



art & chronic pain - a self portrait  
soula mantalvanos



art & chronic pain, a self portrait  
soula mantalvanos

one day  
i'll chop my strings...  
it'll be because of you, theo.



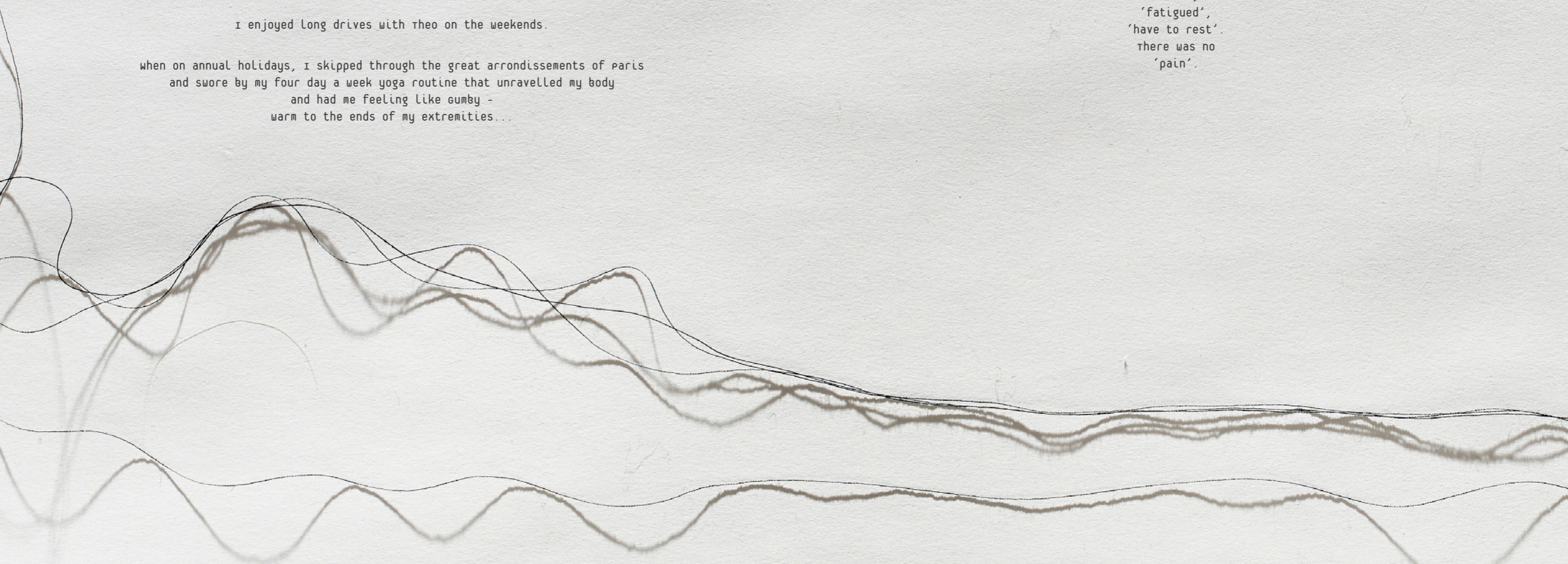
i worked very long and wonderful days.

i walked everywhere, lunching, dining, starting every day at a local cafe,  
picking up art materials, walking the dog, to carlton, the city, fitzroy.

i enjoyed long drives with theo on the weekends.

