

Dear Me, with FNS in a world that wants to understand or fix everything
(Letters from a body that is failing and a heart that refuses to give up)

Foreword

They said: 'It's all in your head.'
As if that would make it less serious.
As if your head isn't part of your body.
As if your brain can't crash from overload, trauma, or just... bad luck.

And suddenly there's a label. A diagnosis. FNS.
Functional Neurological Syndrome.
It sounds clinically neat.
But it doesn't feel that way.

Not for me (yet), anyway.

It feels like there's a short circuit in your nervous system.
As if someone has fixed your wiring with duct tape and paper clips -
and every time you think: now it's working again,
something else fails.

Sometimes it's your leg.
Sometimes your speech.
Sometimes your concentration, your balance, or your confidence in your own body.
Sometimes it's double or blurred vision. Or temporarily not being able to see anything at all. Difficulty swallowing - or suddenly choking for no reason.
Slowed thinking. Information that doesn't come through, or sticks in my mind like sludge.
Sometimes tremors in your body. Paralysis.
Loss of strength in your arm, your leg - or both.
And in the meantime: sounds that come in far too loud, lights that cut,
a supermarket that feels like a maze full of sirens and unexpected obstacles.
On top of that, a fatigue that cannot be solved by 'a good night's sleep'.
And on some days... everything fails you at once.

And the outside world?
They don't see anything.
Or they think you're exaggerating. Or that you "need to think more positively".
Or "just do something fun".
As if positivity and distraction are the off switch for your complaints - well-intentioned, of course.

It is there.
In your head.
In your left hand that suddenly doesn't work anymore.
In the fear of not being taken seriously.
In your legs, which sometimes don't know if they'll cooperate today.
As if you've lost control of your own body.
Even though you're trying so damn hard to stay on your feet.

I'm writing this book because I'm tired of explaining.
Because I'm done with the looks of doubt.
And because I know how it feels to dance on a good day,
and then almost feel guilty afterwards -
as if laughing invalidates FNS.

This book is not a manual. Not a solution. Not a plea for pity.
It is a collection of letters.
Raw. Loving. Uncomfortably honest.
Sometimes with humour, sometimes with tears.

Letters to myself. To other people with FNS.
To doctors, civil servants, social workers, family, friends, neighbours —
to anyone who may not know what FNS is,
but is willing to listen.

Because FNS is not "all in your head".
But it is there.

So I write.
Because words can open things up.
Like light shining through a crack in the door.
Not to understand or fix everything, but to finally see it for what it really is.

Letters that make FNS just that little bit more visible – that's my hope.
For you. For me.
For that one family member, friend, doctor or civil servant who still thinks it's
not that bad.
And for those – including myself – who don't quite understand yet.
Because that says more about this condition than about the person living with
it.

For everyone who lives with a body that sometimes doesn't cooperate –
and a heart that refuses to give up.

Welcome.
You are not alone.

Letter 1

Disconnected (*My first signs of FNS*)

Dear Me,

My body knew before I did.
A tremor that I quickly dismissed.
A leg that suddenly started to drag.
Eyes that became blurry, as if my gaze was withdrawing from the world.
And somewhere inside – that little voice: 'Something's not right.'

I kept going. Of course.
Gritting my teeth, because what else could I do?
I didn't want to be difficult or weak.
I really didn't have time for that.

I thought: maybe it will pass.
Maybe it's just stress. Or lack of sleep.
Or grief. Or overstimulation.
Or my imagination.

But then, more and more often:
words that wouldn't come,
a body that wouldn't follow,
a head that emptied or froze – sometimes all at once.
I thought: 'What is this?'
And even though I didn't understand it myself, I also wondered: how can I
expect anyone else to understand?

While my world was slowly shrinking,
the outside world was still in full swing.
There was chatting, laughing, cycling, dancing –
normal life going on, which I so wanted to be a part of.
The world was deaf to what was standing still inside me.

As if nothing was wrong.
And I watched –
half present,

half absent.
With a body that betrayed me.
With a mind that let me down.

They asked, 'What's wrong with you?
I shrugged my shoulders. I didn't know.
That ignorance ate away at me inside.
Because if I couldn't explain it myself,
how could anyone else understand that something was really wrong with me?

I felt lost in my own nervous system.
As if the connections had suddenly changed,
as if the power had gone out.
In places where I desperately needed it.
I wanted to, but I couldn't.
And that "not being able" felt like failure -
even though it wasn't my fault.

And in the meantime, I had to function.
Act normal. Participate.
They still needed me — family, friends, life going on.
I wanted to be there for them, even though it completely drained me.
Every time I fell back, but I couldn't help it.
I dragged myself along, spoke words that my body didn't follow,
tried to pretend I was whole — while inside everything was breaking.
While my body screamed out.
Or said nothing at all.

On those grey days when everything came to a standstill, taking good care of
myself was already quite an achievement.
Taking a shower felt like a difficult task without the right tools.
Making a phone call felt like talking through a thick fog where words get lost.
Making a decent breakfast seemed like an impossible mission.

I started to withdraw.
Because explaining took too much effort.
And the looks of incomprehension cut too deep.
As if I was making it up.
As if I was too sensitive.
As if I was putting on an act.

So I fell silent.
And in that silence, loneliness grew.
Not because I was alone,
but because no one could really reach me.

And yet here I am.

Still.

I write.

Because I need words that create space.

For myself. For others.

Because I know: if I'm going through this, I'm not the only one.

And if one person feels a little more seen after reading this letter,
then it won't have been for nothing.

I am not my complaint.

Not my label. Not my limitation.

I am so much more.

So I keep writing.

For the part of me that always carried on.

For the part of me that whispered: don't give up.

For that stubborn part of me that, despite everything, believes that love and
compassion are stronger than body and mind in revolt.

I am allowed to be here.

Love,

Your searching, silently discovering self



'You don't have to understand everything to bear it.'

Letter 2

The day it got a name

(Relief, confusion and the struggle to accept)

Dear Self,

The diagnosis came on 31 December 2024, at exactly 2:30 p.m.

Not exactly a festive end to the year – but then again, holidays are for people
who don't constantly doubt their own bodies, which can let you down at any
moment.

I sat in the waiting room, full of confusion, and went home even more confused.

At first, I was relieved: it wasn't MS.
Something recognisable, something with a name.
But that relief quickly gave way to even more confusion.
And resistance.
And a flood of questions without answers.

FNS. Functional Neurological Syndrome.
Sounds like a technical malfunction in a complicated machine.
Something that happens to your body without a clear cause or cure.

How do you explain that to yourself? Who the fuck ordered this? Where's the complaints line? The manual? And will I get compensation points for it at the karma desk?

And how do you explain FNS to a world that clings to diagnoses with hard results?
In a world that seeks reassurance in facts and clear answers, it is almost impossible to understand what I am going through.
How do you explain that something is so tangibly real, even though there is no measurable evidence for it?
That my body and mind are stuck, with no reset button, switch or key to restart it.

That makes it lonely.
Because it seems like everyone is waiting for a label, a result, something concrete they can hold on to.
But my reality cannot be captured in numbers.

So I live between two worlds:
The visible one, where everything has to be logical and clear -
and the invisible one, where my body struggles without anyone seeing it.

And yet I continue to hope that understanding begins with listening,
with really seeing and making room for what cannot be measured.
Because FNS is a diagnosis that makes sense on paper,
but in practice makes you feel uncertain
and repeatedly encounters incomprehension.

That diagnosis did not end my confusion.
Instead, it opened a new chapter of questions, fear and resistance.

They said, 'It's not psychological.'
But my head was full of doubts and fear.
As if I were trying to tame a hurricane of emotions and uncertainties -
without a compass or anchor.
As if I were the only one who had doubts,

and at the same time was abandoned by everyone who did not.

I wanted to get a grip on what was happening.
But it felt like I was trying to solve a puzzle in the dark.
With pieces that didn't fit,
and an image that never became complete.

The diagnosis gave me a name, an explanation.
But accepting it? That took time.
It was a struggle, a battle between hope and despair.
Between wanting to believe that things will get better
and being afraid that they never will.

And here I am now.
With that diagnosis as a starting point, not a final destination.

