping mechanism that works for you.

Returning to the phone call: The only thing that seemed certain, given the short notice, was that something important needed to be discussed – something likely to affect not only me but also my family.

As with the initial tumor diagnosis, the sooner and more directly family members can be included in such discussions, the better! With this in mind, my wife and I decided to go to Munich together that Monday to receive the yet-unknown findings as a team.

At first glance, the results didn't seem so negative:

- One of the metastases had developed significantly faster than the others within a quarter. This was definitely not a worst-case scenario! I felt a small sense of relief.
- However, when you start extrapolating the growth rate of this particularly "growth-friendly" metastasis, it becomes clear: the urgency was justified!

According to my attending physician, the Somatuline injections I had received every four weeks for nearly a year would, in all likelihood, no longer be sufficient to slow the growth of the particularly "motivated" metastasis.

An immediate therapy escalation, as determined by the tumor board, was therefore deemed appropriate. The therapy of choice: Peptide Receptor Radionuclide Therapy, or PRRT.

After a brief moment of clarity, my mind returned to a state of "moderate fog":

- I already had a basic understanding of PRRT. I had learned about it months earlier at the 2023 Tumor Day hosted by Netzwerk-NET in Herzogenaurach.
- I still vividly remember the event. There, I received extensive information about various NET treatment options, including PRRT.
- I also took several photos of the presentations. One talk illustrated the different treatment methods using an anonymous example case.

At the time, I naively thought: "PRRT? That doesn't apply to me!"

I likely did so subconsciously, clinging to a related hope. Even during the presentation, I suspected that while PRRT represents a significant opportunity, it is uncertain whether and to what extent PRRT will be effective in individual cases. Additionally, one thing was already clear to me at Tumor Day: PRRT, no matter how effective, is undoubtedly very time-intensive!

When faced with the new findings, I even remembered statistics about PRRT. I had looked them up out of curiosity after Tumor Day. Among other things, I vaguely recalled the Netter-1 study¹²:

PRRT success statistics based on studies approx. 80%			
	strong regression	partly regression	stabilization
percentage	≈ 1-4%	≈ 10-35%	≈ 50%

After Tumor Day, I had almost completely forgotten about PRRT. However, with the announcement of the new findings and the therapy recommendation, the memory immediately came back. It was now clear that PRRT did, in fact, concern me – and much sooner than I had anticipated. Almost instinctively, with a rough understanding of the circumstances, I began estimating which course of progression I might expect.

In my internal evaluation of the three scenarios outlined in the table, my psyche played a subtle yet crucial role:

¹² further graphics and statistics: <https://www.fda.gov/drugs/drug-approvals-and-databases/drug-trials-snapshots-lutathera>

...che Behandlung in welcher Abfolge?

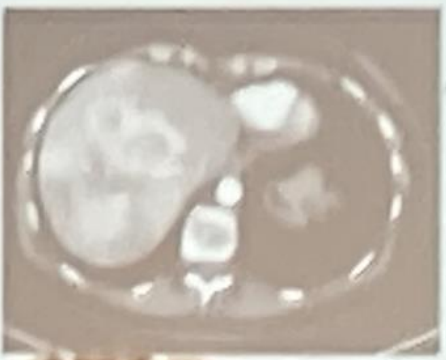
Ursprungsort

Dünndarm →



Zuwarten (Watch & Wait)

Pankreas →



Bei Tumorwachstum ...

SSA → PRRT → Everolimus



Chemotherapie

Everolimus
PRRT
Sunitinib

Nutzen und Risiken abwägen

Tumorbedingte Faktoren

Symptome:
• Schmerz, Gewichtsverlust
• Tumormasse: Risiken, wenn der Tumor weiter wachsen sollte?
• Aggressivität des Tumors:
• Größe, Wachstum, Tumormarker

Patientenbezogene Faktoren

- Alter
- Allgemeinzustand
- Begleiterkrankungen
- Präferenz



Risiko der Behandlung

Risiko durch Tumorwachstum



Therapiebedingte Faktoren

- Kurz- und Langzeitrisiken
- Reversible Nebenwirkungen

Änderungen vorbehalten

Samstag, 23. September 2023

11:10 – 12:10 Auf der Suche nach der besten Therapieempfehlung:
Ein NET-Patientenfall
Interdisziplinäre Tumorboard-Diskussion zur
Therapiefindung

Präsentation: *Dr. Tanja Bergmann*

Moderation: *Prof. Dr. Marianne Pavel*

12:15 – 12:35 Verleihung des **GLORINET-Preises*** mit Laudatio

Laudatio: *Prof. Dr. Marianne Pavel*

12:35 – 13:00 Vortrag des/r GLORINET Preisträgers/in

Renommiertere/r NET-Experte/in

13:00 – 14:30 *Mittagspause (gemeinsames Mittagessen)*

14:30 – 15:30 **Workshop-Reihe A** (Parallelvorträge)

W 1

Möglichkeiten der interventionellen Radiologie
zur Behandlung von Lebermetastasen

PD Dr. Axel Schmid

W 2

Individuelle Fragerunde rund um NET

Prof. Dr. Marianne Pavel

W 3

Systemische Chemotherapie: Voraussetzungen,
Prävention und Management von Nebenwirkungen

PD Dr. Norbert Meidenbauer

- Fundamentally, from an oncological perspective, even stabilizing metastases is considered a positive therapeutic outcome.
- From a patient's perspective, however, the prospect of stabilization can feel ambivalent, as it may perpetuate existing uncertainties.
- In this sense, the subjective assessment of PRRT's success probabilities resembles the so-called "paradox of prosperity"¹³: Stagnation is difficult to grasp and often only marginally satisfying in the case of a worsening cancer diagnosis – even though, medically speaking, stagnation is actually good news.

To put it differently: I felt, and still feel, remarkably fit and healthy in every respect. However, as I later researched, this very sense of well-being can unexpectedly backfire. The better you feel before starting a therapy, the more pronounced any impairments may seem.

Psychologically, this effect can be explained by several recognized behavioral patterns¹⁴:

- The "contrast effect" often causes people to perceive negative influences more acutely when compared to a pre-existing sense of well-being.
- Through "hedonic adaptation", we grow accustomed to positive states, making deterioration feel like an unpleasant deviation.
- The "loss aversion" effect amplifies this, as losses – such as a decline in positive mood – often weigh heavier subjectively than equivalent gains.
- Finally, the "optimism bias" makes negative events that don't align with positive expectations feel particularly disruptive.

Bingo! Precisely because I felt so fit, had developed so many (new) plans after the successful tumor surgery, and continually allowed myself the optimism that things could continue to progress positively despite the metastases, I soon found myself in a legitimate emotional slump when confronted with the persistent, impenetrable, and lengthy "PRRT fog" – despite knowing that my chances with the therapy were relatively high.

From a statistical standpoint, there were even positive indicators in my case: PRRT is particularly effective when – like in my situation – the NET is non-functional and the therapy is started as early as possible, while the metastases are still relatively small¹⁵. Specifically, for smaller metastases, PRRT is not just a suppressive therapy but also an important and proven preventive measure.

¹³ https://en.wikipedia.org/wiki/Paradox_of_prosperity

¹⁴ https://en.wikipedia.org/wiki/Contrast_effect; https://en.wikipedia.org/wiki/Hedonic_treadmill; https://en.wikipedia.org/wiki/Loss_aversion; <https://www.scribbr.com/research-bias/optimism-bias/>

¹⁵ Very worth reading for the earliest possible use of PRRT: <https://link.springer.com/article/10.1007/s41969-018-0034-7>

However, the relatively time-intensive PRRT is closely associated with the so-called prevention paradox¹⁶, which also plays a significant role in medicine:

- It suggests that preventive measures are often undervalued because they prevent dangers from occurring in the first place, making their success difficult to see.
- As a patient, one might wonder whether PRRT is truly necessary in relatively early cases: Couldn't one wait a bit longer?
- Some (public) health insurers also scrutinize under which conditions the cost-intensive PRRT is appropriate and genuinely the therapy of choice.

Against this backdrop, this section was deliberately titled "The decision for PRRT":

- Because multiple parties are involved in this decision, each playing a different role and bringing a different perspective.
- For example, the patient or the payer or health insurance may have a different opinion than a NET specialist or an expert in oncology or nuclear medicine.

Ultimately, the decision hinges on a three-part benefit/risk assessment regarding the next best therapy for NET or metastases. The three aspects are:

- Tumor-related factors
(e.g., symptoms, tumor mass, growth aggressiveness, operability)
- Patient-related factors
(e.g., age, overall condition, comorbidities, preferences, and other circumstances)
- Therapy-related factors
(e.g., prognosis of effectiveness, short- and long-term risks, reversibility of side effects)

As a patient, you are generally responsible for independently assessing the second aspect. Points 1 and 3 largely fall under the expertise of specialists. However, as a patient, you have the right to refuse PRRT against medical advice or to advocate for a delay.

For instance, it is possible that the situation might stabilize on its own. This is especially feasible with smaller or less aggressively growing metastases. If specific metastases escalate, procedures like radiofrequency ablation (RFA) or microwave ablation¹⁷ may also be an option. Compared to PRRT, these are relatively minor and short interventions – without multiple, time-consuming stays in isolation wards. Potential side effects would also be relatively minimal.

From this perspective, there are indeed pros and cons to weigh – although patients may not be equipped to fully evaluate the technical details. Ultimately, you must trust the medical recommendation!

¹⁶ https://en.wikipedia.org/wiki/Prevention_paradox

¹⁷ Overview on NET therapies in German language <https://www.netzwerk-net.de/krankheit-net/therapien-therapiearten/>

In the patient's assessment of whether and when a PRRT should be carried out, the extended timeline of the therapy therefore plays a role that should not be underestimated. In my case, it looked something like this:

Measure	Period	Note
Initial diagnosis	End of April 2024	Medical information
PET/CT #1	Beginning of May 2024	Zero measurement before PRRT
Somatuline therapy	End of May 2024	Termination important for PRRT
First cycle	Middle of June 2024	four days Hosp. + post-isolation
Second cycle	End of August 2024	four days Hosp. + post-isolation
PET/CT #2	Middle of October 2024	success analysis 1.-2. cycle
Third cycle	Middle of October 2024	four days Hosp. + post-isolation
Forth cycle	Beginning of December 2024	four days Hosp. + post-isolation
PET/CT #3	Beginning of February 2025	final success analysis

As you can easily see:

- From the time the diagnosis is communicated to the final assessment of whether and to what extent the PRRT has been successful, a therapy period of 8 to 10 months can easily pass.
- Depending on the intervals between cycles (ranges of 6–12 weeks are mentioned online), the total duration may be somewhat more or less.

However, it's not just the overall duration that matters. Considering the potential side effects, which will be addressed in more detail later, the following question is highly relevant:

What can you realistically still do (personally and professionally) between cycles?