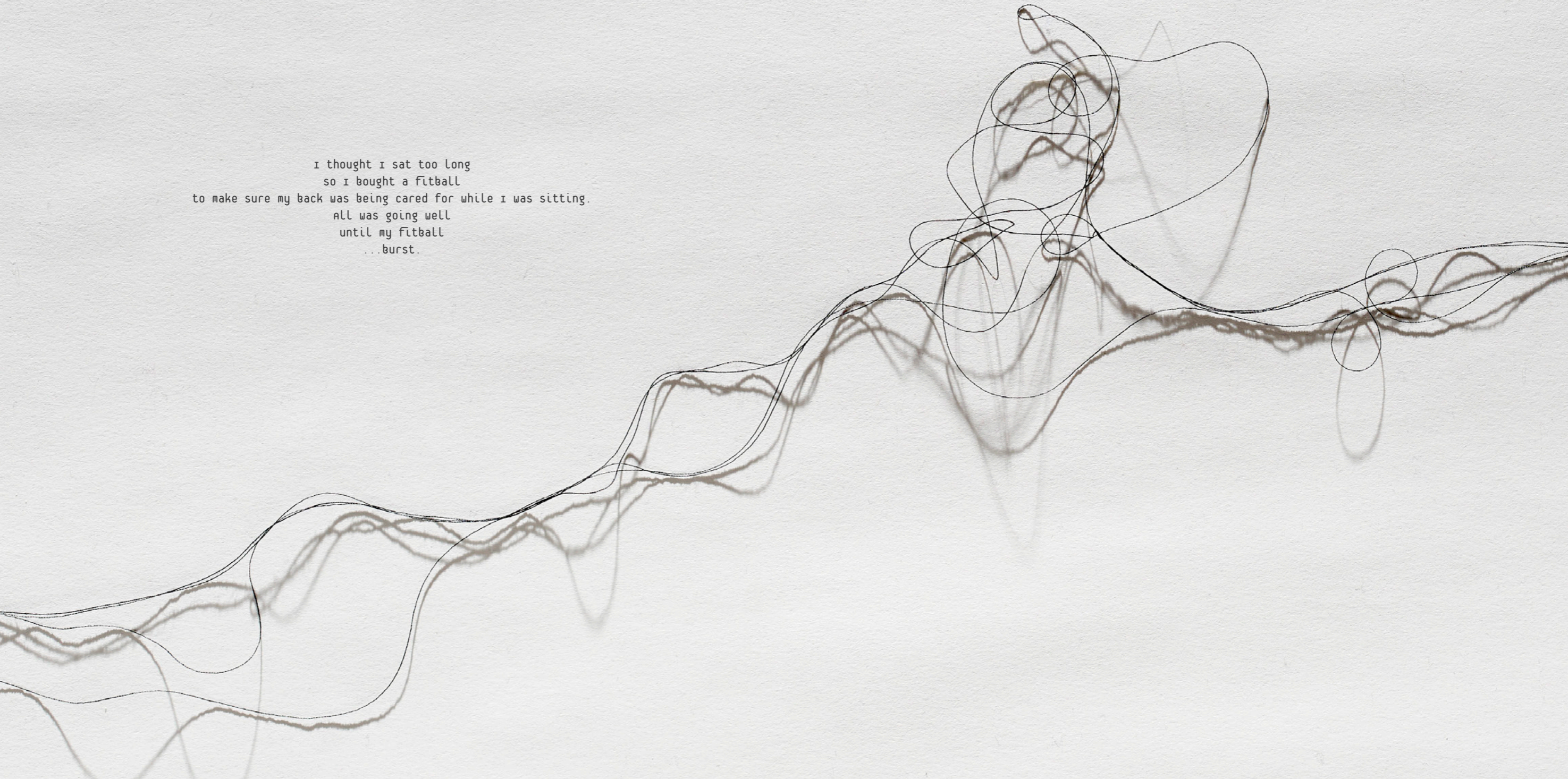
when on annual holidays, i skipped through the great arrondissements of paris  
and swore by my four day a week yoga routine that unravelled my body  
and had me feeling like gumby -  
warm to the ends of my extremities...

there was no  
'tired',  
'sore',  
'fatigued',  
'have to rest'.  
there was no  
'pain'.



in a split second,  
i had dropped to the concrete floor.

i thought i sat too long  
so i bought a fitball  
to make sure my back was being cared for while i was sitting.  
all was going well  
until my fitball  
...burst.