So I write.
To share what it means to live with something I don't yet fully understand,
but am trying to find my way in.

Because I know I'm not the only one.

Love,
Your vulnerable and slowly accepting self



'Unexpected strength grows amid chaos, pain and doubts.'

Letter 3

When natural was no longer natural
(About the loss of everyday movement, and how something small can suddenly turn everything upside down)

Dear Me,

It's strange how loss sometimes doesn't announce itself with blaring sirens, but creeps into your body. How something that always came naturally suddenly encounters resistance. Not with a lot of pain, not with blood - but with silent

resistance. As if your body has started following a secret agenda without your permission.

I used to just take one step, and then another, without thinking.
Running without brakes, just moving forward, dancing until dawn,
and just carrying on - into the day, without stopping.
My legs cooperated,
my brain followed faithfully,
like a silent stream, always present, always along for the ride.

Until they stopped.

I remember it well. That morning when I got up and my right leg felt like an erased sketch. As if my body had drawn a leg but forgotten to colour it in. I hobbled across the room, trying to ignore it. Cup of coffee, washing machine on, straighten my back — because I had to.

Maybe that was the hardest part. Not that I suddenly couldn't do as much. But that I didn't want to show it.

So I carried on.
Sometimes I walked crookedly, but I smiled straight.
I said, 'I'm fine,' while moving my foot under the table to check if it was still there.

And no one noticed. Even I didn't want to see it.

Perhaps I no longer recognised myself - in that body that no longer functioned on its own.
I felt betrayed. As if my body had abandoned me just when I needed it most.
But somewhere, deep down, I knew: maybe it wasn't betrayal, but a last attempt to be heard.
Not a surrender, but a signal.
Maybe my body wasn't asking me to fight, but to finally listen.
I now understand why I kept it hidden for so long. As soon as you make something visible, it suddenly becomes real. And then often follows silence.
The comment: "But you look fine, don't you?" Or the question: "Are you ill again?"

I became a master of masks.
Smiled on Instagram.
Said yes to invitations, but made up excuses on the way.
Deleted words from my vocabulary: exhaustion, overstimulation, help.
And replaced them with: busy busy busy, it is what it is, I'm fine.

There was a moment when I was standing at a party laughing while my left foot was completely numb. I held my drink in the air, made a joke, and meanwhile

thought: I hope no one sees that I'm leaning on the bar stool as if it were a walker.

But it eats away at you.
At your energy.
At your self-image.
At your courage.

Because how can you fight when your own body has already raised the white flag?
How can you trust in tomorrow when today already feels like a marathon without a warm-up?

And yet.

Yet there is something that does not break.

A glimmer that remains.
Sometimes in the loving gaze of a friend who does see what you are hiding.
Or in the small moment when you give yourself permission to rest without guilt.

Slowly, I am learning that rest is not a surrender, but an act of love.
That not being able to do something anymore doesn't mean you are nothing anymore.
That my value is not in speed, but in presence.
In how I keep looking for ways to be gentle, even when everything is screaming.

Perhaps you recognise this too. Or do you recognise it in your loved one, a colleague or a mother in the school playground who has... what's it called again? FNS?
That your body sets your limits before your head realises it.
Then know this: you don't have to prove anything.
You are already brave enough.

Love,
My brave, gentle self



'Living with FNS is hard, but that's where you find your footing.'

Letter 4

Caps, Breaks & Priorities

(About surviving, making choices and 'Learning to pause without guilt')

Dear me,

Some days I wake up with plans, hope, lipstick.
Other days with... a Nike baseball cap on my head.
Or the choice is made for me out of necessity.
I stay in bed.
My body refuses what I ask of it.
My mind clings to what was once taken for granted.

There are mornings when even brushing my teeth feels like my arms have to lift a heavy load, jerky and endless.

The simplest things — washing my hair, answering an email, having a conversation — sometimes feel like a tangle of wires that just won't come together, no matter how hard I pull.

And so I learn to choose.

I learn to prioritise like an accomplished crisis manager. Not because I want to, but because I have to. Today: cook, leave the vacuum cleaner alone. Or go for a walk, but no phone calls.

Or: oversized sunglasses, Nike baseball cap and lipstick – the holy trinity of my FNS survival kit.

I even wear those sunglasses on rainy days. Not to look hip, but to tolerate the light that fries my nervous system. And that cap? Sometimes for my unwashed hair, sometimes as pure camouflage. Sometimes against stimuli, sometimes against people.

I'm getting good at it, almost creative. I come up with tricks, band-aids, ways to make life with FNS just a little more bearable.

Some days are better than others.

My brain sometimes repeats signals like a damaged LP under a blunt needle. Or the signals don't come through, resulting in blackouts or overstimulation. Patience is a virtue in those moments. That inner noise, that continuous reset without end – that is the most exhausting thing of all. And on top of that, there is an exhaustion that really cannot be solved with the best will in the world.

I keep explaining.

To people who mean well, really –
But comments like, 'Yes, I get tired sometimes too'
hurt, because they don't see the difference.
My fatigue means that on some days, even with the best will in the world, I can't
even take care of myself a little bit normally.

And yet... I keep showing up.

For myself.
For life.
At my own pace.

I have balls, even if you can't see them on an MRI.
FNS forces me to be honest. To say no more often, without feeling guilty. To let
go of what I can no longer carry.
To make choices: a cap instead of clean hair. Silence instead of explanation.

And that's okay.

I'm not lazy. I work hard to survive.
To recover. To adapt. To accept.
That takes more courage than anyone can see.

Finally, I want to give you a gentle invitation, dear Me:
Be kind to yourself – even if it means being out of action for a few days or
weeks, with a dose of guilt, sadness and frustration.
It's okay to feel, to pause, and to accept that some days are just harder than
others.
And it is precisely that gentleness that can help you find strength again, to get
back up and keep going.

So when I look in the mirror again later – with my cap and sunglasses –
I know: I'm actually doing f*cking well.

And tomorrow? Tomorrow I'll see.

Love,
Your growing self, who doesn't give up easily



'Failure and pain show that perseverance also requires gentleness.'

Letter 5

Boundaries & Breathing Space

(About the moment when I learn to listen, let go and protect myself)

Dear Self,

There are days when the world pulls at me.
So many voices, expectations, faces.
And I feel my body recoiling a little further each time.

Not because I don't want to.
But because I can't.
So I start listening – to the echoes in my body.
To the signals I've ignored for too long.
To the quiet, clear language of overstimulation, breakdown and exhaustion.

I am learning not only to recognise boundaries,
but also to protect them.
Without explanation, without excuse, without criticising myself.

No is not a wall.
It is a form of love.

Sometimes that means:
Putting my phone on silent.
Rescheduling an appointment.
Doing nothing for a day without punishing myself for it.

I don't choose out of convenience,
but out of necessity.
And that takes courage.

I am learning to no longer measure myself against others.
My day is not a competition. My pace is not a failure.
What is rest for someone else
is recovery for me.

I don't have to prove myself to earn my right to exist.
I don't have to get better to be valuable.

Sometimes I feel like a balloon -
kept inflated by all the "musts".
Sometimes that works out well. Often it doesn't.
But little by little, I let the air escape.
Gently. Steadily.
Until I take on my own shape again.
Not inflated, but real.

Today, I am allowed to just be.
With everything that is.
With everything that doesn't work out.

And when I look in the mirror again -
without masks, without pretensions -
I see someone who is working hard on gentleness.
On healing.
On acceptance.
On being true to myself.

And that is more than enough.

Love,
Your wise, confused, incorrigible Self



'Boundaries are not walls, but the breathing space in which I can reset myself.'

Letter 6

What is FNS anyway?

(About understanding, acknowledging and finding hope)

Dear Me,

Functional Neurological Syndrome. Such a mouthful of words that turn your world upside down - while doctors continue to emphasise that there is nothing wrong with your brain.

Sometimes it feels as if my body and brain suddenly take a break, an FNS attack that brings everything to a standstill. My thoughts race, my body refuses to cooperate, and time seems to stretch out into a strange, slowed-down rhythm. It is confusing, exhausting, and at the same time a moment in which I learn to listen - really listen - to what my body needs.