For instance, it is difficult to predict in advance how long a sick leave might last – both over the entire course of therapy and after each cycle:

- PRRT appears to have quite variable side effects, depending on the specific primary illness and a range of individual factors.
- In my discussions with doctors and other PRRT patients, I noticed that some experienced little to no side effects or only for a short time.
- Others reported quite severe and long-lasting limitations, both during and after each cycle. Symptoms such as nausea, persistent fatigue, and exhaustion seemed to be particularly noticeable side effects.

The phenomenon of fatigue¹⁸ – perceived as extreme exhaustion or a "lead-like fatigue" after relatively minor exertion – strikes me today as a particularly insidious aspect of the PRRT fog!

In a separate discussion paper titled "Pros and Cons of Part-Time Sick Leave – Exploring New Paths?!"¹⁹ I examined several aspects that (not just) PRRT patients rarely discuss openly with their doctors, but which can be highly significant:

- The potential personal, professional, and financial impacts of the PRRT fog.
- The potential real-life consequences and, in some cases, legal questions associated with PRRT.

For me, there were various tangible consequences of PRRT that necessitated a comprehensive overall assessment. As I mentioned earlier:

- Starting in April 2024, I had ambitious professional plans!
- Until then, I hadn't felt my metastases to be a limitation, either personally or professionally.
- The overall duration of PRRT seemed long, but exact dates were difficult to predict.
- For each cycle, I estimated one week of therapy plus several weeks of recovery – give or take an "X" factor.

To foreshadow the conclusion: even my most conservative calculation was ultimately too optimistic! The third cycle in particular came with surprises, as the typical side effects of PRRT can apparently occur with a delay – more on that later. Additionally, there's another phenomenon I will address:

The better the PRRT works and the shorter the intervals between cycles, the more intense the side effects can be in individual cases. This is hardly predictable!

When you consider all of this before PRRT, you may need to take a deep breath before clapping your hands with joy. Some patients may seriously struggle to compare not just apples with oranges but rather with sour lemons or bitter grapefruits.

The following analogy reflects the thought process of the passionate e-biker in me as I worked through the real-world consequences:

- The fact that a single metastasis – which still felt relatively small – could cause eight months of uncertainty was like the tiny ball bearing of an e-bike's wheel. If that bearing is defective, it can put the entire e-bike out of action for an extended period!

¹⁸ <https://my.clevelandclinic.org/health/diseases/17720-myalgic-encephalomyelitis-chronic-fatigue-syndrome-me-cfs>

¹⁹ only in German on the basis of the special rules of the German healthcare system www.prrt.info/diskussion



Small problem, big effect: Defective ball bearing of a gear wheel

- I still vividly remember when exactly that happened in the summer of 2021: right in the middle of the COVID-19 crisis. This crisis – previously unforeseeable – led to a situation where various spare parts for e-bikes, which were otherwise readily available, suddenly couldn't be delivered for extended periods²⁰.
- The chain reaction of interdependent uncertainties, in my experience with PRRT, creates a kind of gamble where you don't fully know the stakes but still have to take the plunge if you decide to proceed. The good news: there's a lot to gain, which significantly outweighs the unknown stakes!

The previous analogy of the defective small wheel has, in my opinion, further parallels to the subjective perception of the benefits and risks of an unfamiliar PRRT:

- As a passionate e-biker, you don't want the "stabilization" of an existing defect – you want a repaired e-bike. A lack of repair progress feels like regression!
- You also don't want to wait months for the spare part; you want it as quickly as possible. In other words: order the part, install it, done. No lengthy therapy.
- And who would hand over their e-bike to a bike shop that can't guarantee it will be road-worthy after months of repairs?

Many of the things you wish for with PRRT simply aren't possible. It requires time and patience! Along with that comes enduring various forms of uncertainty.

From a patient's perspective, all individual pros and cons of PRRT must therefore be carefully weighed against one another. This is especially true in relation to the previously mentioned tumor-, patient-, and therapy-related factors:

- Starting PRRT as early as possible offers above-average short- and medium-term success rates. Long-term effectiveness also appears to be quite positive in such cases²¹.
- If surgery for small metastases (as in my case) does not promise success, PRRT also has the major advantage of significantly reducing the overall metastatic burden.
- To return to the e-bike analogy: PRRT can "repair" many small wheels at the same time better than any alternative (and that's exactly what happened for me in the end).

Nevertheless, deciding on PRRT wasn't easy for me:

- My immediate reaction was, "Phew – lucky. It's not the worst case." In other words, no chemotherapy or anything similar.
- But the more you think about the practical consequences of PRRT, the more uncertain you become. At least, that was the case for me because so many different factors had to be weighed against one another.

²⁰ <https://www.rnd.de/wirtschaft/fahrrad-nachfrage-steigt-in-corona-pandemie-ersatzteile-werden-knapp-2SPN36JK34EX6PV4OD7Z3X5QYA.html>

²¹ <https://link.springer.com/article/10.1007/s41969-018-0034-7>

In this sense, I was, without ifs or buts, quite frustrated some time after receiving the new findings, especially the moment the decision for PRRT was finalized on my part. I felt abruptly slowed down – like an airplane with running turbines that had already taxied to the runway, only to have the takeoff suddenly aborted. The prospect of spending months grounded with no clear restart in sight was anything but uplifting:

- You simply don't know how you'll truly feel during and especially after each PRRT cycle: everything is, at best, vague speculation.
- You have even less idea of what to expect during the four multi-day stays in isolation wards: this is not a "normal" hospital stay!
- And perhaps the most important question: Will the long therapy ultimately bring the hoped-for progress or not?

I asked myself: What if, after all those months of therapy, no significant and lasting success is achieved? Would chemotherapy be necessary? What comes next? How could I cushion new uncertainties?

As I've hinted before, I'm not inclined toward false optimism regarding my cancer diagnosis. The mere fact that the new findings were even possible, contrary to expectations, is reason enough to remain cautious with positive expectations.

For this reason, the "PRRT fog" increasingly thickened on its own. Nevertheless, together with my wife, I made a swift decision in favor of PRRT: the fog wouldn't lift on its own without this decision.

On the contrary, without this decision, the fog could have grown even denser.

Ultimately, I realized:

- Immediately freeze all existing plans! Instead, focus entirely on PRRT!
- Aim for the best possible satisfaction with an otherwise unsatisfactory overall situation!
- Get in touch with the psychotherapist who had already helped me after the tumor surgery (unfortunately, long waiting times are often required for this²²).

Shortly after the new findings, I began the inner reflection on my own NET zebra mentioned in the first section. My zebra now had a few clearly recognizable new stripes – but at the same time, older stripes suddenly seemed blurrier and more ambiguous than ever before.

Against this backdrop, my wife and I began preparing for the first PRRT cycle together.

²² <https://www.aerzteblatt.de/nachrichten/146677/Psychotherapie-Laengere-Wartezeiten-auf-Therapieplatz-seit-Strukturreform>

Recommendations from patient to patient regarding PRRT decision:

- Be aware that during PRRT, you will need something that is neither easy to achieve nor maintain: a lot of patience!
- Trust that PRRT is an effective therapy overall – use your personal coping mechanisms to deal with remaining uncertainties.
- Carefully weigh the overall situation regarding the pros and cons of starting PRRT early: Early PRRT is more effective but comes with its own "challenges" from a patient's perspective (keyword: prevention paradox).
- In consultation with your doctors, get an early understanding of the likely overall duration of PRRT.
- Consider whether and to what extent an appropriate postponement of PRRT could be an advantage or disadvantage in your specific case.
- Involve family members, as much as possible, in deciding how to best handle the new situation.
- Prepare for the possibility of experiencing a long-term alternation of "fog," "sunshine," and other "weather conditions."
- Even though it's not easy: Remind yourself that even the stagnation of the disease is a success. The chances of this are good with PRRT!
- Consider seeking psychological counseling to help you navigate the challenges outlined above as effectively as possible.



3



**Like a downhill ride in inversion weather conditions:
From the sun (again) down into the fog ...**

The first PRRT cycle

The first PRRT cycle can be compared to an e-bike tour during an inversion weather pattern²³. In the valley, it's often gloomy and cold. Then comes a thick layer of fog, and eventually, higher up on the mountain, the sun (hopefully) shines again.

Now imagine riding an unfamiliar route during such weather:

- Either you're in the valley, below the fog, in a gray world looking up at a higher gray wall of unknown extent.
- Or you're above the fog, basking in the sunshine. But suddenly, the path leads downhill again – toward a thick gray fog bank. What happens next?

For me, it was the second scenario. Since the tumor's removal, I felt like I had been "riding in the sunshine." I knew there was fog further down, but as long as I didn't unnecessarily ride straight into it, it wouldn't bother me.

With the newly described diagnosis and the announcement of PRRT, isolated fog patches began to appear – sometimes dense, sometimes light. But from that point onward, the bright sun would not return for a long time.

By preparing for the first PRRT cycle, I felt as though I was riding out of the sunshine and straight into the fog – right in the middle of spring. In practical terms, this meant:

- The first cycle wouldn't begin until mid-June 2024.
- I would spend Monday through Friday in an isolation ward.
- Afterward, I would need to isolate myself from others, including my pregnant daughter and one of my grandchildren.

One question, especially during the first cycle, proved surprisingly difficult to answer despite the wealth of information online:

What can, should, and may you bring to the hospital? And what shouldn't you bring?

After all, this is a radioactive therapy. Whatever you bring could potentially become (permanently) contaminated! More on that shortly.

In addition to logistical preparation for the hospital stay, my psyche once again played a significant role as the first cycle approached. I tried to arrange an appointment with my psychotherapist soon after receiving the new findings. She had been a great help after my tumor removal. However, due to unfortunate circumstances, the appointment wouldn't take place until after the first PRRT cycle. By then, it was certainly needed.

²³ [https://en.wikipedia.org/wiki/Inversion_\(meteorology\)](https://en.wikipedia.org/wiki/Inversion_(meteorology))



This thick fog is only a kilometer away. In the fall of 2024, it extended over many kilometres from Aschau to the north – over several weeks

Against this backdrop, I developed an important rule for my well-being:

“The closer the first cycle approaches, the more often you should indulge in things that make you feel good.”

In practice, this meant, among other things, that I – being an insulin-dependent diabetic due to NET – allowed myself to eat more sweets without constantly worrying about the impact on my blood sugar levels. Looking back, this was a good and important strategy! When preparing for PRRT, you absolutely can and should allow yourself “a little more” of everything!

Additionally, I prescribed myself long-term professional relaxation – though this proved harder than I’d have liked. I tend to exhibit “professional passion”. Time and again, I’ve found myself diving deeply into professional topics with full enthusiasm, eventually wanting to harvest the fruits of my labor. Having been self-employed for a long time, I’m still prone to working weekends and nights on various projects – even as an employee, I never saw this as a negative. On the contrary, interrupting a flow state of work simply because the clock says so is something I still struggle with.

Put differently: acceleration and deceleration have always been part of my life. But now, everything pointed toward sustained deceleration. Faced with a loosely predictable PRRT timeline of at least seven to ten months, I had to come up with something to keep my spirits up during this period – something that offered opportunities for meaningful activity without imposing strict obligations on others or myself.