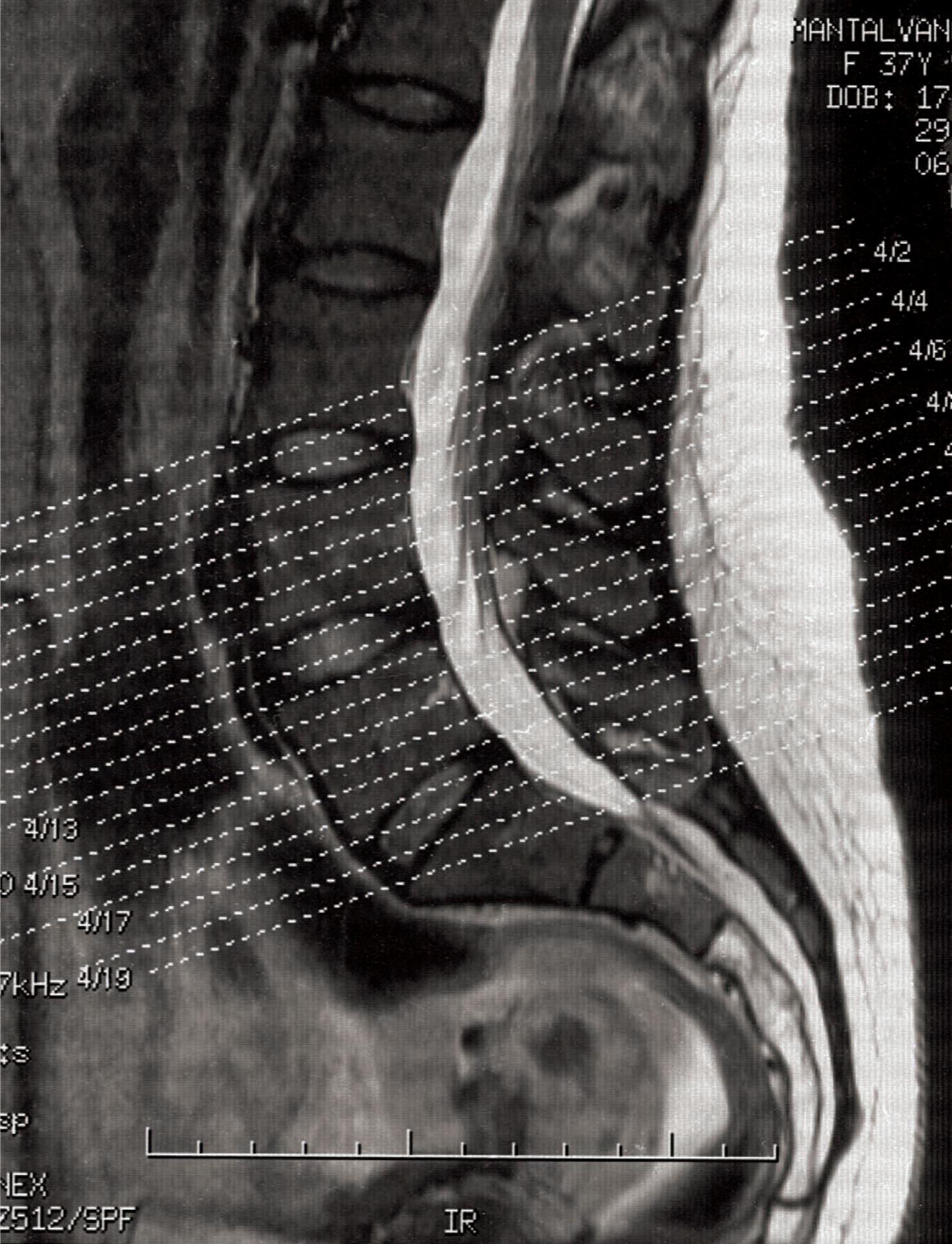
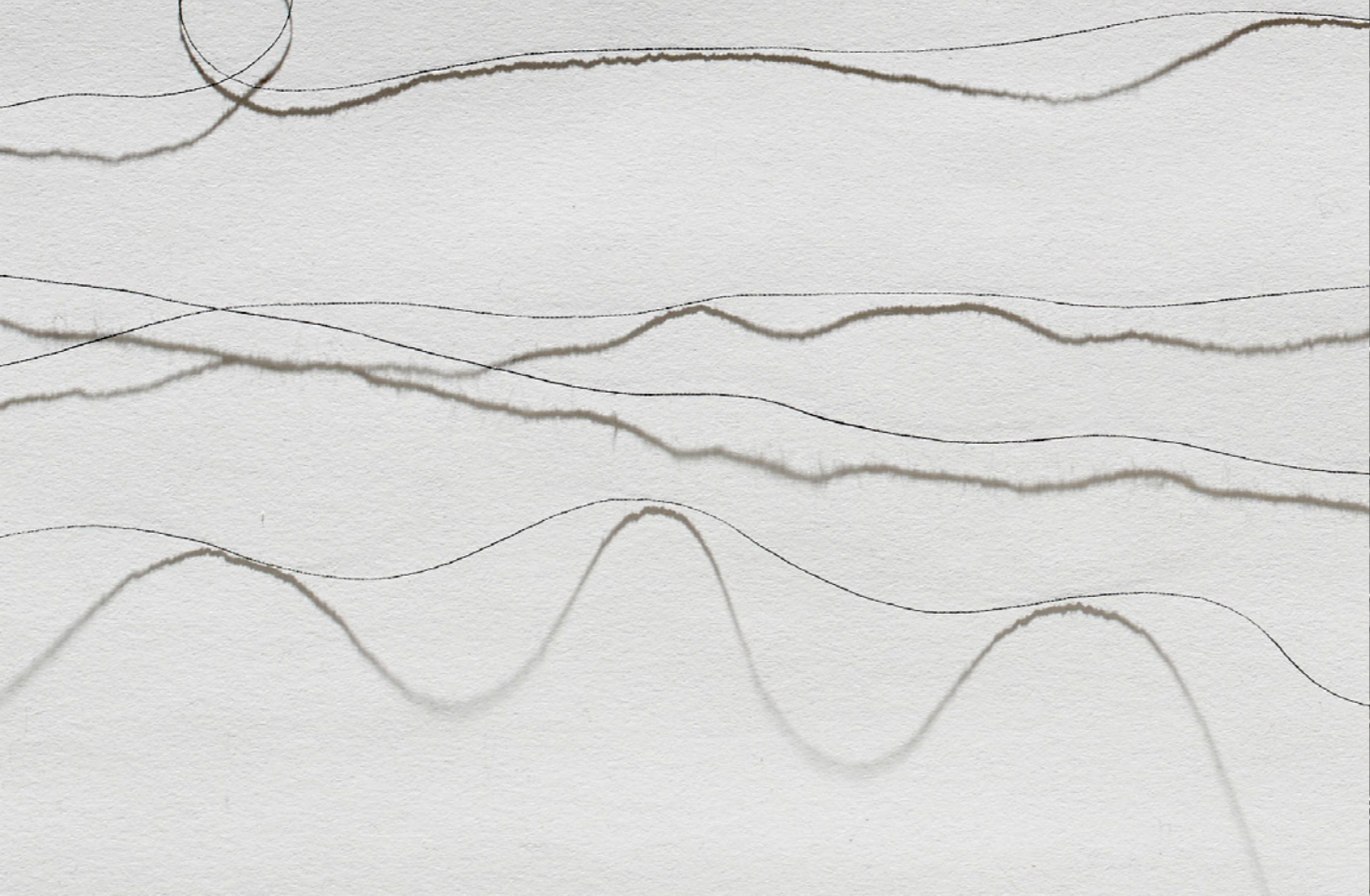