How is it possible that my body and my brain rebel? That they become so confused that working together seems impossible?

FNS is a neurological disorder in which the connection between the brain and the body is disrupted. There is no visible damage, but a functional malfunction — nothing is broken or damaged, but the software is stuck — while your hardware is working fine.

My nervous system becomes confused, causing symptoms that are tangible and real, but cannot be seen on scans or standard tests.

It is confusing. It is frustrating. Sometimes I feel trapped in a body that follows its own rules, needs a reset, a pause in which everything comes to a standstill – a reset that is both a relief and exhausting.

The symptoms can vary greatly: paralysis, tingling, jerky movements, seizures similar to epilepsy, hearing loss or blurred vision. Pain is common, sometimes intense, sometimes subtle. Yet everything remains invisible on scans, as if what you feel is not real.

FNS is often misunderstood. Sometimes it is thought to be “all in the mind”. But it is real. Every symptom, every frustration, every moment of uncertainty demands recognition and appropriate care.

An estimated 85,000 people in the Netherlands live with FNS symptoms, 2,000 to 3,000 of whom are severely affected. According to neurologist Jon Stone from Edinburgh, approximately 1,350 people are officially diagnosed each year.

The cause? It is rarely clear-cut. Trauma, stress, infections or an overloaded nervous system can trigger it. But FNS is not my fault. It is a signal from my body that something is out of balance.

And what can you do about it, I wonder?

What can help? Therapies that strengthen the connection between the brain and the body: functional neurology, physiotherapy, cognitive behavioural therapy.







Self-care: being patient, accepting, learning to listen to my body.

Calming techniques for my nervous system, such as breathing exercises, meditation, QiGong or body-oriented therapy.

And support from fellow sufferers – so that I know I am not alone.

Support and Networks

There are various organisations and online communities that offer support to people with FNS:

- FNS Foundation – Offers information, webinars, legal assistance and support for patients and healthcare providers.
- 
- www.stichtingfns.nl
- Living with FNS – Patients share experiences, information and tips on treatment options.
- 
- www.functioneleneurologischestoornis.nl
- FND Hope International – International network for awareness and online support groups.
- 
- www.fndhope.org
- FND Hope Netherlands – National organisation for recognition and support.
- 
- www.fndhopenederland.nl
- FNS Self-Management Group (Facebook) – Private group for experiences and support.
- 
- [Self-management group FNS](#)
- FNS Patient Association – Improves care and represents the interests of patients.
- 
- www.fnspatiëntenvereniging.com

Full recovery is not always possible for everyone, and that can be confronting. But every step you take in listening to your body, accepting and seeking support is a victory in itself.

At the moment, I am literally and figuratively stumbling through a transitional period: I am trying to accept, gain recognition, find the right help, and show my loved ones what is really going on inside me. During an attack or the reset afterwards, I want to hide, retreat into silence. But slowly I am learning that this does not help me — that it is precisely sharing, letting others feel, that helps me to breathe again.

I remind myself: my symptoms are not failures, but signals. My body is trying to

communicate. And I am learning to understand that language better and better.

And that is already a victory.

Love,
Your courageous self



'Knowledge is power. Let people know what you need, find hands to carry you, and give yourself the support you deserve.'

Letter 7

New routines & unexpected homecomings (About rhythm, resetting and discovering micro-happiness)

Dear Me,

When your body stops working, a new path begins.
They say that after a breakdown, you can find your way back.
But what if you no longer know the pace?
What if the old route no longer works?

Every morning starts with a fresh start.
No more autopilot, but slowly and consciously waking up
in a body that doesn't yet know what it can handle today.
No more sprinting, but step by step.
And on some days? I'm allowed to just do nothing at first.

I learned to plan again - but without overdoing it.
And even with all the care and preparation, sometimes it doesn't work out and I
have to cancel.
Carefully searching for a balance between stability and space.
Daring to build in enough rest
without immediately thinking that I am lazy or useless.
My days increasingly took on softer, gentler edges.

Something new emerged.
Not a rhythm of performance,
but of being present.
And when I forgot, my body reminded me loud and clear:
tired, foggy, overstimulated.
As if it were saying:
'Not on your old terms anymore.'

Still, it felt good. After a mandatory rest period, I was back there in the gym.
With lead in my legs, I dragged myself inside.
But I went. And I did.
And I listened - really listened - to my body.

Not just to my body.

One of my gym buddies caught me
with a broad, warm smile.
'Nice, isn't it, that air conditioning?' he said,
followed by a nod and:
'Train, eh.'
A look that said: you're back. We see you.

Later that afternoon, between two sets,
an unexpected open conversation arose about rock bottom -
and especially about what comes after.
No judgement. No advice.
Just really listening.
Therapy in sportswear.

And suddenly I realised:
this is also coming home.
Not because someone wants to judge you when you're not at your strongest,
but because you're just allowed to be there.
Just being there is enough.

I'm no longer looking for a tribe to save me,
but for people who see me.
Who are there on bright days,
and also on dark ones.
And if possible,
I'll keep moving.
I'll keep connecting.

Every night before I go to sleep,
I do something I learned from Dr. Daniel Amen -
neuropsychiatrist and guest on many worthy podcasts.

He calls it a treasure hunt:
a search for micro-moments of happiness from that day.
Especially on days that feel extra tough.

That one cup of coffee, smelling in the morning sun.
A friend who says, "I'll come with you".
A conversation at the gym that feels warmer than the weights themselves.
A mint plant blooming in your garden – stubborn, fragrant, living proof.
Birds singing to you as if they knew you needed it.
The full moon, a sunrise – moments that are quiet and grand at the same time,
full of promise, full of new hope.

Gratitude. Repetition. Every night before I go to sleep.
It makes your brain happy – a gentle reminder that happiness is often found in
the little things.

Sometimes that's all you need.

Step by step, I am learning that this is my new rhythm –
my own gentle strength.
Continue to be kind to yourself, you deserve it.

In solidarity,
Your resilient, awakening self



*'Coming home is not about being perfect, but about being recognised in your
weakest moments. In small things – a smile, a ray of sunshine, a word of
encouragement – you discover that you can get back on your feet again.'*

Letter 8

Whistled back

(About breakdowns, acceptance and new neurological pathways)

Dear Me,

Well, that's just great! After rereading the previous letter, I was called back to reality. Breakdown. For three bloody days.

My left leg - heavy and paralysed, as if it no longer belonged to me. Dead, but at the same time veined with tingles that went deep into my toes. As if my body wanted to remind me that there was still something inside it, but the connection refused.

Days that sucked me in like quicksand. Uncertain. Unpredictable. They seemed endless.

I have ADHD, so when my body asks for rest, my brain screams for action. The two fight each other - especially when things seem to be going better again.

You could almost forget you have FNS, until it destroys you.

And you forget your ADHD, until you stand still and your head keeps racing.

Just before an FNS attack, it feels like my head is being squeezed. My brain seems to be in a tight vice, every thought becomes heavy, slowed down, almost unreal. At the same time, a sharp pain shoots through my face - in my jaws, my temples, my forehead - as if my body can't keep up with the signals my head is sending. It is a confusing mix of pressure, pain and disorientation, which forces me to stand still and listen to what my body needs at that moment.

And then that inner journey begins. A path without signposts. Raging, sighing, standing still. Trying to breathe through it, while your body calls for everything except rest. Accepting what you cannot understand. And trying to remain gentle, even when you feel that you may have ignored the signals for too long again.

Sounds came in like punches. My eyes refused light. My leg? Shut down. As if someone had pulled the plug. Tingling, nerve pain, but zero movement. There was nothing to force. No willpower that could override this. Only surrender. And waiting.

Then comes the waiting. Hoping that things will get better again soon.

But FNS doesn't stick to a schedule.

There is no clock counting down to relief, no bell ringing when it's "over".

One moment you are still in conversation with the outside world, the next you are on hold in your own body.

Time distorts. Everything revolves around: when can I do something again?

And the answer remains elusive.

It's like sitting in a room with no windows, no clock, no exit - and every fibre of your body wants to get out.

Day three was exhausting. Weekend. The height of summer.