I began to do something I’d call “positive repurposing”:

- Deep down, I was incredibly frustrated. To borrow the words of "Ranger" (played by Christian Tramitz) in “Manitou's Shoe”²⁴, I felt tied to the “PRRT-torture pole” and was thoroughly “dissatisfied” with the overall situation.
- I started looking for ways to stop seeing PRRT time primarily as “lost” time. Instead, I wanted to view it as “gained” time, provided to me through PRRT.
- I chose to focus more than planned on an existing goal and set myself at least rough milestones. It was a time-intensive topic that strongly interested me both personally and professionally. A topic that allowed me to flexibly expand or scale back my engagement with it, depending on how PRRT progressed.

I’m intentionally choosing not to specify the topic here – it’s “my” topic. One that, in all likelihood, would only be accessible in a similar form to very few others. This PRRT guide should instead focus on the underlying principle. You should ask yourself:

“What do I suddenly (or once again) have more time for because of PRRT?”

²⁴ Famous scene from “Manitou’s Shoe” – till today the most successful film in Germany: https://de.wikipedia.org/wiki/Liste_der_erfolgreichsten_Filme_nach_Zuschauerzahlen#Erfolgreichste_deutsche_Filme_in_Deutschland

In light of this, here’s a recommendation for the time before starting the first PRRT cycle:

- Every patient has a potentially different topic they could explore as part of a "positive repurposing." This could be painting, reading, writing, photography, music, learning new skills in general, or anything else.
- PRRT imposes noticeable restrictions on one’s life for an uncertain period and brings various uncertainties.
- However, it also subtly creates new opportunities to start activities whose scope and pace you can adjust to fit your situation during therapy.

To summarize the previous recommendations, here’s a structured overview with two categories for preparing for the first PRRT cycle:

Preparation of PRRT		
	Goal	Duration
A. entire PRRT	"positive repurposing" as mental preparation for overall therapy, which can take effect even before the first cycle	affects several months
B. 1. Cycle	best possible preparation for the stay in the hospital, including nuclear therapy and isolation ward	affects a few days

I consider "positive repurposing" a suitable measure within Category A:

- In the context of diabetes, it functions like "basal insulin," providing a psychologically positive long-term effect.
- Even when you’re fully aware of feeling deeply disappointed about the overall situation, "positive repurposing" can help cushion much of the negativity – perhaps even lead to small successes you wouldn’t otherwise achieve.
- "Positive repurposing" spans the entire PRRT period. It should be initiated before the first therapy cycle and, if possible, already actively practiced.

Category B, by contrast, is more like an "insulin injection": it provides short-term relief to manage situational peaks. This category primarily includes specific measures for preparing for your stay in the isolation ward.

For Category B, practical considerations (e.g., "What clothes should I bring, and what shouldn’t I?") and psychological aspects (e.g., "What do I need on-site to feel as comfortable as possible?") work together.

I include an exercise recommended by my psychotherapist in Category B. At first glance, it may resemble "positive repurposing," but it is distinct. The focus is on finding short-term, positive "mental images"²⁵ that can be accessed during moments of situational crisis to stabilize the psyche.

Here's a drastic example I personally experienced:

- On a PRRT isolation ward, you may encounter "truly" ill patients. You might even share a room with them.
- These could be patients with advanced illnesses for whom PRRT represents a "last hope." Such individuals can, in an instant, remind you that a NET diagnosis can also take a very unfavorable course.
- Combined with the confinement of an isolation ward and a range of critical stressors on-site (which I'll discuss later), you might find yourself unexpectedly overwhelmed by anxiety or even panic attacks of varying intensity.
- To quickly alleviate such stressful impressions, it helps to have easily accessible, rapidly effective positive emotions, such as memories of a vacation featuring beautiful visuals, pleasant sounds, and soothing scents.

For me, it's the image of enjoying a cappuccino on the Adriatic coast with the sound of the sea in the background. I see the blue ocean and sky. I smell the salty sea air and hear the gentle, repetitive rhythm of the waves.

However, such mental tools need to be practiced early and repeatedly before a cycle, so they can effectively activate their positive impact quickly on-site.

To reframe the challenge in other words:

- If you've decided on PRRT, it's likely because you've concluded that the overall benefit/risk ratio is positive. That's a good thing!
- But, as outlined earlier, the perceptible positive effects of PRRT require significant time and patience. There is no quick "return on investment."
- The first PRRT cycle, in particular, offers no immediate tangible benefit. Instead, it is the first "big unknown" in terms of potential challenges.

For me, the first cycle was quite difficult – partly because I underestimated some aspects and overestimated my own resilience in certain ways. I experienced things during the first cycle that I didn't want to repeat in subsequent ones.

This is also why I decided to write this guide: Had I known what to pay attention to during the first cycle, I could have spared myself quite a bit.

²⁵ <https://pmc.ncbi.nlm.nih.gov/articles/PMC4595480/>

The following overview illustrates how my well-being changed from therapy cycle to therapy cycle in two distinct ways:

- I. During the multi-day stay in the nuclear medicine isolation ward (shared with other patients).
- II. Afterward, during the time spent at home, which is highly likely to follow immediately after each cycle.

	I. Isolation ward	II. Afterwards at home
1. cycle	rather high load	rather high load
2. cycle	medium load	medium load
3. cycle	low load	high load
4. cycle	low load	rather low load

As you can clearly see, my experience with Point I, the hospital stays, improved positively from cycle to cycle:

- By the second time, I knew what to expect and was significantly more relaxed than during the first cycle.
- By the third cycle, I even felt a sense of routine while in the isolation ward. I now had a much better understanding of what I should or shouldn't do.

Point II, the time spent at home after leaving the isolation ward, was a completely different story:

- Despite increasing familiarity with the process and awareness of individual side effects, I initially felt better after the second cycle than I had after the first.
- However, to my surprise, after the third cycle, I experienced a significant "low point" – both physically and mentally.

Why was this possible? One can only speculate. I'll explore the potential reasons in more detail in the upcoming chapters.

What seems particularly important to emphasize here is that you can and should prepare relatively well for Point I, the first multi-day stay in the isolation ward.

Before providing more detailed recommendations, I'd first like to share how my wife and I prepared: our primary source of information was the internet.

Looking back, I now understand better than ever that the information available online about PRRT can vary widely. Most of it is written from the perspective of healthcare providers, particularly nuclear medicine specialists or oncologists who are well-versed in both NET and PRRT.

The advantage:

- You gain access to a wealth of valuable technical information.
- This includes details about how PRRT works, the procedural steps, expected duration, typical side effects, and specific conditions at the hospital.

The disadvantage:

- Each (university) hospital has its own guidelines for PRRT.
- Information from one hospital may not be fully applicable to others.
- Many of these informational offerings are, to some extent, "digital brochures."

Let me provide a striking example of why, even with something as standardized as a PET/CT scan – required for the preparation and follow-up of PRRT – there can be significant discrepancies between theory and practice. These discrepancies aren't due to any "fault" of the attending physicians but arise naturally from the system's realities.

The example concerns online information that describes the "ideal" process for a PET/CT scan. Many nuclear medicine websites contain statements like:

- "You'll wait in our comfortable waiting room for 45 minutes to an hour, then..."
- "The whole-body scan takes 30 to 60 minutes, then..."

Based on the abundance of similarly positive descriptions, one might prematurely conclude that a PET/CT scan is a quick and straightforward process, allowing you to return home relaxed and without surprises. That's the theory!

Now for the reality: My personal "record" for a PET/CT scan involved nine hours at the hospital, plus two one-and-a-half-hour commutes. Many patients I spoke with, as well as the doctors and nursing staff, admitted that a PET/CT is often difficult to predict in advance. This unpredictability reflects the broader challenges of the healthcare system, including:

- The entire healthcare system is operating at its absolute limits.
- Fewer and fewer medical professionals must deliver more and more services.
- Since COVID-19, the number of illness cases has increased across all sectors – including hospitals.
- The supply chains for medical services are becoming increasingly fragile²⁶.

²⁶ for Germany: <https://www.ndr.de/ratgeber/verbraucher/Lieferengpaesse-bei-Medikamenten-Was-sind-die-Ursachen.lieferengpaesse104.html>

As a patient, it's essential to be aware – at least broadly – of these circumstances and their potential impact on your therapy. Delays of various kinds during the entire PRRT process, including preparation and follow-up, can no longer be ruled out due to these escalating systemic challenges.

It's advisable to build flexibility into your schedule for all appointments related to PRRT, rather than expecting an "ideal scenario." This is particularly important because nuclear substances used for PET/CT scans or PRRT introduce additional complexities:

- Radiopharmaceuticals²⁷ cannot be stockpiled due to their short half-lives. They must be precisely planned, prepared, and delivered on time.
- Short half-lives are fundamentally beneficial for patients: the shorter they are, the faster you are decontaminated.
- However, short half-lives pose a significant challenge for production and delivery. Even the smallest error in the supply chain can cause "chaos."

This applies to both PET/CT scans and PRRT! The doctors in nuclear medicine are entirely dependent on receiving the required radiopharmaceuticals "on time" and "in quality." If this doesn't happen, then ... it takes longer! In the worst-case scenario, delays can cause a domino effect, impacting multiple treatments.

The following overview explains how radiopharmaceuticals for a PET/CT scan are produced. Reading through the accompanying description makes it clear, even as a patient, why theory and practice²⁸ can differ significantly when it comes to appointments involving radiopharmaceuticals.