at is this pain? what's wrong with me? is this a long-term thing? why does it come and go? why do i feel like i'm being punished for my activity? why can't i sit? why can't i be seen? where is it? what's that flickering? why is it like a toothache? why does my rectum spasm? what happened to my toilet signals? why do i get so fatigued? why am i always tired? what is this toothache in my backside? am i getting worse? is there anyone out there that can help me? why is this pain so itchy and why is it gnawing me? **do i stay on the horrific medication and be a turned down version of myself forever?** do i need some operation? why do the backs of my legs hurt so badly? why was the heat bag giving relief at the start and now it's not? are specialists missing something really obvious? how can there be so much pain and no evidence for it? did i fracture my coccyx? did it heal before i had my x-rays? why do i get so sleepy when the pain comes? **why does noise make me sleepy?** is this a disability? will i get depressed? is this what frida kahlo felt? is this going to lead to ms? did i damage my nervous system? how can i live like this? **how would anyone believe i'm horizontal at times when i look fine?** in what age do we live in? what is this flare? how can this not be visible on my x-rays and mris? how can it be possible to be distracted? how does distraction lead to excruciating pain? why is it worse after activity and not during? is it a coincidence i feel the flare at the 24 hour mark post activity? what is with the car, why does it bring me so much pain? **How can no one understand this?** why do professionals look at me with such dumbfounded expressions? why can't anyone understand my pain language? why hasn't anyone heard my explanations of pain before? **is it all in my head? could i really have a psychological condition?** am i going crazy? **is this real?** why does it hurt to talk loudly, sing or raise my voice? why does loud noise hurt? will these appointments ever end? how many people can i see? why do i feel a surge up my back when i get frightened? **why are my legs weak?** why can't i lie on my back? how can so much pain be invisible? why do i hear i'm the worse case scenario everyone has seen? why does the anaesthetic give me so much relief. how can i possibly 'go home and get comfortable'? why does the pain feel as if i fell yesterday? **should i chop my coccyx off?** what is a nerve block, will it help? how long does a nerve block last? is cortisone bad for me? will it help, why doesn't it last? how do i live this way? how do nerves work? what is this excessive and most uncomfortable stimulation? why does this feel like i have my finger stuck in a powerpoint? why does it hurt so much to walk barefoot? **why does my heel cause shrilling pain up my spine?** why is it still possible for me to bend or reach for something but it hurts later? why does it hurt to walk quickly? why is it easier to walk on my toes? does a nerve block hurt? is it possible i could wake up one day and this could be gone? what is fibromyalgia? what is pudendal neuralgia? can my pelvis just get over it? why can't i find much information about my pain? will i be like this to the day i die? what if i can't make art anymore? **am i just going to exist?** what at the end of my working life? will i never be able to return to work? will i never return to my beautiful active life? how did i do all that i did before my pain? how can i drop to concrete create such a nightmare? will i become suicidal? **how can theo cope with this?** why didn't i rest more after the accident? did i cause this? **how can i only achieve a few tasks a day?** what sort of a life is this? can i go on? **is there trauma in my head?** what's in my memory? what's in my pelvis's memory? if i take all that medication now, what will become of me later? **how will i age?** i'm hardly moving, what is this doing to my body? will i get more sick from this anxiety? **why can't i hold thoughts, concentrate?** how can i live with pain distracting my brain even for a few seconds? how can i achieve anything this way? how can i not be able to paint for even 10 minutes? **how is it possible that i'm knocked out just preparing to bake a cake, or start some art?** will i never drive again? will i never 'zip over to the shop' and buy something? will i never see my printing press that was delivered the afternoon of my accident? how can i explain this so people understand? what sort of cruel tease is that? will i just be watching the world go by? **ever doing? do i give up the hunt? am i kidding myself, causing more angst? maybe i should consider the advice, 'go home and get comfortable - it's quality of life for you now soula'**. i can't stand the interruption all the time. pain is in the way every minute. i'm sick of juggling my priorities and minor activities. i'm sick of making sacrifices, all day. if i do this, i won't be able to do that, sick of it. my life couldn't be any more different. maybe i'll try yoga. how can explain this so people understand? i'm so sick of being judged. i'm going to sleep the rest of my life away. **i'm like a walking zombie, a living dead person.** i can forget about buying shoes, no more heels, great boots, even nice flats. i can't even hold a hairbrush. my iphone is too heavy. if my brain can create a tune why wouldn't it find the tune it played for 38 years? if my brain can grow then why is choosing to grow badly? **what the hell is fatty tissue and why is it just in my tail?** how come no one has seen a 'fatty tail'? **do i give up the hunt, never investigate again? is it really possible for me to 'go home and get comfortable? is it just about quality of life for me now?**

MANTALVAN  
F 37Y  
DOB: 17  
29  
06

no,  
it can't be.

my fatty tail and i  
had some more investigating to do...