Everything outside was bursting with life, while inside I was retreating further and further into myself.

It was as if the world was just carrying on without me.

I had to cancel plans I had been so looking forward to.

Me, myself and I – at war with the battlefield that FNS had left behind.
And somewhere I thought: how many more times?
How many more times do I have to pick myself up?
How many more times do I have to learn to live with what I never chose?

Thinking was slow.
As if my head was wrapped in cotton wool.
I couldn't read small letters, even with my reading glasses.
Sentences slipped away.
The world became vague, as if I had one foot out of it.
Fortunately, I had discovered podcasts by then.
Voices that calmly talked about new neurological pathways.
About how you don't have to identify with your illness.
How the brain is malleable.
That there is hope.
Even if your body lets you down.

That acceptance remained an issue.
I used to have such a nice, cheerful gait.
And now I sometimes couldn't even walk normally anymore.
My body felt like a joke without a punchline.
As if it kept embarrassing me, right in the middle of the street.
As if I had forgotten how to do it – move forward.
As if I had to learn to walk again,
but without the cuteness of a toddler or the medal of a marathon runner.
Just... unsteady, rickety, searching for balance on a floor I once knew.

The recovery was slow.
On day four, I stumbled along as if I were carrying a secret.
As if every step betrayed something I didn't dare to name myself.
Not exactly a boost to your self-image.
I caught myself avoiding mirrors.
Sighing at a flight of stairs, hesitating at a kerb.
My body was no longer my armour.
More like an enigmatic costume I hadn't chosen
and whose zip I still had to find.

But suddenly I felt something else: admiration.
For people of all ages who, for whatever reason, are immobile.
Who, despite everything, find their way with courage and perseverance.
Who learn to live in a body that sometimes doesn't cooperate, but never gives up.
Their strength does not lie in speed or ease,
but in persevering with every step – even when it's hard.

The great thing about the Netherlands is that you see all kinds of transport for disabled people. From mobility scooters and special transport vehicles to

pimped wheelchairs and adapted electric bikes.
People who, despite their limitations, get around in their own way.
It is a quiet strength, a form of freedom that is not lost.
That gave me hope – that there are always ways, even when you are stuck.

But my pride got in the way.
The pride that often kept me going now held me back.
It felt like I had to hide my weakness,
as if asking for help was a loss.
And it was precisely that pride... that often got in the way of my recovery.
Because the harder I tried to prove that I could do it myself,
the more often I got stuck.

Slowly, the reset begins.
I take a few steps again.
I go to the shop again.
My bicycle – and that rickety shopping trolley – are my best friends.
To lean on.
To surrender to for a moment.
Step by step.
Through trial and error.

Love,
Between doubt and recovery,
Your courageous and persistent self



'Moving forward with FNS is not a sprint, but daring to move while you are still unsteady.'

Letter 9

Golden days & gentle hope
(About good moments, breathing and growing in confidence)

Dear Me,

There are also days – not weeks yet, but hey – when I am FNS-free.
Those days are golden. They feel lighter, smoother. As if someone has lifted the

weight off me and I can move again as I once did.
The gym sessions go smoothly.
On those days, I enjoy my body intensely.
My brain is friendlier.
My signature happy walk is back, almost flawless.

And you know what?
I don't need to go back to perfection.
I really want to.
To really feel, really move, really live.
And I appreciate it so much more now.

At first, on days like that, I had the tendency to catch up on everything.
To make up for everything I had missed in a single day.
As if I were in a frantic race against the clock of my own limitations.
But now I know:
even on good days, I can take my time and go at my own pace.
I can breathe.
I can rest in the confidence that my body will give something back.
I don't have to squeeze anything out of it.
I can just be.

Putting flowers outside has taken on a whole new meaning.
When your vision returns, your leg works again, your head is clear -
when you don't collapse every five minutes,
it feels like you're learning to live again.
Being outside, laughing, moving - it has almost become sacred.

Yes, I am changing.
I had no choice.
But somewhere... I also want it a little bit.

Still, I sometimes catch myself falling back into old patterns.
Covering things up. Overcompensating.
Making promises that I now only make with reservations.
That feeling of guilt when I have to cancel something remains an issue.
It gnaws at me, even though I know I'm not doing anything wrong.
Becoming aware is a work in progress, and that's perfectly okay.

It's now August 2025 and I still don't have any real professional support to
really shape my FNS recovery.
Even though everywhere it says that early intervention is essential for full
recovery.
It's frustrating.
Time is ticking.
But I'm not giving up.

I'm applying what I've figured out myself through our friend Google and stories shared on social media.

And you know what? I appreciate every story that's been shared.

Thank you, dear fellow FNS warriors.

For your openness, your vulnerability.

For the tips, the insights, even the raw, heart-wrenching cries for help.

It makes you feel less alone in this bizarre FNS battle.

Together, we give FNS a voice.

A voice that deserves to be heard —

and hopefully, one day, understood with more compassion.

We create connections.

Because the connection between head and body has already had a setback - let's at least keep the connection with each other warm.

My situation was still too unstable for the final stage.

Three days a week in a group was simply too much.

The strain, the stimuli - it just wasn't possible (yet).

Fortunately, I will soon be receiving one-on-one physiotherapy from someone with FNS knowledge.

And I remain hopeful.

Hopeful that, with the right adjustments, I will be able to function better for a longer period of time.

And on days when it works?

Then confidence grows.

In my body.

In my abilities.

Then my head is happier too.

My mood is calmer.

Then I feel: I'm still here.

Not just surviving,

but bit by bit...

living.

Love,

With light in the little things,

Your awakening Self



'On days when everything works out, I feel that recovery is not a race, but a gentle movement of breath, attention and connection.'

Letter 10

Care and Surrender

(About caring, nurturing and your brain that no longer wants to cooperate)

Dear Me,

Caring for someone else while you yourself are faltering is a struggle without a pause button. Your heart reaches out, but your body lags behind. It is giving without any guarantee that you will be able to keep going yourself. A dance between love and exhaustion, in which you try again and again to stay on your feet.

My father had dementia, his body battered after many nasty falls that robbed us of the sleep we both so desperately needed to be able to function reasonably well during the day. That would break even someone without FNS. The car journeys – picking him up at the temporary care home, getting him in and out of the car – were already a challenge for someone with both feet firmly on the ground. For me, it was an almost impossible mission.

But it had to be done. So I ignored the signals from my body and closed my eyes to the battle raging in my head: between listening to myself and not disappointing anyone. With blurred vision and a leg that dragged behind me like lead, I went back home to wait, hoping that everything would turn out well, so that I could then get him back safely to his temporary safe bed.

I gave him the reassurance and comfort he so desperately needed. And I needed it myself. But there was no room for that. The “I’ll manage” mentality took over. Followed by days of exhaustion and fatigue. My brain felt like it was being squeezed.

My father kept calling. I asked for a little space. But how could I expect that from a man with dementia? Who still knows that he can never return to his old familiar home?

And yet... that feeling of pushing through, which for someone else was “just a quick thing”, was followed by burnout and resetting for me. And when I let myself get carried away by my emotions, it felt so damn lonely. I had to remain the healthy adult. For myself. For my father. For the outside world. An invisible struggle that never really took a break

Like me, my father wanted to maintain control over his mind and life. He also just wanted to be heard and understood. That sometimes clashed with my need for peace and focus, creating a noise of resistance.

It was the art of balancing between hope and fear, between caring for someone else and caring for myself. Between strength and vulnerability.

Sometimes life requires us to breathe with a heart full of fragility, to love without guarantee, and to carry on even when the silence between hope and fear almost suffocates us.

We may not always learn how to put on our own oxygen mask before helping others. In my reality, it's not always that simple.

But know this: your breath, your strength and your gentleness are the beginning of every care you give. Without losing yourself, but taking yourself with you.

Because caring for yourself with FNS and for the people you love means accepting that relationships change – whether you want them to or not – and requires mutual adjustments, patience and understanding. Especially for yourself.

Slowly, very slowly, I am learning that caring for someone with a body that doesn't always cooperate is not an easy task.

Sometimes you have to say "no", even if it feels like failure.