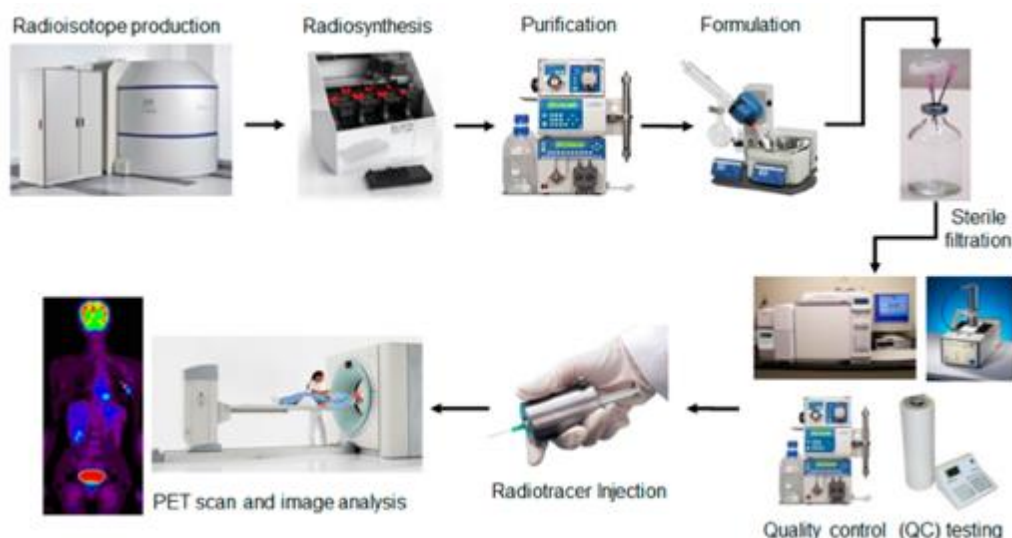


Abbildung: MDPI

²⁷ https://www.radiologie.de/wp-content/uploads/2018/02/130801_Aufklb_PET_CT_2A_FINALsicher.pdf

²⁸ <https://www.mdpi.com/2072-666X/8/11/337>

In my experience, the previous information is of high practical relevance for the preparation of the first cycle of the PRRT. Strictly speaking, the first PRRT cycle begins with a PET/CT, as the following overview illustrates:

	Process	Note
flexible	Preliminary examination with PET/CT	Initial measurement
day 1 monday	Initial examination of, among other things, the kidneys using scintigraphy	Blood values, kidney function test, medical consultations incl. explanation of risks etc.
day 2 tuesday	Start of the actual therapy; isolation, monitoring of blood values, etc.	Administration of infusions and injection of lutetium (¹⁷⁷ Lu)
day 3 wednesday	Isolation, monitoring of blood values, etc.	largely free organization of the day
day 4 thursday	Isolation, monitoring of blood values, follow-up examination of the kidneys with scintigraphy (if necessary also on Friday)	largely free organization of the day
day 5 friday	Doctor's letter and discharge	usually at midday
one week	Isolation of pregnant women and children	is generally recommended with restraint

If "unexpected surprises" occur during the initial PET/CT scan, the anticipation of the first PRRT cycle is likely to be even more subdued than it already might be.

This is partly because, as a patient, you tend to internally conflate the (negative) experiences from different procedures performed in the same nuclear medicine department – whether it's a PET/CT scan, a scintigraphy, or PRRT. While these processes are evaluated very differently from a medical perspective, they often blend into a crude overall impression for the patient. This applies to all sensory impressions, many of which you may subconsciously absorb as a patient.

To clarify what I mean, I'd like to present a few real images:

- The first image highlights the "charm" of a nuclear medicine setting during a PET/CT scan.
- The following images pertain to the facilities and procedures involved in PRRT.



Access to PET/CT: A taste of PRRT?



Corridor of an isolation ward – not romantic, but enough space for (some) movement



Terrace of a nuclear medicine: meeting place with other patients and fresh air



Eating and drinking in the isolation ward – a "special" topic



First of all: Infusions to protect the kidneys



Lutetium (^{177}Lu): Healing radioactivity and active ingredient of PRRT



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Continuous measurements after injection

Images 1 and 2 can leave potentially similar impressions – regardless of whether the first image pertains to the PET/CT and the second to the corridor of the isolation ward. In this sense, the "experience" of the preliminary PET/CT examination serves in many ways as the most important basis for imagining what a multi-day stay in an isolation ward might be like.

The more negative the experience, the more "mixed" the expectations!

Put another way: If, like me during a PRRT-related appointment, you unexpectedly spend nine hours (from 10 a.m. to 7 p.m.) largely in a dull hallway resembling Image 1, this could lead to the formation of "specific" expectations about the first PRRT cycle. You might find yourself asking:

- What will it be like in the isolation ward?
- How can I better prepare for uncertainties?
- What can I realistically plan?

For me, a personal trauma compounded the situation. I experienced it in 2020 due to postoperative fistulas, and it unexpectedly intertwined with my thoughts about the stay:

- During the chaotic COVID-19 period and its strict safety regulations, I had already spent two days alone in an isolation room. Not a pleasant experience!
- Immediately afterward, I had to share a room for two additional days with a patient suffering from a highly contagious illness unknown to me – a true nightmare! This experience (thankfully) led me to seek my first psychotherapy.

Beyond any questions of "why" or "how," this was the lowest point in my journey with the disease so far. The prospect of the first multi-day PRRT cycle in an isolation ward was therefore far from relaxing because ...

... much of the preparation happens only in your mind. It's a product of imagination, rooted in prior experiences or subtle, sometimes subconscious fears.

This is why I intentionally included additional photos. A nuclear medicine isolation ward, in a positive sense, is not much different from a well-shielded hospital ward. In my case, it even included a fairly comfortable terrace. Moreover, I experienced the emptiness and size of the corridor in Image 2 during the first cycle as overwhelmingly positive.

Returning to the actual experience of the first cycle, it both surprised and challenged me:

- Positive aspects: The atmosphere of the isolation ward was less distressing than I had anticipated, which is why I included the images. The rooms themselves were not what weighed on me.
- I found the doctors and nursing staff to be extremely positive. In my opinion, they took exemplary care of me and all the other patients I was familiar with.

- Negative aspects: Despite all our prior research, I was suboptimally prepared. I deliberately avoided bringing many things I would typically take to a hospital because my wife and I overestimated the risk of contamination.
- Particularly challenging were smells, food, and drink. These are critical because they are difficult to manage consciously.
- Far more negative than expected was how quickly I found interactions with some other patients emotionally taxing.

To make the previous points more tangible, I'll first outline the concrete process of PRRT, which was more or less the same for all cycles:

I. Day 1 – Preparatory Tests and Procedures

- The first day begins with a scintigraphy to assess kidney function. The kidneys bear the primary burden of flushing out the radiopharmaceuticals after infusion. As such, they need to be both highly functional and well-protected.
- Additionally, the day includes admission procedures, blood tests, and various medical briefings. You are also assigned your room.
- Afterward, you are generally allowed to leave the isolation ward and move freely within the hospital.

II. Day 2 – The Therapy Begins

- The therapy starts in the morning with a significant amount of infusions to protect the kidneys.
- After some preparation, you receive the Lutetium (^{177}Lu) injection in one arm. This injection is relatively quick, but the infusion continues for some time.
- During the infusion, a blood pressure monitor is attached to the other arm. From the beginning of the first infusion to the final removal of all devices, several hours pass.
- During this time, an increased urge to urinate occurs and lasts for many hours.
- The injection start time can be delayed if any small issue arises in the radiopharmaceutical supply chain. For instance, I've seen cases where patients had to wait several hours because quality assurance checks required additional time. In such situations, the key is to stay patient!

III. Days 3/4 – Mandatory Isolation

- Due to radiation protection regulations and recommendations from the Radiation Protection Commission (SSK)²⁹, patients must remain isolated for at least 48 hours. This means you cannot leave the nuclear medicine ward during this time.

²⁹ For Germany https://ssk.de/SharedDocs/Beratungsergebnisse/DE/2022/2022-09-22_Nuklide_in_der_Nukleartherapie.pdf?__blob=publicationFile&v=6

- Doctors (at least in Germany) have little to no discretion in this regard. Mathematically, the first cycle could end by Thursday afternoon when the 48 hours are up.
- However, in practice, many hospitals follow internal guidelines that extend this period to approximately 72 hours, meaning you can only leave the isolation ward and return home by Friday at the earliest.
- I had several discussions with the specialist doctors about this because I didn't want to stay on the isolation ward longer than "legally required." On the other hand, these discussions helped me realize that there are good reasons why these guidelines vary from hospital to hospital.
- My assessment: The more experienced a nuclear medicine department is with PRRT, the less likely they are to adhere to the "legal minimum" – and rightly so!

The previously outlined process doesn't really convey how the inpatient therapy feels subjectively or how to best prepare for a stay in the isolation ward. As mentioned earlier, I was able to prepare better for the stay with each subsequent cycle. This involved numerous details that, in hindsight, I consider very important and will elaborate on later.

For now, here's my overall impression of the first PRRT cycle. My "perceived condition" during and after the stay looked something like this – above the weekend, my impressions during the stay; below, my impressions after being discharged:

	Psyche	Physis
day 1	very good - hardly loaded	very good – top fit
day 2	good - hardly loaded	First headache, slight nausea after injection
day 3	Medium load, among other things due to conversations	Increasing headaches, aching limbs, tiredness
day 4	higher load	Severe headaches, nausea when smelling food, severe tiredness, sensitivity to the sun
day 5	inner relaxation	moderate tiredness
weekend	good - hardly loaded	good - hardly any restrictions
following week 1	Increasing stress due to internal review and perception of physical weakness	various corona-like symptoms, headaches, increased fatigue, exhaustion

following week 2	clouded view of the future, listlessness, slight feelings of anxiety	sometimes very severe tiredness, fatigue symptom; persistent exhaustion
following week 3	Doubts about the two previous weeks as a potential permanent state	Continuous physical recovery
following week 4	Unwillingness for the next cycle, uncertainty about the success of the therapy, doubts of all kinds	good - physically fit

The previous overview should not only be read column-wise (vertically) in terms of chronological progression but also row-wise (horizontally) to understand the interplay between psychological and physical states:

- For example, in the second week after the cycle, the sharply increasing physical limitations (right column) naturally led to higher psychological strain (left column).
- Additionally, there was the phenomenon of the "rollercoaster ride in the fog": Over the weekend following my discharge, I prematurely thought, "Great – everything feels fine again." But two weeks later, I felt an intense frustration upon realizing that this was merely a temporary phase – a brief "sunny high-pressure system."
- This up-and-down dynamic became even more pronounced during and after the third cycle, which I will discuss in greater detail in the next section.

In hindsight, I still consider the first cycle in the isolation ward surprisingly challenging – despite the fact that the physical side effects were minimal.

Three factors in particular caught me unpleasantly by surprise:

1. Conversations with other patients

On one hand, I was part of a temporary "patient community." As a "PRRT newbie," I wanted to absorb as much as possible about the experiences of others undergoing PRRT. On the other hand, after some conversations, I realized that I probably shouldn't have done so. There were two types of "unsuccessful" interactions that I'll describe here:

a) A conversation with a "seriously" ill patient: On the first day, I spoke with a patient about my age who appeared outwardly healthy. She had recently become a grandmother and was quite sociable. Her frequent smoking – something that didn't initially bother me as an occasional smoker myself – stood out. Then she shared her medical

history, which was vastly different from mine – much more severe! My highly sensitive "mirror neurons" seemed to kick in, and I immediately began to internalize her difficult story, partially projecting it onto myself. I was shaken to the core. How would I feel if I were in a similarly dire situation? This conversation triggered a cascade of self-perpetuating doubts about the side effects and ultimate success of PRRT in general. The patient had shared details of her experiences, some of which I would also encounter – albeit with, as it turned out, much more positive outcomes for me. This experience left me deeply unsettled, illustrating the psychological challenges of engaging with others in such vulnerable circumstances.

b) During the cycles, I also had another type of patient interaction that left a less-than-positive impression. In my self-perception, I openly shared that while I was grateful for my relatively positive overall situation, I still didn't feel particularly well and was plagued by uncertainty. Against this backdrop, I encountered some patients who seemed unusually composed. I found it hard to believe that they could genuinely be so much calmer than me, despite their (compared to mine) far less favorable medical circumstances. Were they truly more resilient and optimistic by nature than I was? Were they trying to mask their inner doubts with a display of strength? Or had they already come to terms with their lives? Each of these possibilities was equally un motivating for me.