4/2  
4/4  
4/6  
4/8

4/13  
4/15  
4/17  
7kHz 4/19

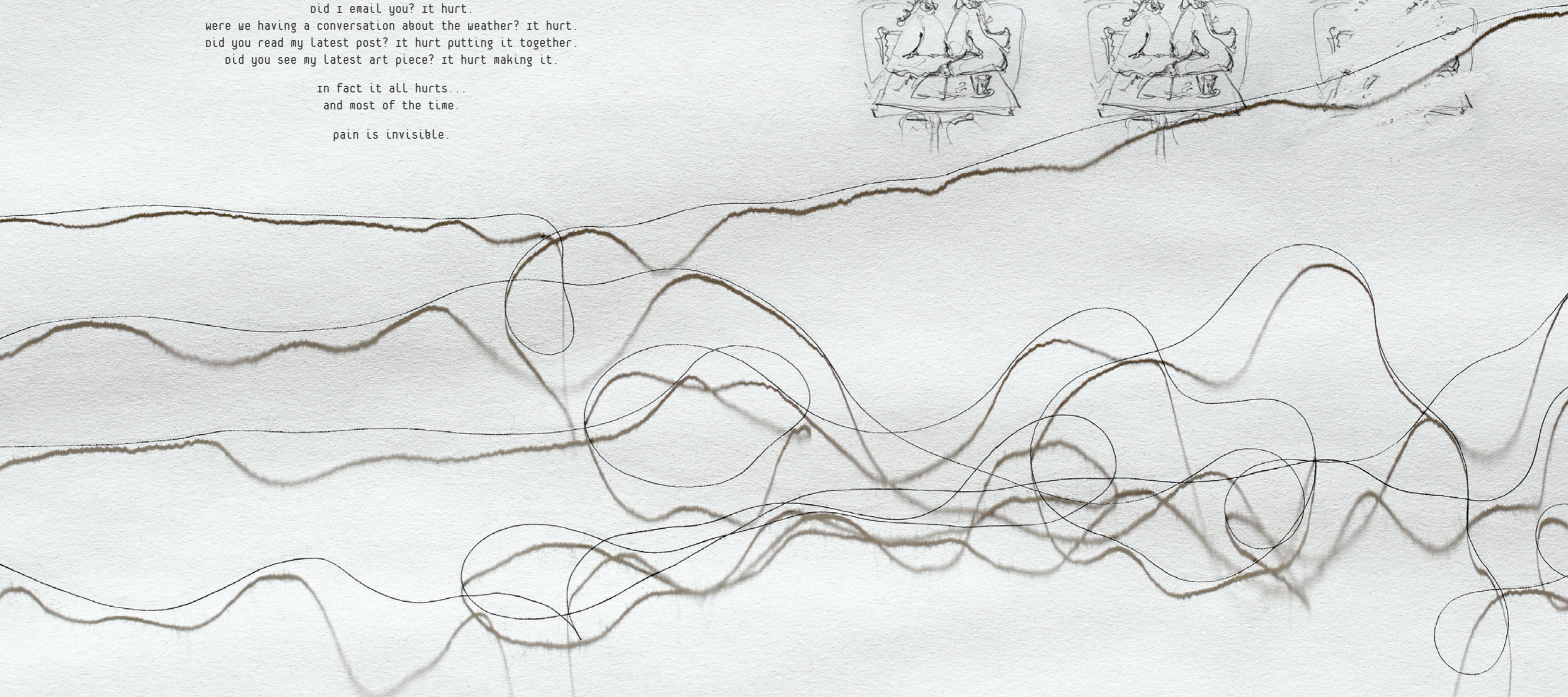
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seen me smiling? it hurts. seen me having coffee with a friend? it hurts.  
seen me walking up the street? it hurts.  
seen me having a glass of wine? it hurts.  
seen my online social activity? it hurts doing that.  
heard i went away for the weekend? it hurts... more.  
did i email you? it hurt.  
were we having a conversation about the weather? it hurt.  
did you read my latest post? it hurt putting it together.  
did you see my latest art piece? it hurt making it.

in fact it all hurts...  
and most of the time.

pain is invisible.