Being vulnerable is not always beautiful and shiny - sometimes it's just hard survival.

But hey, that's caring too. In its rawest and most authentic form.

Love,
Your struggling, loving self



'Caring for someone else while you yourself are faltering is not failure - it is surviving with heart and soul, step by step, breath by breath.'

Letter 11

Self-care in Chaos

(About recharging while everything around you is draining)

Dear Me,

How do you take care of yourself when everything inside you is screaming that you have to keep going?

When the world sees you as "strong", "kind" and "capable" - while you are literally and figuratively stumbling over the fatigue etched on your face.

I thought I knew what it meant to take good care of myself by now.

That it was about making choices. Setting boundaries. Taking time. Balance. Compassion.

But with FNS breathing down my neck, a father who needs care, bureaucracy chasing you, and a body that fails like an old router – self-care sometimes feels like a word from a wellness brochure that I accidentally opened in the middle of a war.

What are you supposed to do with "step by step" when your head literally forgets how?

Micro-recovery in macro-chaos

Self-care became something else.

Not pretty. Not smooth. But necessary.

It was a choice between staying on the ground or dragging yourself up by your own sleeve.

It was eating in silence, not for the peace and quiet, but because every sound was too much to bear.

It was unplugging your phone and saying: not now.

Not because you're "zen". But because otherwise you have nothing left to give, not even to yourself.

I often felt guilty because I no longer had room for others.

Because sometimes I had no patience left for people who meant well but didn't understand at all.

Because I withdrew.

Because I couldn't explain what it means when your brain breaks, but no one sees it."

But you know what?

Every time I chose myself — even if it was only a little, even if it felt like betrayal, like selfishness, like weakness — I was quietly finding myself again, piece by piece.

Not as a patient. Not as a carer. Not as a pillar of strength.

But as a human being. As a woman.

As a body with limits, a heart that also needs rest.

And that, dear Me,

is also a form of love.

Perhaps the most fundamental one.

Love,
Your overstimulated but brave Me



'Self-care is not a luxury, it is a silent revolution in a world that never stops.'

Letter 12

Parties, Love & Collapsing Later

(About wanting to be there and the price you pay for it)

Dear me,

Sometimes you just want to be there. Period.
Not as a patient. Not as the woman-with-something-vague.
But as a friend. As a woman. As a human being.
With mascara and lipstick that smudges after an hour,
but hey — you're there.

So I go. I squeeze myself into my “will-I-survive” outfit,
take my supplements like a soldier — magnesium, omega 3, B12, ginkgo biloba
— as if I'm preparing for a rocket launch.
And in a way, that's true.
My body just doesn't know it yet.

Magnesium is my relaxed friend who gently whispers to my muscles: ‘Hey, chill out, we're not going full speed today,’ and according to studies, it helps calm my nerves so I don't keep pressing the stress button.

Omega 3 swims like a smart fish through my blood, giving my brain a boost - hello, clarity! According to research, it also helps temper those annoying inflammations that I don't need.

B12 is my personal energy kickstarter, saying, ‘Come on, come on, this party's not stopping now!’ And yes, according to science, it keeps me from sinking into fatigue.

And ginkgo biloba? It's like a traffic cop with a megaphone instructing my blood vessels: ‘Keep moving, keep moving, focus on the brain!’ Studies show that it gives my concentration and memory a big boost.

I'm not a doctor or anything — but hey, every bit of support counts. If it doesn't work, I fake it with a mindset that temporarily overcompensates. Sometimes all

that little bit of support is exactly what you need.
Together, they form my secret support team, working invisibly as I drag myself through life's parties - without me even noticing.

It's a birthday party —
children's voices chattering happily
and parents doing their utmost with love and far too much food
to make it unforgettable.
You smile. You talk about this and that
and the weather, which is either too hot or too changeable.

Your head is already pounding after twenty minutes.
Your nervous system sings its own death metal version of Happy Birthday.
But you stay.
Because the child whose birthday it is means something to you.
Because it feels like you're giving up something again if you leave now.

So you smile. You eat cake — almost without spilling it because your hands are shaking. You help clean up.
And only when you get home, when you take off your coat and your legs are shaking, your body is jerking
as your head is spinning and your words are going nowhere,
only then do you collapse. Literally and figuratively.

Then comes that moment when the silence sounds too loud,
and your body feels like it's being held together with rubber bands.
Then you stand there — woman, mother, human being —
and you wonder: why am I doing this to myself?

Because love is sometimes stronger than your head.
Because social hunger doesn't disappear with a diagnosis.
Because you want to belong so badly that you even whisper your own boundaries:
"Not today, okay? Just not today."

And yet...
As you lie there, exhausted and silent,
somewhere deep inside you also feel a kind of pride.
But a quiet acknowledgement:
you were there.
You gave, you laughed, you persevered.

And so did I.
I who feel this with you, standing here next to you.
Not only as a writer, but as a woman who knows your struggle.
Who knows how it feels to balance between wanting to be there
and going under.

Who also experiences parties, balancing on the tightrope of stimuli and picking up the pieces afterwards.

Who knows that "fun" is sometimes another word for living with a system that crashes and going home on time.

So if no one else says it, I will:

I see you.

I see how brave it is to even show up.

To choose love over comfort.

And then to pick yourself back up

in a world that has no idea about your FNS daily prize.

Love,

Your bravest, rebellious self



'Being there is sometimes a victory that no one understands but you.'

Letter 13

Shit Happens

(But my bowels took it personally)

Dear Self,

It started innocently.

A little stomach ache.

Some nausea.

I thought: it must be stress.

Or maybe that damn menopause.

But my stomach had other plans.

Food stayed in my stomach.

As if my stomach was saying:

'Sorry, we're closed today.'

Every bite felt like my bowels were on strike.

Without warning. Without consultation.

The weight just slipped away.
Kilo after kilo.
As if my body had decided:
'Let's just let go of everything.'

And then I was lying there.
Unexpectedly, but then again, not really.
Because I simply couldn't take it anymore.

I was now eight kilos lighter.
I could no longer eat normally without unpleasant consequences.
No matter how hard I tried.

Two weeks in hospital.
Tests. IVs. Liquid food.
Days of laxatives. Biopsies.

I looked at my arms, my legs, my thin face.
Thinner. Paler.
And I wondered: how quickly can a body disappear?

The doctors talked about "intestinal dysfunction".
Fine words, but it felt as if they didn't really know either.

After a test for Crohn's disease - negative - the gastroenterologist sat down by my bed.
He looked at me and asked:
'What's going on in your life?'

Those words hung like a shadow in the room.

Test after test came back without an answer.
No explanation.
Just a deep void full of questions.

What the hell is going on?

As if my intestines were screaming something I didn't dare to hear yet.

I was barely back on my feet when the blow came.
A month later:
the diagnosis of Functional Neurological Syndrome.

Suddenly, a piece of the puzzle fell into place.
Only it was a picture I never wanted to put together.

My nervous system sometimes just “shuts down”.
Signals don't get where they're supposed to go.
Even my bowels were completely confused by it.

It wasn't reassuring.
But it was an explanation.
And a silent warning:
you can't win this with sheer willpower alone.

Months later, there was still no real treatment plan.
No guidance. No plan.

I did have a nice GP, a supportive gastroenterologist and an empathetic neurologist.
They took me seriously, and that was worth something.

But honestly?
I started to think I was a huge whiner.
With all those vague, strange symptoms.

So I started to investigate myself, without any medical background.
Hours, days, weeks of reading.
Listening to podcasts.
Trying to understand how my nervous system works.

That's how I ended up at the vagus nerve — the longest nerve in your body.
It runs from your brain stem to your abdomen and controls your heart rate, breathing and digestion, among other things.

Your intestines and your brain are closely connected.
They exchange signals all day long – a constant flow of information back and forth.

When the nerve that controls this becomes unbalanced or overstimulated, it can cause a domino effect: your energy becomes disrupted, your stress levels skyrocket, your intestines protest... and sometimes you even experience burnout.

I learned that you can stimulate or “reset” the vagus nerve with simple, gentle exercises.
Exercises that help your body switch back to rest and digest mode.