It's paradoxical, but my experience with PRRT revealed a surprising contrast between objectively intense challenges and seemingly minor discomforts. Here's how it unfolded:

2. Patient Interactions

By the end of day one, I had lost almost all desire to engage with other patients. Still, the conversations I described under (a) linger with me to this day.

3. Physical Discomfort

Unexpectedly, I experienced severe headaches starting on the second day – before the actual therapy even began – and they worsened each day. This was due to the "special" hospital pillow, which triggered neck tension I can only compare to a strong migraine.

These headaches intensified shortly after the Lutetium (¹⁷⁷Lu) injection due to a heightened sensitivity to smells and tastes:

- Coffee: One of the photos I shared included a pot of coffee, which I usually love. The hospital coffee was good, but after the injection, I couldn't stand its smell or taste.
- Food: Hospital food is already "special," but after the injection, I couldn't tolerate the smell of anything remotely fragrant. I often placed my meals in the hallway immediately to avoid smelling them, regardless of whether they tasted good or bad.

- Carbonated water: I used to love sparkling water, but after the first cycle, this changed completely. Even at home, I now drink it only when flavored (e.g., with lemon or apple juice). This was particularly problematic during PRRT because you're required to drink large amounts of water to help flush the radiopharmaceuticals from your system.

When reading this, even I have to admit: These are minor inconveniences! My extensive tumor surgery, which involved lying motionless in bed for days, was objectively much more significant.

But that's precisely why I bring this up: The subjective effect of PRRT can feel like an unspecific mix of many "small" issues. The combined impact of these seemingly minor factors was, for me, far harder to endure than the more severe but straightforward tumor resection. Here are three "anecdotes" from my tumor surgery in March 2020 to illustrate why I was so surprised that PRRT (especially the first and third cycles) destabilized me more than I anticipated:

1. Before the lengthy tumor surgery, I needed an epidural. Unfortunately, the procedure didn't go as planned. For over an hour, multiple doctors tried unsuccessfully to inject into my spine. At one point, two strong nurses held me steady while more pressure was applied to my back. I was also given an opiate, which caused LSD-like effects – everything spun, and images blurred. The start to the surgery was objectively chaotic, yet I remained shockingly calm and relaxed.
2. After the operation, I woke up in the ICU unable to feel my left leg. To investigate, my pain medication was temporarily reduced – too much, as it turned out. For an hour, I experienced excruciating pain, yet I still felt surprisingly positive.
3. While in the ICU, I heard the screams and labored breathing of other patients – some with truly dire conditions. One patient had been there for weeks with a thoracic drain due to water in their lungs. While I empathized deeply with their suffering, I remained in good spirits, repeatedly thinking to myself: "I'm doing great!"

Through all these objectively intense experiences, I felt no internal burden – none at all! Even during similarly difficult moments later, I often pinched myself, wondering: "Why am I staying so calm during such heavy situations?"

Now I ask myself: Why, then, was I unable to cope well with a relatively harmless PRRT?

Why? I don't know. I only know that it was this way for me.

Perhaps it's because PRRT doesn't allow for a clear, concrete analysis of the situation in my perception:

- As mentioned, the liver metastases were abstract to me. Building on that, any need to escalate therapy felt like a step backward.

- The accompanying fog is persistent. If the sun briefly breaks through, returning to the fog feels even more negative.
- I lacked short-term, tangible successes that could be projected into the future. Instead, over a longer period, I only experienced subtle, unclear, and often burdensome impressions.
- Encountering other patients who (understandably) lacked any "positive energy" could suddenly shake my entire inner structure!

While I felt objectively and subjectively well as a NET patient before starting PRRT, it seemed to me that, during therapy (at least at times), my subjective condition worsened significantly.

How bad exactly?

As I've already written, this perception is very likely a matter of individual psyche. Particularly during the first cycle, every patient should expect to be surprised by the subjective impact of PRRT's "special" overall circumstances, including its potentially uncertain long-term success.

The good news, in hindsight: After some time, you realize that it was all just a temporary phase of discomfort, shaped by the unpredictable interplay of physical and psychological factors I've described.

Looking back, I allow myself the following recommendation or assessment:

- Accept all doubts, lows, crises, and fears for what they are! Even with great effort, you're unlikely to resolve them sustainably during the first PRRT cycle.
- These feelings may even subtly intensify over the course of therapy, accumulating with additional new uncertainties, fears, etc., despite growing "routine."
- Nevertheless, it's essential to hold on to the deep belief that the persistent PRRT fog will lift at the end of therapy.

I'll provide more concrete tips on all this in the next section, as the third PRRT cycle challenged my previous observations even more intensely.

For now, I want to emphasize that the first cycle can bring "surprises." It certainly did for me, and others may have similar experiences – especially if they (like me) are poorly prepared for the first cycle.

Below are a few – seemingly trivial – recommendations for preparing for your first stay in the isolation ward. They are each important in their own way. Note that visits from family members are usually not allowed. This means: As a patient, it's best to bring everything you'll need with you! Fetching forgotten items during the stay can be difficult.

Recommendation	Background
Take food and drinks with you	Almost every nuclear ward has a refrigerator for patients. Ask in advance whether this is the case for you and whether there is space for your own food and drinks and how much. Pre-packed snacks, cookies etc. can also make your stay much more pleasant. I later took food and “luxury foods” with me for almost every day - an important feel-good factor. This applies, among other things, to juice, which I now mix with mineral water: as I said, the PRRT has given me a subtle “water defense attitude”, which is mainly to do with the taste.
Have (warm) food delivered	Delivery services make it possible to have a “really tasty” meal in the meantime that you are not sensitive to: A pizza, a steak, whatever! Ask locally which delivery service you have had good experiences with. The food can also be enjoyed in the communal room for patients - so your own room remains odor-free. Don't forget: The smell of your steak could disturb the people living in your patient room.
Take the entertainment with you	<p>Don't be afraid of permanent contamination: smartphones, laptops, tablets etc. make your stay much more entertaining - provided you have a functioning or powerful WLAN. After therapy, devices can be decontaminated again using simple means. Don't forget your headphones! I had also installed an app from my streaming service on my laptop in advance. This can be easier at home than in hospital.</p> <p>But it can also be fun to take something (creative) with you to the hospital. I found the nursing staff's idea of giving patients stones to paint particularly funny. Some patients created real masterpieces. Others found it childish. I thought it was great - even though I didn't create any masterpieces (see photo below).</p>
Take headache pills with you	Even if the nuclear station most probably has all the medication you need: There are advantages to having your own “first-aid kit” with you. This allows you to decide for yourself which tablets to take and how many without any great formal effort. The nursing staff will certainly be happy to help, but they must always check

	and record all medication and the corresponding causes and tolerances.
take comfortable clothes with you	Sounds obvious, but due to radioactivity you might hesitate to do this right from the first cycle. I now know that you can absolutely trust this: After your stay, the radioactivity washes out relatively easily, even from your favorite clothes. Before the first stay, my wife and I were not quite so clear about this.
take a good pillow with you	The same applies here: don't be afraid of permanent contamination! Be sure to take your favorite pillow with you, but put it in two/three covers on top of each other. After your stay, the covers can simply be cleaned. The pillow itself is usually sufficiently protected. I would never go back to the isolation ward without my own pillow, because any additional (physical) tension adds to the other (psychological) tensions.
Take the fragrance spray with you	In my experience, odors of all kinds can have a significant impact on well-being after the injection. This was almost the biggest surprise for me. Once the smell of hospital food is in the patient's room, it usually dissipates very slowly. Other odors such as disinfectants etc. can also have an unexpectedly strong impact on subjective well-being after the injection. Regardless of whether it is a scented spray, deodorant, eau de toilette or perfume: it can help to reduce the feeling of nausea that quickly arises.
Bring food out of the room immediately	For me, this is perhaps the most important reaction during the first stay (without fragrance spray etc.): If you react negatively to (food) odors, the food should be taken back to the hallway immediately. You may not eat it (despite being hungry) in some cases. It also makes sense to leave the patient's room if other residents are eating their food. To reduce the smell afterwards, not only open windows help, but also (better in the short term) open doors.
move a lot, but don't exert yourself	I've always used the hallway to walk back and forth 20 times a day. Then you do receive a "smile" from other people, but that's ok. In my opinion, it is important not to make a mistake that I made during my first stay: I overexerted myself (the usual push-ups etc.) when I felt I was at my best and had a great urge to

	<p>exercise. The “revenge” for this came after the injection. Now I know: less is more!</p>
<p>only have the right conversations</p>	<p>As already described: Conversations with other patients can provoke unexpected reactions. That was certainly the case for me. As soon as you realize that a conversation is bothering you for whatever reason: Stop! No justification is needed. In return, it seems important to me that the nursing staff in particular can be an important discussion partner: They usually have a lot of experience with the subtle aspects of PRRT. In addition, they may also have (slightly) more time on a nuclear ward than nursing staff on other wards to discuss psychological or other aspects with you: It's part of the job!</p>
<p>generally reduce expectations in advance</p>	<p>The lower your expectations for the first cycle, the better. Also, don't take on too much! During the first cycle, I made the mistake of setting myself some “activity goals” (of a professional nature). Also with regard to the “positive rededication” outlined above, I initially had too strong an “urge to be active”. Less can also be more in this respect!</p>
<p>do not expect a single room</p>	<p>An isolation ward is “special” in every respect. Even private patients may only be able to enjoy the usual comfort to a “limited extent”. Many things are comparatively simple and “rustic”: for example, there may only be one central shower for all patients. The reason for this is the contaminated waste water. As a patient with health insurance, it is even more important not to have high expectations of a single room. Even if other rooms are recognizably empty: It should also be noted here that each room must be cleaned continuously and sometimes at great expense. Two patients per room is not harassment, but also a consequence of radioactive peculiarities.</p>
<p>Take Oropax with you</p>	<p>If a roommate shares the room with you: It could get louder at night! Perhaps you yourself will also be perceived as “perceptible”. Early open communication and Oropax can “defuse” the issue.</p>

It wasn't until the second and even more so the third cycle that I realized that a stay in the isolation ward can be quite pleasant. The following pictures might give you an impression of this.



Order food? Usually no problem. Treat yourself to things that taste (and smell) good



Freundliche Zone

Lab und Küche

Das allgemeine Ziel der Lab- und Küche ist es, die Patienten in der Isolation zu unterstützen und ihnen eine angenehme Umgebung zu schaffen. Die Lab- und Küche ist ein zentraler Bestandteil der Isolation und dient der Versorgung der Patienten mit Nahrung und Getränken. Die Lab- und Küche ist in der Isolation zu finden und ist für die Patienten zugänglich. Die Lab- und Küche ist ein wichtiger Bestandteil der Isolation und dient der Versorgung der Patienten mit Nahrung und Getränken. Die Lab- und Küche ist in der Isolation zu finden und ist für die Patienten zugänglich.