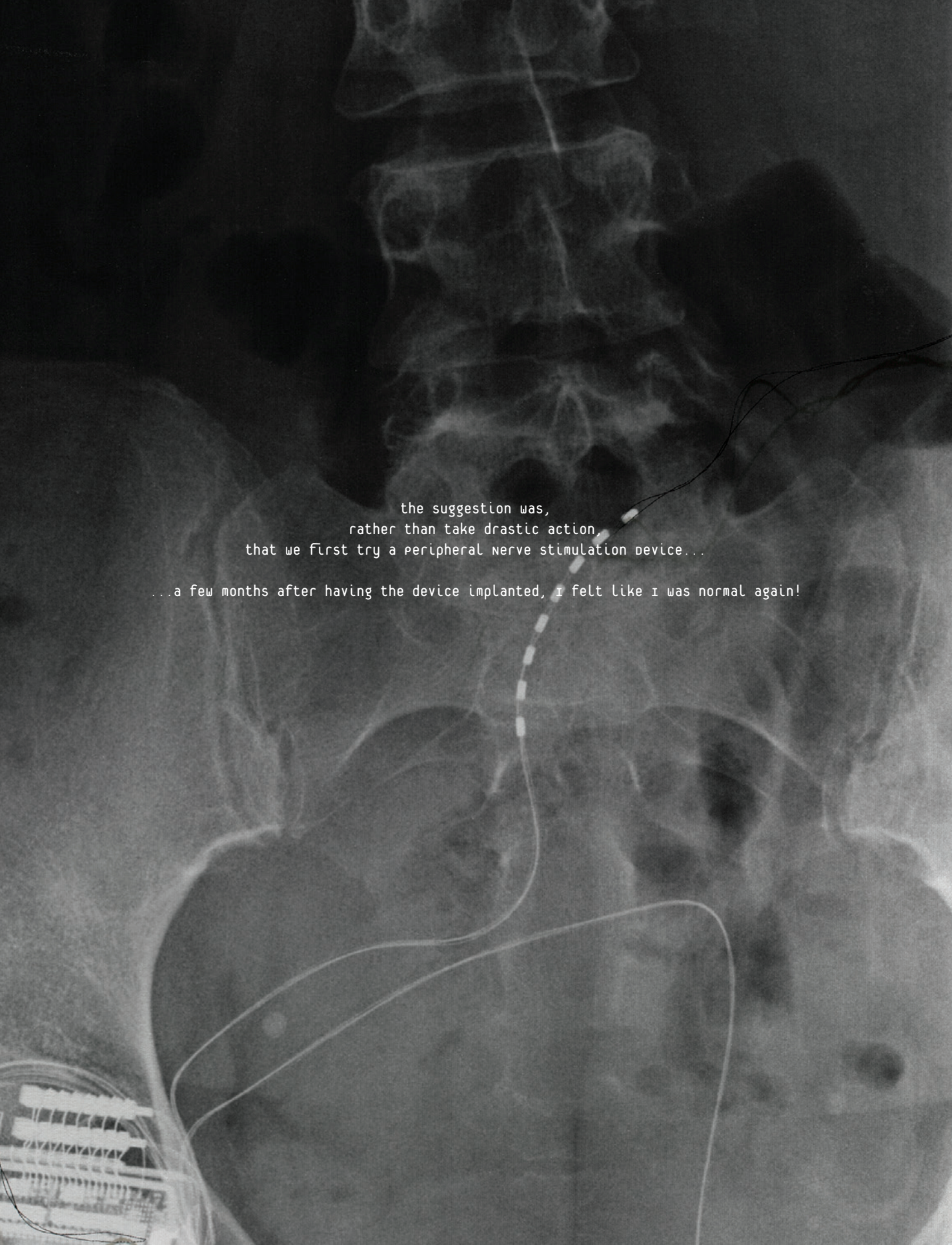


# Calendar

2007 2008 2009

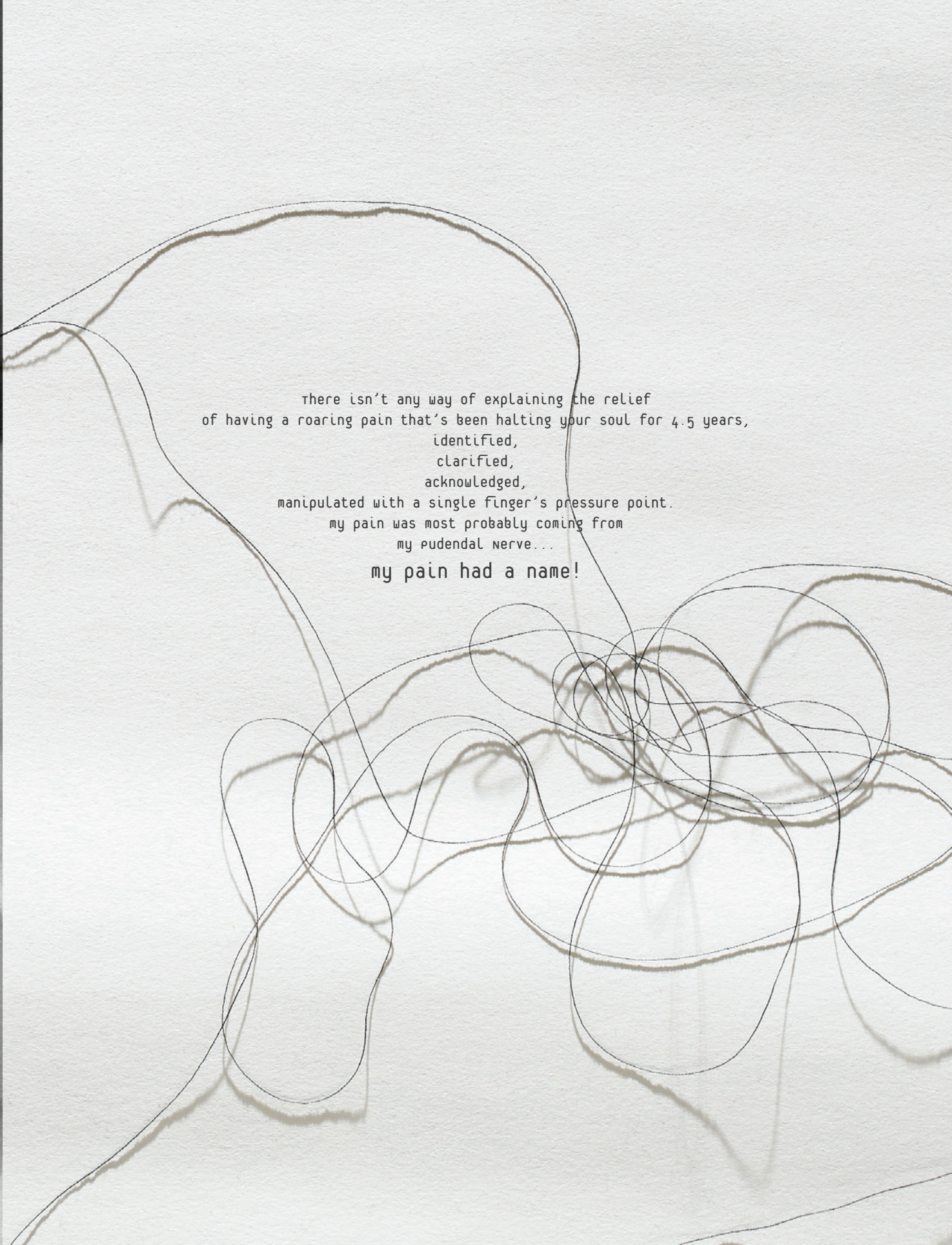
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Gynecologist Orthopaedic Surgeon Rheumatologist Neurosurgeon Physiotherapy	Clinical Plates Psychologist Pain specialist Pain psych MRI			Alexander Technique Water Therapy Clinical Plates Chiropractor		Remedial Massage Psychiatrist Neurosurgeon Clinical Plates			Orthopaedic Surgeon GP Water Therapy Chiropractor			Sleep Nap rest	Sleep Nap rest
GP MRI Jaw X-ray Psychologist Orthopaedic Surgeon Remedial Massage Chiropractor	Water Therapy Neurosurgeon Pain psych Ultrasound therapy Alexander Technique Pain specialist		X-ray Alexander Technique Pain specialist Rheumatologist Carisone shot Doctor Acupuncture		Alexander Technique SI Joint shot Pain psych MRI Physiotherapy Remedial Massage Psychologist			Water Therapy Psychiatrist Alexander Technique Neurosurgeon Ultrasound therapy Clinical Plates Carisone shot				rest steep nap	rest steep nap
Psychiatrist X-ray Alexander Technique Acupuncture Chiropractor	Orthopaedic Surgeon Psychiatrist Pain specialist gynecologist Alexander Technique		Acupuncture Psychologist gynecologist Neurosurgeon		Pain specialist Psychologist Alexander Technique SI Joint shot			Orthopaedic Surgeon Water Therapy Chiropractor Psychiatrist				steep Nap rest nap	steep Nap rest nap