Again, I am not a medical expert — just me and the lessons my body has taught me since I started really listening.
And because no clear path was offered for months, I took matters into my own hands and began exploring my own FNS path.

5 gentle ways to stimulate your vagus nerve.

This will help your body regain its rest and balance:

1. Deep breathing
2. Breathe in through your nose for 4 counts, hold for a moment, and breathe out slowly for 6 counts.
3. Repeat 5–10 times. Exhaling slowly helps your nerves to relax.
4. Soft humming or singing
5. Sing a simple song or hum for a long time.
6. The vibrations in your throat give your vagus nerve a gentle nudge towards calm.
7. Cool water on your face
8. Gently rinse your face or place a wet washcloth on it.
9. This activates a natural reflex that calms your nervous system.
10. Gentle movement
11. Walk, stretch or stroke your muscles slowly and consciously.
12. This will help you reconnect with your body and calm your nerves.
13. Gargle with water
14. Gargle for a few seconds as if you were rinsing your throat.
15. This stimulates the nerve endings near your vagus nerve and helps to calm your heart rate and body.

Together with my lovely, committed dietitian, we slowly found our way back.
To gain weight again in a healthy way.
And try to maintain it.

Sometimes that went well.
Sometimes it didn't.
I noticed that on those days I also had other FNS symptoms.
Every single time.

But every day is a new attempt to find balance.
Through trial and error.
But always with the realisation that it's okay not to be perfect.

My body needs time to heal.
And I'm finally giving myself that space.
Sometimes it goes well.
Sometimes it doesn't.

I'm sharing this with you – my vulnerable self – because I know how damn lonely it can feel.
How you long for understanding, while the words are missing.
How hard it is to keep trusting yourself when your body keeps working against

you.

But also because I believe in resilience.
In small rays of hope.
In moments of peace.
In finding strength in vulnerability.

Continue to be kind to yourself.
Continue to breathe.
And know: you are never alone in this struggle.

And even though it can all feel too much at times, continue to hold yourself lovingly – your body and you deserve all the patience and compassion there is.

Love,
Your loving, resilient self



You cannot force your body to be silent when it is the only voice that still dares to speak honestly.

Letter 14

Invisible burden

(About misunderstanding, doubt and keeping yourself going)

Dear Me,

Sometimes it feels like my body and I
are performing a play that no one understands.
Often, I don't understand it either.

They only see the mask:
the days when I get up,
get dressed,
put on my lipstick,

and wear that forced 'I'm fine' smile that hides everything.

They don't see the struggle behind it:
getting myself ready for an appointment
while my body has completely different plans.

If things are going okay, I keep going.
Believe me... some days that resistance eats up every ounce of energy I can muster.

And they don't notice what I pay afterwards:
the silence behind the door,
the oppressive fatigue,
the feeling of failure, the loss of vision,
powerless, as if my body speaks its own language
and I can't understand it.

Maybe on those days when my FNS is messing with me, I'm extra sensitive.
Extra vulnerable.
On those days, judgements hit harder, like a kick in the teeth.
Maybe it's also because I'm still searching myself:
for a balance between the days that go well
and the days when my brain shuts me down.
And sometimes I judge myself for that, when all I'm really trying to do is survive.

People say things like:
'You just don't feel like it.'
'Aren't you exaggerating a bit?'
And my personal favourite:
'You just want attention.'
As if my body and my nerves are putting on a play – and I'm the only one who can see it.

And sometimes I try to explain it politely,
a short dialogue that says more than a thousand words:

They: 'But you were so active at the gym last week...?'
Me: 'Yes, and then completely wiped out for three days.'
They: 'Oh... but you don't look sick at all.'
Me: 'That's right, you can't always tell. But that doesn't make it any less real.'

Sometimes those words cut deep, harder than I want to admit.
That's why I often pretend to feel better than I actually do —
I've become a superstar at that.

But I've also found a few ways to keep myself going,

even though I'm still searching, still learning:

1. Have standard phrases ready – something short I can say without laying out my entire medical history.
2. For example: 'It varies, today just isn't a good day.' Done. Full stop.
3. Saving my energy – not every misunderstanding deserves an explanation.
4. Sometimes it's better to keep my mouth shut
5. and save my energy for myself,
6. like a treasure chest that I cherish.
7. Following my own compass – only I know what my body needs.
8. If that means cancelling an appointment, then so be it.
9. Without feeling guilty. #itsstillworkingprogress
10. Staying kind to myself – it affects me because I am human, not because I am weak.
11. I don't have to be invulnerable to be strong.

I know there will always be people who don't understand.

Sometimes because they don't want to, sometimes because they simply can't.

Maybe they are fighting their own silent battle behind closed doors.

That is not my responsibility.

I don't have to convince anyone of my reality.

My time and energy are too precious to waste on discussions I can't win anyway.

So I keep trying.

Keep breathing.

Keep listening to what my body and feelings tell me.

Sometimes with trial and error,
sometimes with tears and frustration,
sometimes with a smile that is half real.

And I know: that's okay. That's enough.

Because even if no one fully understands, I'll keep going.

Whether that's lying down, stumbling,
or with every fibre I can find.

Even if the world thinks I'm exaggerating,
that I'm being dramatic
or just want attention.

I'm here.

I exist.

I try.

And on the good days? Then my rebellious self emerges -
the one who likes to create awareness and dares to open an open conversation
about FNS or other chronic illnesses.

And that alone is special.

Love,
Your enduring, unbreakable self



'Every step I take, even if it's small or unsteady, is proof of my strength.'

Letter 15

Small victories

(About celebrating small steps and personal growth)

Dear Me,

Today I got up and my body thought: 'Hahaha, go ahead and try.'
My head thought: 'Yeah, right, what could go wrong?'
And somewhere in between, I thought: 'Okay, let's give this circus a chance.'

Socks. Two different ones. And one with a hole in it. My reflection looks at me
and says: 'What a mess!'
I laugh: 'Thanks, friend. Chaotic is the new chic.'

Making coffee. Without my arm going on strike. A little applause for myself.
Ping - a message from a friend: 'Is everything okay?'
I grin: 'Yes, weeds don't die, do they?'

Outside, a ten-minute walk feels like an expedition to the top of the Himalayas.
Not that I've ever been there, but you get the picture.
The wind blows through my hair, the sun pricks my nose.
My legs protest like a bunch of whining children: 'No, really, no, I don't feel like
it!'
I mumble: 'You'll all get a place in the will, okay?'

A cheeky jay lands on a branch and looks at me as if to say: 'Girl, relax.'

I smile and take a deep breath, wondering why my body is being so dramatic about something that used to come naturally.

These are such small things. Invisible to the outside world. But to me, they are mountains.

A cup of coffee without spilling, climbing stairs without support, an unexpected, genuine smile from myself in the mirror — every step, every “survived until now” moment is a victory.

The world may expect big victories.

But you know what? I celebrate every little victory as if I've won the Nobel Prize. Like having a little extra energy, or being able to think clearly without my head protesting – in this madhouse called FNS, small triumphs are actually the only thing that matters.

Today I celebrate that I am here.

Today I celebrate that I keep trying.

Today I celebrate myself, in all my chaos, vulnerability and wonderfully crazy side – I do a little dance under the motto: a day without dancing is a day not lived.

Dear Me, remember this:

Small steps are not small successes.

They are proof that I am alive, laughing and surviving.

And sometimes, just because I can, I dance in two different socks – one with a hole in it, as a silent middle finger to FNS.

Mini exercises & Reflection

With these exercises, I help myself to really see and feel today's small victories. I take my time, breathe deeply and am kind to myself. It doesn't have to be perfect; I focus on recognising, embracing and cherishing the small moments of joy, connection and resilience.

1. Writing down daily triumphs

Every evening, I write down one small moment that I have endured or attempted — no matter how small. Like the smell of my freshly washed bedding (picture this: when your FNS attack is in full swing, changing bedding feels like a complicated choreography in slow motion), a quiet Qigong session without bouncing around, or a few minutes of mindful breathing in the morning sun. Sometimes a short walk, lovingly caring for my plants, or putting my thoughts on paper. Small victories that show that I did something today, no matter how small.