Pictures of the isolation ward at the Euro 2024: The perfect distraction!



Painting stones? Why not! A nice souvenir for children, grandchildren or (as here) the wife

er
an

Lupecke Marzipa

Rohmasse

ZUM BACKEN

& DEKORIEREN



Food for the nerves is important: Don't be afraid of embarrassment! I love e.g. marzipan paste



Sunset in the isolation ward: What more could you want?

Recommendations from patient to patient regarding the first PRRT-Cycle:

- The first cycle is the big unknown, both in terms of the overall PRRT process and the initial stay in the isolation ward. Both can be challenging and should be well-prepared.
- Regarding the overall PRRT preparation, a "positive repurposing" approach can be helpful: In what ways have you gained (or regained) more time over the months because of PRRT?
- Regarding preparation for your first stay in the isolation ward, several types of preparation are recommended:
 - Treat yourself to a little more of everything that makes you feel good. Do this especially during your hospital stay.
 - Find your personal "comfort image" to help mitigate potential stress quickly. Practice this in advance – it takes some effort to master!
 - Prepare a variety of small items that might be important during your hospital stay (e.g., pillows, scented sprays, entertainment, etc.).
 - Lower all expectations for the overall stay, including things like having a private room.
- Avoid engaging in difficult conversations with other patients unless you're confident you can handle them emotionally.
- Share any concerns with the nursing staff or doctors. They're familiar with the overall situation and can often provide excellent support.
- The first cycle is undoubtedly the "thickest fog" in the PRRT journey. However, you'll quickly gain experience during the hospital stay. This fog is likely to diminish with each subsequent cycle.



4

**A pretty flat tire:
How and why does the air escape?**

The thing with the side effects

The previous image shows an almost flat tire: there's still some air in it, but not enough to make the associated e-bike usable. The side effects of PRRT can feel similar: it slowly or suddenly lets the "air" out of the patient's "health tire." It may take some time before this tire is refilled and the health "e-bike" is ready for regular use again.

This means: patience is essential when it comes to the ebb and flow of side effects.

As a nuclear therapy, PRRT can cause side effects that last for days³⁰, weeks, or even permanently. These may occur during the hospital stay but are more likely to emerge after (temporary) discharge. Of course, not all side effects are equally impactful or frequent. Severe long-term side effects are quite rare, resulting in a generally favorable benefit/risk ratio.

However, as a patient, you should expect that some side effects will occur.

Below, I'll differentiate between three types of PRRT side effects, focusing on the middle category based on my own experience. Column A was already discussed in the previous section.

A. short-term	B. medium term	C. long-term
during inpatient stay in isolation ward	during inpatient stay in isolation ward	persistently after the end of the PRRT
including nausea, vomiting, fatigue, headache and abdominal pain, flush symptoms, circulatory and respiratory problems, allergies, increased blood pressure, psychological problems	Including tiredness, fatigue symptoms, headaches and stomachaches, hair loss, kidney problems, flush symptoms, increased blood pressure, mental health problems	e.g. hair loss, kidney problems, changes in blood counts, functional limitations of the liver

When considering all three categories, it is essential to differentiate between psychological and physical side effects. Both types are interdependent, as previously described, and the progression of the underlying disease (NET) also plays a significant role:

- Many cancer patients already experience increased psychological strain, and PRRT with its unique characteristics can amplify this burden³¹.

³⁰ An overview of the different side effects can be found here: <https://pmc.ncbi.nlm.nih.gov/articles/PMC5825944/>

³¹ <https://www.paracelsus-kliniken.de/psychische-belastung-bei-krebs-ist-enorm/>

- Cancer-related fatigue, common in many cancers, manifests as atypical exhaustion and weakness across multiple dimensions³². Here too, physical and psychological factors interact. PRRT can trigger new effects or exacerbate those linked to the underlying disease.

Fatigue is a recurring theme in the following discussion, alongside other information primarily based on my personal experiences in Phase B.

Important Notes:

- During the cycles and related preparatory or interim examinations like PET/CT scans, I had numerous conversations with other patients and healthcare providers.
- I noticed that the range of side effects appears at least as individual as the many variations of the previously discussed NET "zebras."
- The different types of NET likely influence both the potential success and the side effects of PRRT.
- For example, according to some studies, a non-functioning pancreatic NET statistically has a higher likelihood of success with PRRT compared to other NET variants.
- However, a higher success rate doesn't necessarily mean fewer side effects. It's even possible that with increased PRRT success, side effects become more pronounced. For instance, as metastases regress significantly, a large number of cells are destroyed, potentially weakening the body.

In my case, this might have been exactly what happened:

- On the one hand, I seem to belong to the group of patients who experienced a significant reduction in metastases after PRRT.
- On the other hand, I experienced relatively strong, prolonged, and in some cases unusual side effects compared to publicly available information.

Therefore, when I write in more detail about the side effects I experienced as a patient, it's with the conviction that there might be a connection between therapy success and the intensity of side effects.

Before detailing these experiences, it's essential to note that at least two causes of side effects can be differentiated across Phases A, B, and C:

1. In Phase A, short-term nausea and other effects are often caused by protective infusions³³.
2. In Phases B and C, the healing effects of the radiopharmaceuticals, along with their other impacts, play a key role.

³² <https://selpers.com/lektion/nachsorge-bei-krebserkrankungen-psychische-folgeerscheinungen/>

³³ <https://www.uniklinikum-dresden.de/de/das-klinikum/kliniken-polikliniken-institute/nuk/therapie/FlyerPRRT2.pdf>

To make the second aspect more tangible:

- The healing effect of radiopharmaceuticals ideally causes the tumor or metastases to regress significantly or even completely. This healing process is intentional but inevitably places strain on the body by destroying cells.
- Other side effects, such as changes in blood counts or impaired kidney function, are unintended yet unavoidable possibilities. This applies to all side effects, whether short-, medium-, or long-term.

Whether the side effects experienced in Phase B are potentially "healing in nature" can only be determined after the second cycle, when a PET/CT scan is performed for the first follow-up assessment. Until then, the period may feel particularly unpleasant because:

1. You might experience lingering side effects for an extended time.
2. It's still unclear whether these effects are a positive sign (indicating healing) or a negative sign (suggesting complications).

If you want to find a silver lining in this uncertainty, it's that strong side effects can often be a sign of the therapy's healing effectiveness. Even the impression that the side effects seem atypical doesn't necessarily mean something negative.

The real difficulty lies in identifying, structuring, and evaluating the many nonspecific, subtle, diffuse, and interdependent side effects – especially during Phase B. This is particularly true if you're not being treated by doctors with extensive PRRT experience:

- As a patient, you may lack the precise language to describe the broad spectrum and interactions of PRRT's often delayed effects.
- Simultaneously, doctors may lack sufficient data and experience, particularly regarding Phase B. The reasons for this will be outlined below.
- This mismatch can lead to a frustrating *déjà vu*: revisiting the doubts already encountered during the diagnosis of a NET Zebra. Questions arise about whether and to what extent your subjective, often subtle side effects are being correctly understood and assessed by medical professionals.

For example, during Phase B, you might experience a side effect that has never been medically documented. The assumption might then arise that it isn't related to PRRT but rather stems from other causes. At that point, you might hear a familiar and painful phrase from your diagnostic journey:

"Common things are common, and rare things are rare."

If you, as a patient, hear this phrase in the context of side effects during Phase B, you have every right to question it. Regarding the post-inpatient Phase B of PRRT, it seems that, due to the currently limited data available, one can only distinguish between "rare" and "even rarer" side effects of PRRT:

- Based on my (extensive) research, it appears certain that existing statistics and studies on PRRT side effects are based on relatively few cases.
- This is compounded by the fact that side effects specific to Phase B are only loosely documented and are often described vaguely by patients. As a result, they are rarely or not at all reflected in PRRT studies.
- Additionally, in Phase C, the problem arises that PRRT is a relatively new therapy. Long-term experience is still quite limited.

I mention this because, in the following sections, I will not only describe side effects that have been confirmed by studies to be associated with PRRT. I will also outline perceived side effects that may be unusual and, to my knowledge, have not yet been reported in any PRRT or Lutetium (¹⁷⁷Lu) study.

General Context – Particularly Relevant to PRRT:

- Identifying therapeutic side effects remains a "systemic gray area" in oncology.
- Across all medical studies, the statistical recording of side effects is often inadequate³⁴.
- This is inherent to the process: collecting "real-world data" after a therapy is becoming increasingly important in oncology³⁵, but it is not easy to implement operationally. Such efforts require technical infrastructures, validated questionnaires, participation from patients and researchers, often, a sponsor to fund the study.

Against this backdrop, I intentionally describe the side effects I experienced in detail, without regard to whether I, as a layperson, can definitively determine how much they were caused by PRRT or other factors. However – and this brings the argument full circle – even PRRT experts may struggle to assess this comprehensively due to the limited data currently available.

While the lack of reliable data is unfortunate, it can partly be explained by two key factors: The relative novelty of PRRT: As a recently developed therapy, it lacks a robust foundation of long-term studies. The therapy's specific structure: The repeated alternation between short hospital stays and long breaks presents unique challenges for documenting side effects, especially during Phase B. This context underscores the need for further data collection and research to enhance the understanding of PRRT's full spectrum of side effects.