the suggestion was,  
rather than take drastic action,  
that we first try a peripheral nerve stimulation device...

...a few months after having the device implanted, i felt like i was normal again!



there isn't any way of explaining the relief  
of having a roaring pain that's been halting your soul for 4.5 years,  
identified,  
clarified,  
acknowledged,  
manipulated with a single finger's pressure point.  
my pain was most probably coming from  
my pudendal nerve...  
**my pain had a name!**



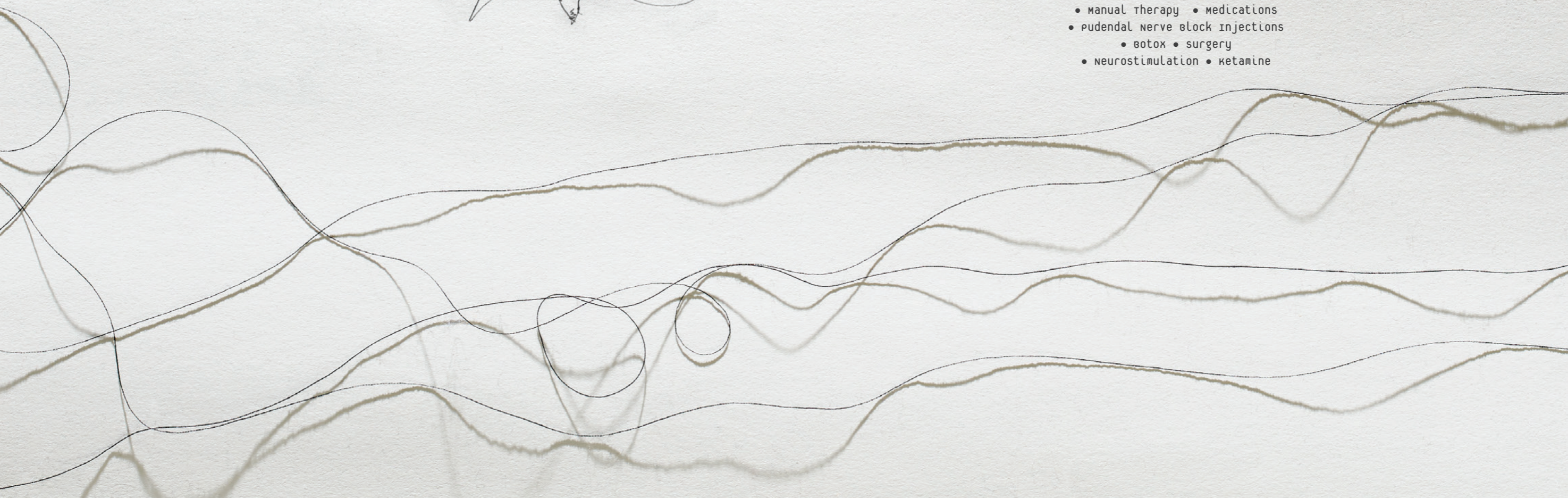
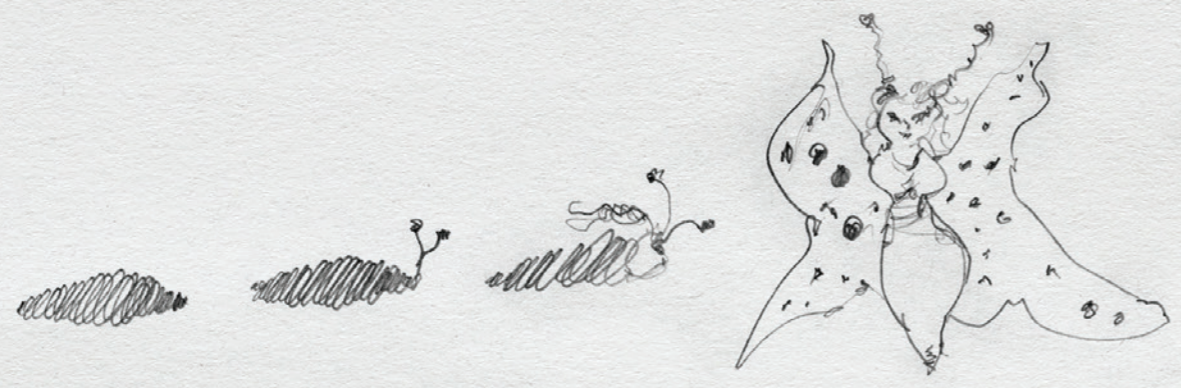
pudendal neuralgia (PN) is a painful neuropathic condition of the nerve that innervates the rectum, anus, urethra, perineum, and genital area.