2. Celebrating micro-victories

I give myself a round of applause, a smile, or a silly gesture in the mirror when I have a small moment of success. My favourite podcaster, Mel Robbins, calls this the High Five habit: giving yourself a high five every morning - a boost to self-confidence and motivation, simply because I am worth it, even when chaos protests or getting started is difficult.

3. Use humour

I write down a situation that normally frustrates me and turn it into something absurd or funny. Sarcasm is my secret weapon — like tripping over my own feet because one leg won't cooperate, and pretending it's a clumsy FNS dance routine. Or that the letters on paper seem to dance because of my blurry vision, only to find them standing still later. My eyes clearly have a more vibrant social life than I do.

4. Mini walks or breathing moments

I plan one short walk or breathing moment of 5-10 minutes and observe how my body and mind react without attaching any emotion to it.

5. Gratitude jar – count your blessings

Every day, I write down one moment of happiness on a piece of paper. I put it in a special jar.

On those grey days when things aren't going so smoothly, I take out a note and remind myself of what went well. These are small rays of light that give great strength.

Reflection questions

- What small victory did I achieve today, even if it seems invisible to the outside world?
- How did it feel to recognise or celebrate this moment?
- What role does humour or absurdity play in my daily survival?
- What blessing or moment of happiness from today can I put in my gratitude jar?
- What does this small victory say about my resilience?

So remember, dear Me: every step, no matter how small, is proof of courage. Celebrate yourself, laugh at the chaos, be grateful for all the mountains you climbed today — and above all, be big in the little things, with a healthy dose of gratitude.

Love,
Your step-by-step dancing Me



'The smallest victories hold the greatest courage.'

Letter 16

Compliments with a bitter aftertaste (Recognition without labels)

Dear Me,

I never thought I would ever receive this compliment: 'Well, you're doing well for an FNSer.' I had to laugh and swallow at the same time. Because somehow it felt like recognition - someone sees that I'm struggling and still finding my way. But at the same time, that label sticks so hard to my forehead that I almost forget that I'm just me. Not a condition in capital letters, but a human being with dreams, jokes, stubbornness and weird habits.

The strange thing is: words like that can be both balm and salt in a wound. Balm, because I finally hear that it's noticeable that I'm not letting everything get me down. Salt, because there's always a 'for someone with FNS' dangling at the end, as if my achievements only count within a reduced framework of expectations.

I did everything I could to avoid receiving any compliments or judgements that smacked of FNS. I became an expert at covering things up, laughing them off, overcompensating. My coping mechanisms were disguised as cheerfulness and positivity. It took a ridiculous amount of energy and time - energy I didn't have. And yet I carried on, in the name of survival. The result? People often didn't take me seriously. Doctors dismissed my complaints. Care workers subtly raised their eyebrows. And yes, the icing on the cake: a psychiatrist who bluntly called me theatrical. Theatrical! As if I were auditioning for a play instead of fighting for my life against a body that refused to cooperate. That word stuck, burned itself into my mind. Because what do you do with your truth when it is reduced to an act?

All this reminded me of the very last conversation I had with my mother in person, two days before she passed away. She looked at me and said softly, 'Don't pretend to be better than you really feel, child.' Those words still echo in

me. So soft, but so full of truth. They remind me that I don't have to hide what's inside, don't have to cover it up or appear stronger than I am. So my tremors, my outbursts, my FNS - it's all allowed. Being real is enough. And that realisation gives me the strength to show myself, in my own way, at my own pace.

Perhaps it was high time I dared to present myself as I really felt inside. That I no longer brushed away my tremors, hiccups and outbursts as if they were something shameful. Because how can someone else recognise my pain if I keep hiding it myself?

I am trying to learn to separate the compliment from the label. To hear 'you're doing well' without the 'for someone with FNS' rubbing me the wrong way. Some days I am better at this than others. On my good days, I can even smile about it: apparently I radiate something that gives others courage, even though I sometimes feel like broken porcelain myself.

The truth is that I am more than any diagnosis. But I can also be grateful for those moments when someone looks beyond the silence, the breakdowns and the fatigue and sees something that is still standing. Perhaps that is where the real recognition lies - not in the label, but in the fact that I live, move and keep trying despite everything.

Love,
Your real self, in pieces and in wholeness
I



'Compliments can sound insincere, but sometimes they point straight to my strength.'

Letter 17

Trials

(When your body sabotages your best days)

Dear Me,

I write with tears I want to swallow. A heart that is bursting. A frustration so

great that I almost suffocate. My child came to stay for a week. Quality time with my eldest, who is doing so well in life. In recent years, she has performed exceptionally well. As a proud mum, you want to celebrate that. Enjoy it to the fullest together.

I had everything arranged. Slept well. House clean. Enough food in the house. To-do list to one side. No FNS for now. But on day three, it started again. A squeezing feeling in my brain stem. Blurred vision. Loss of strength. Pins and needles. Dragging leg. Extreme fatigue. I pretended nothing was wrong – fuck you, FNS – and cheerfully carried on. Old survival patterns, combined with the urge not to let this precious time together be ruined. Until it went wrong.

I had already told my daughter what I have. But when you can't see anything on the outside, and mummy keeps cheerful, it's all the more confronting when suddenly you really can't go on. Complete error in my head. As if everything is short-circuiting. Afraid that I will lose control at any moment. My body in slow motion. Sounds were deafening. My limbs were powerless. Even watching Netflix became a test. Images that hurt. Blurry, double, tiring for my brain.

Meanwhile, my father's care home kept calling. He needed attention too. And me? I'm so angry. Frustrated. Sad. Extremely pissed off. A week without FNS, that was all I wanted. To enjoy time with my child undisturbed. The promised shopping trip? Online order. Eating out? Takeaway. Netflix night? DIY 3D film without glasses.

I'm so sick of this bloody FNS. I've adjusted my lifestyle, given up so much. And yet the world keeps pulling at me. Because apparently I still look too good. So: 'Are you really sick?' Sometimes I want to cry. Sometimes I want to scream. I'm tired of having to repeat that I can't do it right now. I'm tired of seeing special moments ruined by FNS. Sometimes, very occasionally, enough is really enough. Then not only my brain and body, but also my heart loses heart.

And yet. Through the tears and frustration, love remains. My child, whom I don't want to burden. My pride in her. My gratitude that she was here. FNS may hold my body hostage, but my love for her? Untouchable.

Love,
Your Me who curses FNS, stumbles, cries, but never stops loving



'Sometimes my body breaks me and steals days from me, but never my love.'

Letter 18

Between setbacks and unexpected gifts *(Mindfulness, nature and new rituals that sustain me)*

Dear Me,

FNS was never on my bucket list. Yet here it is. And besides everything it costs me, it sometimes brings unexpected gifts. Who would have thought that I would find zen in a dragonfly dancing gracefully across the garden path, while my own legs are failing me? Before FNS got hold of me, I was too busy running around to really see such small wonders of nature. Now I am learning that it is precisely in stillness that the greatest gifts are hidden.

My body still regularly forces me to stand still. My head screams, my legs drag, and somewhere in that crazy duet, I am learning the art of being present. Mindfulness without woolly thinking: breath, heartbeat, silence. A body that protests – and me, who sometimes turns it into a clumsy little dance, where every movement feels like pure freedom on the good days.

Living less online has brought me a lot of peace. I used to start my day with my eyes half closed, immediately reaching for my mobile phone. Now I take the time to wake up slowly: first a few breathing exercises, then a quick check-in to see how my body is doing, followed by a modified Qigong session and a fresh smoothie, while Hz-frequency music plays in the background.

It took time to get used to – for me, and for the people I used to be available to 24/7.

But living more in the present, in the moment, makes room for so many other things that make my body and mind happy.

Self-care took on a new meaning. Hair removal sometimes feels like an Olympic discipline – and yet, on a good day, I lovingly paint my toenails, pamper myself, play the handpan and let my body know that it is seen, felt and cherished.

These small rituals carry me, give me stability in a body full of vibrations and unexpected breakdowns.

Or, as Priyanka Chopra so aptly put it: 'Taking rest is a radical act of self-love in a world that glorifies exhaustion.'