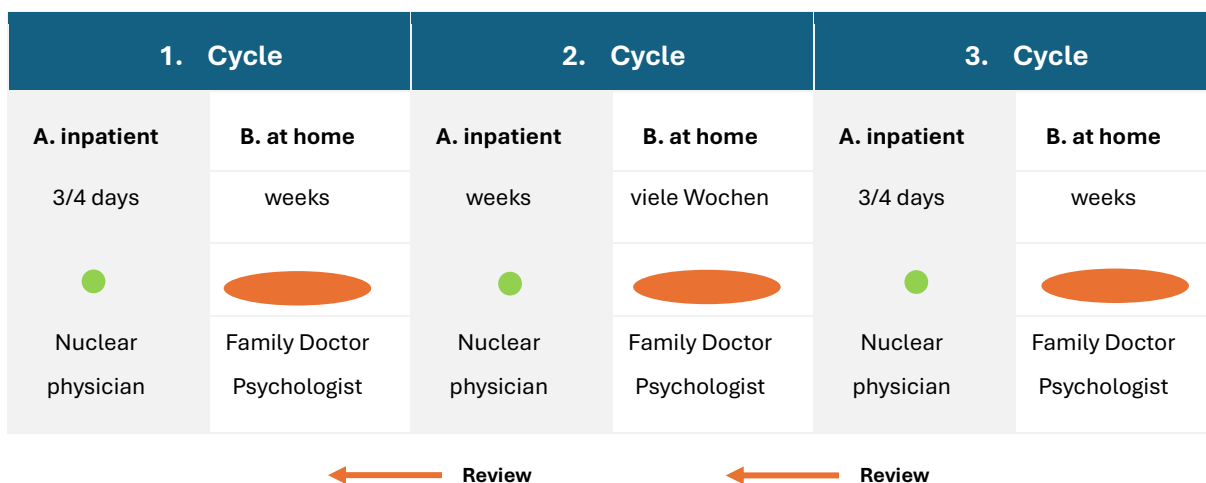
³⁴ E.g. <https://www.deutschlandfunk.de/publizierte-medizinische-studien-die-haelfte-der-100.html>

³⁵ <https://fachportal.roche.de/fachgebiete/onkologie/artikel/das-beste-aus-zwei-welten.html>

The reasons for these challenges can be illustrated more concretely through my personal experiences:

- During the hospital stay (Phase A), side effects of PRRT can currently be captured and monitored relatively effectively.
- Once the patient has left nuclear medicine (Phase B), they typically only see their general practitioner or, at best, a few other specialists over the following weeks:
 - These other doctors are often unfamiliar with PRRT; they may never have even heard of this therapy.
 - If a general practitioner, diabetologist, or psychologist records health complaints following a PRRT cycle, it is challenging for them to determine whether and to what extent these complaints are directly related to the therapy. Even with additional research or consulting supplementary information, understanding such connections is currently quite limited for "regular doctors."
 - Conversely, nuclear medicine specialists typically receive only sparse and unspecific information about Phase B side effects from their patients. Physical and psychological side effects that emerge after a PRRT cycle are often reported weeks later, usually at the start of the next cycle. These reports are retrospective and based on the patient's rough recollection, limiting their accuracy and detail.

When viewed on a timeline, the unique organizational challenges of capturing "PRRT side effects" become even clearer: The repeated interplay between Phase A (hospitalization) and Phase B (post-discharge) makes consistent and comprehensive tracking of side effects particularly difficult.



With PRRT, the intervals between the respective cycles are comparatively long (6 - 12 weeks). The patient therefore does not spend the largest period of time for potential side effects in the clinic, but at home (B). In this phase, the patient is usually hardly in direct contact with the treating PRRT or NET experts:

- The side effects of Phase B are therefore usually not observed through a relatively clear, large medical "windshield."
- Instead, they are typically recorded and assessed through a small "rearview mirror," clouded by patients' nonspecific recollections.

Beyond the already infrequent contact between patients and PRRT experts during Phase B, there is another significant hurdle to consider:

- In Germany, there are approximately 1,800 hospitals³⁶. However, the exact number of clinics offering PRRT is currently (still) not publicly available.
- Estimates suggest that 20 to 30 specialized centers are capable of performing PRRT, representing roughly 1 to 1.5% of all hospitals in Germany.

The Consequences:

- PRRT patients from rural areas or smaller towns face not only long intervals between cycles but also a significant geographical distance between the nuclear medicine center and their homes.
- A (digital) remote monitoring system for side effects would be highly desirable. However, implementing so-called PROMs (Patient Reported Outcome Measures³⁷) requires infrastructure, standardized questionnaires, and active participation from patients.
- Even when care is supplemented by a local oncology day clinic (as it was in my case), the healthcare providers there rarely possess in-depth knowledge of PRRT or its typical and atypical side effects.

Further Implications:

- Due to the long intervals between PRRT cycles and the distributed care provided by various doctors, there is a systemic "information gap" when it comes to systematically recording and evaluating side effects during Phase B.
- While a general practitioner can document some side effects, they – and even an additional psychologist – rarely have the expertise to determine which side effects are plausibly related to PRRT and which are not. The same challenge applies when distinguishing between NET-related symptoms and those caused by PRRT.
- When patients finally meet their nuclear medicine specialist again after many weeks, they often cannot provide meaningful information. Over the weeks, their recollections of side effects tend to fade or become jumbled, resulting in inherently nonspecific reports.

³⁶ <https://de.statista.com/statistik/daten/studie/2617/umfrage/anzahl-der-krankenhaeuser-in-deutschland-seit-2000/>

³⁷ <https://www.bertelsmann-stiftung.de/en/publications/publication/did/patient-reported-outcome-measures-proms-ein-internationaler-vergleich>

For many NET/PRRT patients, there is an additional significant hurdle:

- The particularly insidious psychological side effects, in my experience, require open discussion – something that is far from easy.
- Information shared with a psychologist is especially sensitive, and many patients do not want these details shared – not with anyone, including other doctors.

When the nuclear medicine specialist asks about side effects at the start of the next cycle, the following tends to occur:

- The patient primarily remembers a few pronounced "peaks" of potential side effects that they experienced at some point in the previous weeks.
- For example, if hair falls out in clumps after PRRT, it is almost certainly an "unforgettable" experience. This will remain in the patient's memory and can still be described in detail weeks later.
- The same applies to intense or clear symptoms, such as severe abdominal pain or a sudden, strong allergic reaction that developed afterward.
- Beyond these peaks, however, the information is often nonspecific and relates to general well-being, with remarks like "I felt bad for a few days" or "I was more tired than usual."

With this context, I will now begin listing the side effects I experienced during Phase B in detail. It is essential to note, as previously emphasized, that I assume an above-average positive outcome of PRRT. This very fact might have – according to my hypothesis – led to comparatively intense reactions.

Week	Cycle	Side effect in phase B	Intensity
0	1,2,3	The weekend after I was discharged from the isolation ward, I felt good every time: mentally and physically. I still have no recollection of any symptoms. There was a positive health self-perception with regard to phase B of each cycle before side effects occurred.	
1	1,2,3	Just one week after each injection, usually on the Tuesday after discharge, the first effects appeared, which I interpret as a side effect of PRRT due to the self-similar repetition:	
		<ul style="list-style-type: none"> ○ Overnight development of severe headache, especially severe neck pain in the same place; quite localized pain (felt like a "snake bite"). 	
		<ul style="list-style-type: none"> ○ Loss of balance after getting up, which increased over the course of the week. Sometimes I had to be careful not to fall over, even over short distances. The balance problems only subsided after standing for about a minute. Similar to a positional vertigo effect, which sometimes lasted over a week. 	

		<ul style="list-style-type: none"> ○ Strong lack of concentration, limited ability to focus on content-related topics. 	
		<ul style="list-style-type: none"> ○ Increasing burning of the facial skin over several days. This is accompanied by tinnitus. 	
		<ul style="list-style-type: none"> ○ Increasing pain in the upper abdomen on the right and left. Atypical in comparison to other pains (including chronic pulling in the abdomen as a result of hernia surgery) 	
		<ul style="list-style-type: none"> ○ Gradually developing corona or flu-like symptoms, including cough, runny nose, sore throat and metallic taste in the mouth. But no fever. 	
		<ul style="list-style-type: none"> ○ Increased sensitivity to light, which correlates with tiredness, among other things: The more light, the more tired I became. This applied to sunlight as well as light from screens. 	
		<ul style="list-style-type: none"> ○ Accompanying this, especially during the first cycle (when the side effects were still unknown), inner restlessness, incipient depression and listlessness. 	
		<ul style="list-style-type: none"> ○ There were also temporary contact restrictions, but these only had a slightly negative impact (if any): 	
		<ul style="list-style-type: none"> ▪ No direct contact with my grandchildren on site. 	
		<ul style="list-style-type: none"> ▪ Also no contact with pregnant daughter. 	
		At the end of the first week of each cycle, there was an interim recovery and a good feeling of well-being.	
2	1,2,3	At the beginning of the second week after the injection, increased effects occurred again after each cycle, which I also interpret as a side effect of PRRT due to the self-similar repetition:	
		<ul style="list-style-type: none"> ○ Massive fatigue after light physical exertion. However, non-linear: sometimes surprisingly little, at other times excessively strong. 	
		<ul style="list-style-type: none"> ○ Stomach and urinary tract problems. Increasing depression with strong downward peaks and subsequent recovery and a feeling of “normality”. 	
		<ul style="list-style-type: none"> ○ I was able to recognize these and other patterns better in the second and third cycle and thus cushion them better internally in the third cycle. 	
		<ul style="list-style-type: none"> ○ Overall strong restraint, e.g. with regard to longer car journeys (> 10 km) due to rapidly decreasing concentration and rapidly increasing tiredness. 	
		<ul style="list-style-type: none"> ○ In all three cycles, there was always a clear inner brightening at the end of the second week with an overall decrease in the negative perception of the overall situation and an increase in physical fitness. 	
3	3	During the third cycle, at the beginning of the third week after the injection, new, sometimes severe, longer-lasting side effects occurred for the first time and completely unexpectedly:	

		<ul style="list-style-type: none"> ○ “Leaden”, sometimes very deep fatigue, even after minor physical activities such as short walks, simple gardening, light e-bike tours, normal computer use; sometimes up to 15 hours of sleep per day over several days (but with intermittent breaks for well-being). 	
		<ul style="list-style-type: none"> ○ Intermediate high blood pressure, but blood test without abnormalities. 	
		<ul style="list-style-type: none"> ○ Persistent aching limbs, considerable slowing down of thought processes and movement sequences; perceived ageing of more than 10 years within a few days. Persistent stomach and urinary tract problems. 	
		<ul style="list-style-type: none"> ○ Three-day psychological low point due to feeling old and doubts about the duration of the side effects; conspicuous lack of interest in environmental information of all kinds; indifference and inner emptiness. 	
		<ul style="list-style-type: none"> ○ Gradual physical improvement towards the end of the third week. 	
		<ul style="list-style-type: none"> ○ Parallel to this, continuously decreasing inner tension and depression. 	
		<ul style="list-style-type: none"> ○ Return to positive physical normality at the weekend; return to stable high motivation. 	
4	1,2,3	Conscious physical rest. Fluctuating temporary side effects, especially tiredness. Improved general well-being. Increasing mental stability.	

As a patient – this is my recommendation – you should start paying closer attention after the first cycle to identify any changes that might subjectively be linked to PRRT. For example, I wrote myself small notes to better recall later whether I experienced the same effects during subsequent cycles in Phase B. Only after observing similar effects repeatedly during later cycles did I become convinced that they were likely side effects of PRRT.