it is a little known condition that is frequently misdiagnosed.

it is common for PN patients to be told their problem is psychosomatic and to seek psychiatric help.

treatments include:

- physical therapy
- manual therapy • medications
- pudendal nerve block injections
  - botox • surgery
- neurostimulation • ketamine



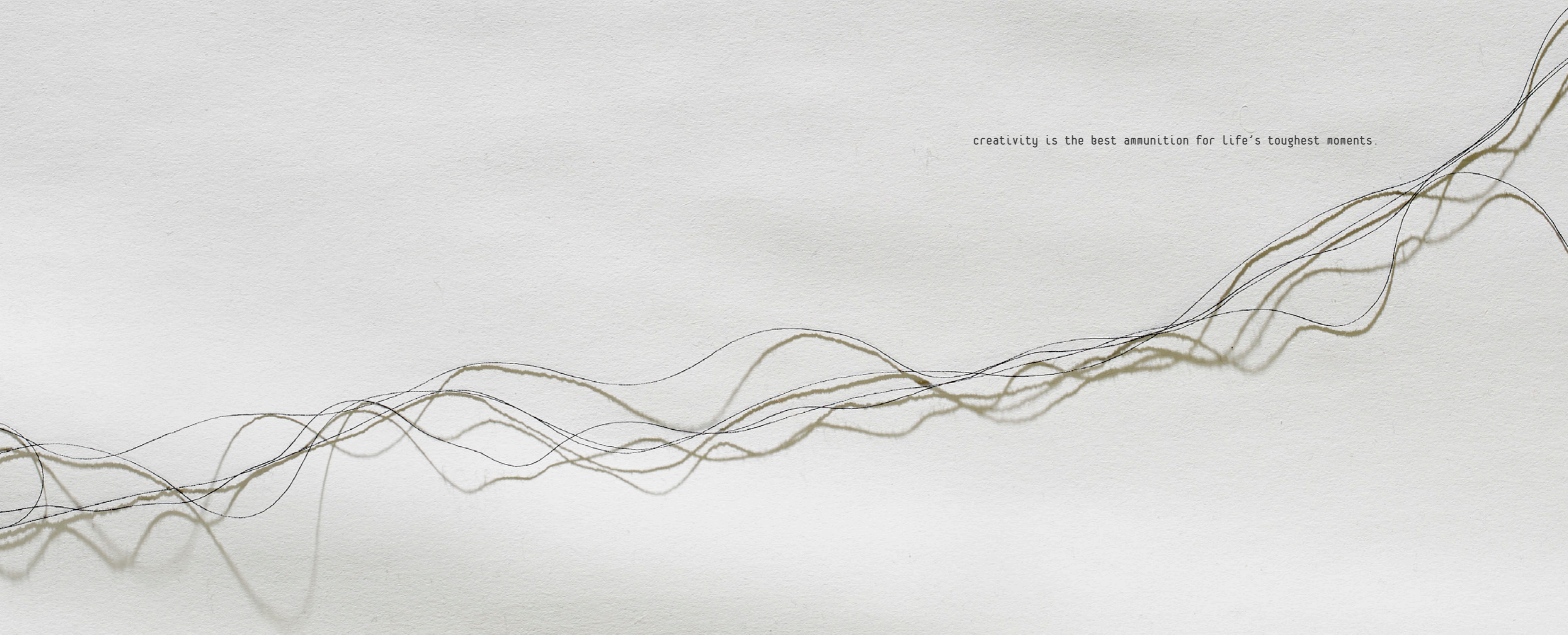
physiotherapist: how is your pain now?

me: my pain is good now.

physiotherapist: laughs... but doesn't really find this funny.  
'pain is never good'.



creativity is the best ammunition for life's toughest moments.



over to ms soula now...  
she can communicate the pain.



A marionette is the only way I thought to express my living with chronic pain.  
I lost my independence  
and yet the debilitating qualities couldn't be seen on my exterior.  
No one could grasp my torment by looking at me, in fact I looked 'well'.

I lost my control in life and the pain dictated my days for many years...  
for some days it still does...

currently this is how I see myself  
but I remain hopeful that this image will change  
one day.





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**artworks**

soula.com.au

dust jacket: *piecing myself together* collage on linen  
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