New friendships blossom at the gym – my happy place – with people who are also recovering. Yoga and Qigong bring back breathing, movement and an unexpected love. They give me moments when my body finally cooperates instead of working against me. It feels like a small revolution: connecting with others and with myself, while discovering that strength can sometimes be

tender and vulnerable.

My fascination with the brain grows every day. Online neuroscience studies open up new worlds that feed my curiosity and wonder. Mindful cooking, preparing a meal and really enjoying it, feels almost magical. Outside, in nature, my breath fills with light. Birds bring rhythm to the days. And every movement - dancing when I can - reminds me that my body can still participate, can still enjoy.

Hobbies are my lifelines. Writing, music, creativity with paintbrushes - yes, my artwork is more crooked than my nervous system, but imperfection is the fashion of today anyway. Small mindset shifts, a dose of black humour and sarcasm help me through the toughest days. I am learning to say no, to make room for things that really make me happy, and to realise that living more consciously is one of the unexpected gifts of this shitty diagnosis. What a gift. Before going to sleep and blowing out my candles, I take another tour through my day. What went well? What didn't go well? Lovingly and with compassion, I count the blessings of the day.

FNS takes, yes. And in the emptiness, I discover new passions, friends who are truly there, and small victories that feel big - and that feels like a fucking blessing.

Love,

You Me — mindful and grateful, with a bag full of blessings.



'Often, standing still shows you more than endlessly moving forward ever did.'

Letter 19

Manifesto of a life with FNS

(From breakdown to insight — and a path of strength and gentleness)

Dear Me,

FNS has brought me to a standstill. Harshly, sometimes ruthlessly. I hid, cried about everything I lost, and laughed at the absurdity of breakdowns at the most inconvenient moments. I struggled with acceptance, repeatedly rebuffed by my body. It was raw, exhausting, and often lonely.

Yet I know I am not alone in this. Almost everyone with FNS recognises something of this struggle: the lack of understanding from the outside world, the fear of new episodes, the exhaustion that sets in, and the mourning for what is no longer taken for granted. The search for balance and the frustration of having to constantly readjust – it is a shared struggle. And yet every story is different: some people mainly have motor symptoms, others have speech or sensory problems. For some, the diagnosis feels like a relief, for others it feels like a heavy label.

My path is my own, but it is intertwined with that of many others. And that gives me strength.

Because FNS also gave me something back. I have learned to love myself again. I have gained respect for my body, which may no longer be able to do everything, but which carries me every day. I have learned to set boundaries – not as a sign of weakness, but as an act of love. For myself, and therefore also for the people around me.

I make more conscious choices. I live more slowly in a society that is in a hurry. I savour the little moments: a good conversation, a bird singing, a glance that lingers a little longer. And I know: this is the life that is there. Not everyone has to understand my path. It is enough that I remain true to myself.

And now, reader – this is for you too.

Know that there is hope. That you are not alone. Seek support, from fellow sufferers, online, or via that little friend Google. There is more help and recognition than you think. Living with FNS requires compassion, but also courage – to communicate honestly and clearly, with the world and with yourself.

Allow yourself the freedom to consciously choose how and with whom you share your time and energy. Make it your mission to be a ray of light, even if it is only for one person. Show that it is possible to live authentically – not despite, but with everything you carry with you.

Living with FNS does not mean the end. It means a different beginning. A beginning in which fighting spirit and vulnerability can coexist. Where silence is not empty, but full. Where enough is truly enough.

Stay true to yourself.
That is more than enough.
And enough is great.

Love,

Your heart and your courage, I



'In the silence of my limitation, I discover my strength, and in my choices, my freedom grows.'

Letter 20

For myself, and for you

(Care, understanding, knowledge and love for yourself, every day anew - and how to explain FNS to others)

Dear You,

Through these letters, I have discovered what an FNS attack does to me - not only in my body, but also in my head and in my feelings. I have learned that it is okay not to always understand, to ask for help, and to take time to reset.

Perhaps you recognise this too: the confusion, the shame, the lack of understanding from others. But by learning to talk about what is happening and giving yourself space, peace of mind can be found. Understanding yourself and being open to those around you lighten the path to acceptance.

An FNS attack feels like your body suddenly goes into aeroplane mode. The connection between your brain and your body is partially lost: you may shake, tremble, fall over, have difficulty speaking, be unable to move an arm or leg, have blurred vision or be completely "out". Sometimes it is caused by stress or overstimulation, sometimes it seems to come out of nowhere. In my case, an attack lasts from minutes to hours, sometimes days, and often leaves you exhausted and worn out. Then the reset period begins — and I still find that the most difficult to deal with. However, I am gradually getting a little better at it.

You can also think of it as a software glitch: your brain is still in charge, but the Wi-Fi connection to your body is faltering. Nothing is broken – it's not a hardware fault, but a temporary disruption in the connection.

This is what an attack can look like – not everything happens to everyone, and it can vary from time to time:

- Seizure-like episodes: convulsions, collapsing, loss of consciousness – no epilepsy can be seen on a brain scan.
- Sudden weakness or paralysis: for example, an arm or leg that

suddenly stops moving.

- Problems with speech: stuttering, slurred speech or inability to find words.
- Movement problems: tremors, jerks, stiff muscles or being stuck.
- Changes in sensation or senses: deafness, tingling, blurred or strange vision.
- Extreme fatigue or dissociation: as if someone presses the "off" button and you become detached from yourself, during or after the seizure.
- Digestion: sometimes unable to swallow, choking, stomach and intestinal pain, nausea, vomiting or diarrhoea. This makes sense, because my intestines and brain are connected via the brain-gut axis – an invisible highway through which the head and stomach influence each other.

Triggers can be stress, pain, overstimulation or fatigue, but sometimes an attack seems to come out of nowhere. It can last from minutes to hours, sometimes (much) longer, and often leaves you feeling exhausted afterwards.

What those around you can do and what you need:

- Time to reset.
- Help with practical things: an appointment, bringing a plate of food, a moment of rest.
- Understanding when you need to reschedule something.
- Space to share your story without judgement.
- Remember: every attack is different; what happens today may be different tomorrow.

FNS is complicated and sometimes unpredictable, but it doesn't have to define you. What you can do is listen to your body, take yourself seriously and learn to communicate what you need. These letters are hopefully there to help you with that – as a mirror, as support and as a guide. So that you, like me, can experience that understanding, love for yourself and practical help from others make you stronger, even when your life seems to be in aeroplane mode.

Love,

Your fellow sufferer who would like to join you in making FNS a little more liveable



'Your body may sometimes jump into aeroplane mode, but with understanding, communication and love for yourself, you will discover that you can always land

safely.'

Afterword

Dear reader,

If you have struggled through this collection of letters, know one thing: you are not alone. FNS is a world that often seems invisible, misunderstood and full of challenges that test your mind and body. Perhaps you recognise the chaos, the frustration, the moments when everything is too much and your body lets you down. Perhaps you laughed at the absurdity, or perhaps tears flowed at situations you know all too well.

I am still searching, with so many questions that sometimes seem to have no answer. There are days when I ask myself how I can keep carrying all this, how I can keep breathing while my body screams 'fuck you FNS' and everything seems to be blocked. Those days are hard, intense, lonely and unfair. And yet I keep trying: falling, getting up, breathing again, over and over.

What I want to share with you is this: there is strength in vulnerability. There is hope in small victories. And above all: your experience matters. You are allowed to see, hear and acknowledge yourself, even if the world doesn't always do so. I would love to hear from you (essyinspires@gmail.com).

Keep breathing. Keep being kind to yourself. Celebrate the small steps, the moments of laughter, light and resilience. And remember: even when it feels like everything is too much, there is always a way forward — step by step, breath by breath.

Because in the end, it's not about perfection. It's about being there. Really. Present in yourself, in your body, in your chaos, in your moments of light and dark. It's about feeling, trying, sometimes failing, but never stopping coming back to yourself.

Keep breathing.
Keep feeling.
Keep living.
Keep looking for adjustments that support you.

And know: every time you come back to yourself, your light shines further than you ever thought possible.

Love,
Essy



'In every breath I find strength, in every awareness I find myself.'