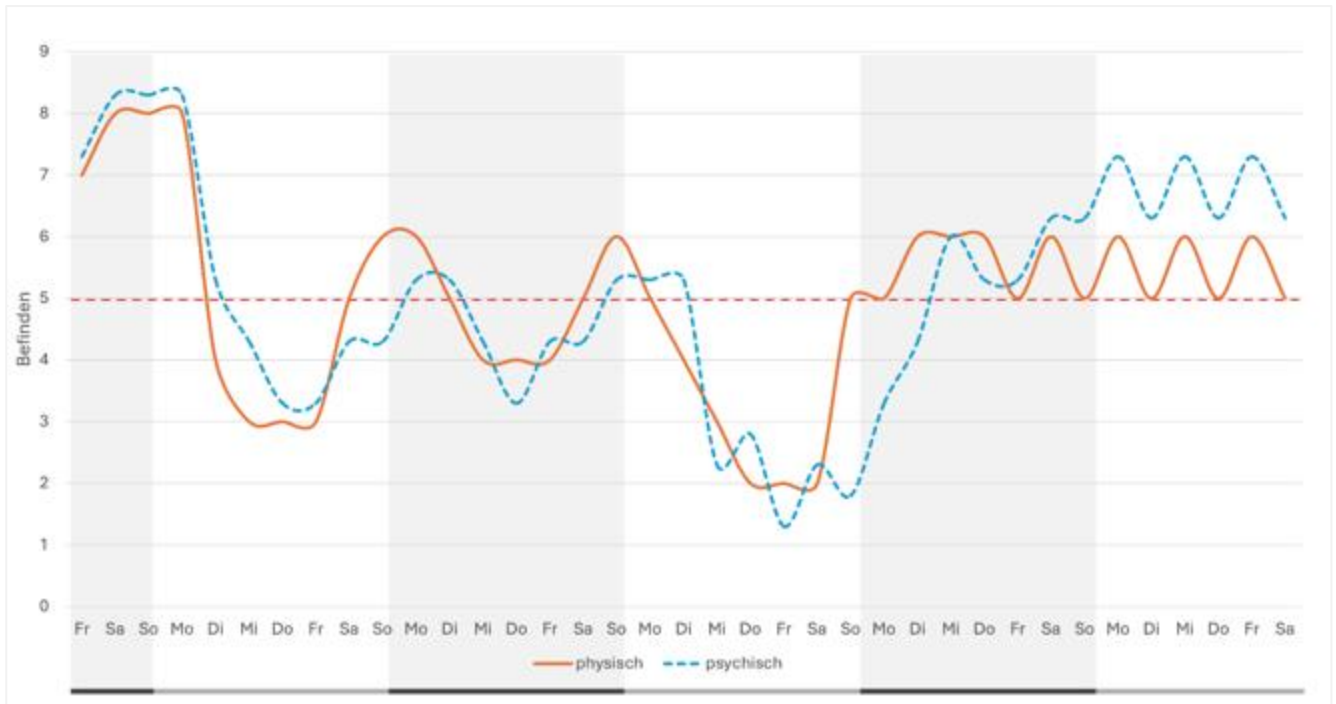
The following information revisits Phase B, focusing on Cycle Three, presented in a slightly altered format on a timeline:

- The next overview pertains exclusively to the third cycle.
- It differentiates only between physical and psychological sensations.
- The insights are retrospective and subjective evaluations.

Despite the inherent inaccuracies, a wave pattern stood out:

- In the middle of the week, I experienced a (varying in severity) low point, both physically and psychologically.
- Conversely, I felt exceptionally good on weekends.

This pattern of alternating highs and lows became a notable feature of my third cycle experience.



The third cycle was particularly notable for the following reasons:

- Unlike the first two cycles, the third week was by far the most physically and psychologically challenging period of aftereffects in Phase B.
- I felt significantly aged over several days – primarily physically, which I perceived through a noticeable slowness in my movements and daily activities.
- What stood out most to me was the element of surprise: contrary to the first two cycles, this was the first time I experienced such intense side effects during the third week post-discharge.

Observations and Final Summary:

1. Understanding Side Effects Over Multiple Cycles:

- It likely takes at least two cycles to distinguish which side effects might be attributed to the underlying condition (e.g., NET or hernia surgery aftermath), which are potentially linked causally to PRRT, and which may be coincidental occurrences (e.g., pain from tendonitis).

2. Notable Side Effects Over Time:

- The injection of Lutetium (^{177}Lu) consistently triggered noticeable side effects approximately one week after administration. These included headaches, dizziness, fatigue, and more.
- One particularly insidious effect was positional dizziness after standing up. This could lead to dangerous situations, as the imbalance became apparent only after standing, creating a genuine risk of falling.

- Short car rides also became problematic due to sudden onset of intense fatigue, leading me to avoid driving as much as possible.
3. Interaction Between Physical and Psychological Factors:
- The recurring interaction of physical and psychological factors was especially burdensome. The already vague fatigue symptom was intermittently very debilitating.
 - The third cycle brought the most significant peak of these effects – occurring in the third week post-injection. This was particularly distressing because I initially experienced an improvement similar to the earlier cycles, only to face a steep physical and then psychological "crash."
4. Recovery Before Each Next Cycle:
- Despite these challenges, my overall condition improved significantly before the start of each subsequent cycle.
 - No long-term side effects persisted in either Phase B or Phase C, allowing for recovery between cycles.

These experiences emphasize the unpredictability and variability of PRRT side effects, highlighting the importance of patient preparation and adaptability across multiple cycles.

Recommendations from patient to patient regarding side effects of PRRT:

- All PRRT patients should anticipate side effects during Phase B. The key question is how to interpret them: frequent and intense side effects are not necessarily negative – they may, in some cases, indicate a positive healing response.
- Take all perceived side effects seriously, even if they seem atypical! The rule of thumb, “Common things are common, rare things are rare,” is only partially applicable to Phase B side effects. The lack of robust data makes this clear.
- Atypical side effects might still provide important insights. If you're uncertain, share all experiences you consider relevant with nuclear medicine specialists at the start of your next cycle.
- Recurrent side effects across multiple cycles often become more manageable due to their familiarity – you know they will come and eventually subside.
- Be prepared for surprises after each cycle. Side effects may vary and can include new experiences. However, they are typically temporary.
- Consider the diffuse interaction of physical and psychological effects: this interplay can lead to unexpected peaks in symptoms. Alongside your general practitioner, consider seeking psychological support early – talking helps!
- Be mindful of side effects that could pose concrete risks, such as positional dizziness (which may lead to falls) or fatigue while driving. Take extra precautions in these situations.

5



**Many opportunities through the PRRT:
But in the end, it's your own path that**

Learnings, Theses and Conclusion

First and foremost: PRRT represents a significant opportunity for many NET patients! The German healthcare system makes it possible for public health insurance patients to access this innovative, albeit costly, therapy.

This is far from guaranteed in many other countries, even within Europe.

Despite PRRT's high success rate, patients might initially struggle to fully appreciate the value of this opportunity:

- PRRT is a lengthy process that can significantly disrupt daily life.
- Terms like “radiopharmaceuticals” and “isolation ward” are not exactly comforting.
- The potential for side effects can also be unsettling.

As outlined in the previous sections:

- Despite generally favorable conditions, I found myself deeply unsettled for an extended period – not only regarding PRRT itself but also concerning its tangible consequences.
- Only through “positive repurposing” did I begin to accept the otherwise frustrating overall situation. Today, I even tell myself that I wouldn't have been able to write this guide without experiencing PRRT firsthand – a positive side effect I didn't anticipate until after the third cycle.
- Enduring the PRRT fog is not easy. Even for someone like me, who considers themselves mentally stable, it was challenging. The combination of nonspecific, diffuse interactions with long-term uncertainty is not a pleasant mix.
- However, the cycles of PRRT are, in some ways, like having children:
 - The first child often raises many questions, which become routine by the second.
 - By the third and fourth, even more so.
 - That said, every child develops individually – and that's a good thing.

PRRT is unquestionably a significant opportunity – not just for patients but also for the healthcare system. It raises many critical issues, which I have explored in three separate discussion papers³⁸:

1. Pro and Con of Part-Time Sick Leave – Exploring New Paths
2. Innovation vs. Regulation in Nuclear Medicine Therapy
3. “The Universal ePA” – Opportunities and Limits Using PRRT as an Example

³⁸ mehr Informationen dazu unter www.prrt.info/diskussion

Moreover, improving the tracking of side effects in Phase B (and beyond PRRT) is particularly important. Effectively addressing this challenge will require a better collaboration between providers, researchers, and patients.

PRRT patients can actively contribute to these efforts:

- By sharing their health data and experiences with other patients and healthcare providers.
- Only with patient support can medical research and practice tackle the challenges of an increasingly strained healthcare system.
- Such engagement ultimately benefits patients themselves, helping them lead the most fulfilling life possible despite NET.



Modell
der Ze
M. Huber und

**Model of a research reactor:
It is needed to create radioisotopes such as lutetium (^{177}Lu)**



FRM2 research reactor at the TU Munich

In My Own Words

Writing a patient guide is easier said than done. You naturally want to project the message: “I’m doing well!” Yet this text reveals: “Not entirely true!” Looking at a photo from an e-bike tour in early October 2024, one might mistakenly think that I couldn’t have been in better shape. But that’s precisely part of the challenge with therapies like PRRT: the diffuse interplay of physical and psychological factors over long stretches of time, coupled with an unpredictable rollercoaster of ups and downs within short periods.

These dynamics only allow for snapshots. Some of these may be positive – presumably, I genuinely felt good when the photo was taken. But there were countless other phases during the months of therapy when I had no motivation to take a picture at all. Perhaps that’s for the better.

By the time this photo was taken, the side effects of the second cycle had finally subsided. Around the same time, I received the encouraging results of my first PET/CT follow-up scan, confirming that the PRRT was working. It had been worth enduring the many uncertainties, and I was glad to have undergone PRRT relatively early in the progression of my disease. Much of the inner tension I’d been carrying began to dissipate.



What I didn’t know when this photo was taken, however, was that the third cycle would bring new and intense surprises in terms of side effects after my discharge. The physical and psychological low point came in early November 2024, three weeks after leaving the isolation ward – weeks after this photo was taken.

You wouldn’t guess from this picture that, shortly thereafter, I would need 15 hours of sleep daily for several days. Even the smallest efforts left me utterly drained. My movements and thoughts became astonishingly slow. I felt as though I’d aged decades in mere days, and it was incredibly hard to imagine that this dire state – both physical and psychological – was only temporary and would soon pass. Yet, as if by magic, it did! Writing this guide played a role in that recovery.

This is what I want to convey: PRRT, especially when effective, can repeatedly bring moments of profound exhaustion and inner paralysis. How you feel inside is not always visible on the outside.

Yet the feeling that the often-mentioned “PRRT fog” can dissipate for potentially a long time is not just comforting – it’s empowering. It’s a source of strength for handling uncertainties in a constructive way, and uncertainties abound in the world we live in today. When illness or therapy side effects are added to the mix, acceptance and coping become even more challenging.

Or is it not rather the other way around: it becomes easier to live with it?!

To borrow the words of T.E. Lawrence from the film ‘Lawrence of Arabia’: he “trick” in certain circumstances is “not minding that it hurts.” This, too, is easier said than done. But through the occasional painful fall while e-biking, I’ve learned:

You should at least try – it really can help.

For making all therapies possible (NET resection, Somatulin therapy, PRRT & patient support) I would like to thank the following:

- Netzwerk-NET
- INCA – International Neuroendocrine Tumor Alliance
- seltenkrankheiten.de
- Kaufmännische Krankenkasse KKH
- Klinikum Großhadern LMU
- RoMed-Kliniken
- Hausarztpraxis Aschau
- My psychotherapist
- and, of course, my family