

Hí,

It's me. Jenny.



Today it's my birthday.

I would love to have a party right now. With lots of music and friends.

Because I like parties. I loved parties. Until the day I met Tinnitus (T) and Hyperacusis (H).

So, no party for me today.

But I do have something to celebrate. I found peace. In my own way I have overcome T and H.

Now I am where I need to be. But 'us together' are not there yet.

That's why I write you this letter. A letter that will be a wake-up call for you and as many people as possible, I hope. Please make use of it and let's do this 'together'.

In that case, my party was successful.

PS

With my letter I welcome you in my life to serve a higher purpose.

But it is quite long to read and scroll. Do you have difficulty with scrolling?

To help you I have also put it on paper for you.

You can download it here.

WELCOME TO MY LIFE



Why? Just because!

I would like to introduce you to my best friend **Iris**. Iris is always there for me. Like today for example: she delivers this letter from me to you. She was the one who stood by my side the day I said goodbye to life exactly a year ago.

I'm not here anymore, that's right.

And yet I am happy, because today Iris gives me, as promised, a voice.

I dare to admit that I doubted for a long time if I would share my story with the world at all. Because as long as I was still alive, it was people's "understanding" that I missed so much, to be able to continue. Only at the very last moment did I know: I will go for it. Why? My story is written to awake patients surrounding and help my fellow sufferers. Who knows, it might encourage more research on T and H. And so I finally gave Iris my

OK to make my story public, in my name. The story that Iris now shares via Dizzy Me on the first anniversary of my passing.

Via Dizzy Me, because tinnitus often occurs in balance patients. And because hyperacusis, which is hypersensitivity to sounds, can put you on a rollercoaster again and again. Just like how this happens with vestibular patients - the 'dizzies'.

So far, so good.

Who am I? An ordinary woman who used to live in Vlaams-Brabant, a province in Flanders, Belgium. Mummy of 4: a girl twin - I lost them both at birth - and 2 boys. But besides being a mummy, I am also **crazy about music, dancing, reading books, cycling and dogs.**

Because my youngest is sick every so often, I move to the Belgian coast. It requires some 'creativity', because I used to work in Brussels in Federal administration services. So I retrain myself and finally get a job in after-school children's care. So far everything OK.

And then everything changes.

We take a trip down memory lane: it is 2006 and everything goes wrong. I crash after a long, stressful period. Burn-out, as they put it. I will never be my old self again. Rather the opposite. You know, as soon as that word 'burn-out' has been spoken, doctors lavishly scatter antidepressants. That does not always feel right. "Perhaps side effects from your regular medication for your blood pressure and cholesterol. We're just giving you another pill, ma'am. "

I am constantly tired; not just tired of sleep deprivation. I'm exhausted. I get a very **sharp tone in my ear** and I do not respond well to **noise**. It feels like hearing and listening is extremely difficult. I don't always understand what is being said, but strangely enough I don't suffer from hearing loss. On the contrary, I hear things that other people don't even notice. No doctor can

explain that.

On top of everything else, my partner dies. *Goodbye love of my life.*

It's all in your head. Just learn to live with it.

"It's all in your head, madam." I have often heard that in recent years. What this lack of understanding brings to me? At first it made me despondent, then determined to get answers, sometimes it made me feel sad and often depressed. Sometimes it scared me and I got so angry very often!

One day these disorders get a name: tinnitus and hyperacusis. Healing is no option. "You have to learn to live with it", another typical reaction. The few treatments they have, for you to learn to live with the condition, are insufficient and often completely irrelevant.

Jenny becomes a Guinea pig

I really did everything and tried to *learn to live with it.*

In 2008 I am one of the subjects who have a **brain electrode** implanted to suppress the tinnitus. After months of searching for the right frequency, they tell me that the experiment did not work for me. Iris is also a guinea pig. That way we bump into each other.

In 2011 I follow **TRT** (tinnitus retraining therapy): a therapy that uses **noise generators to mask the tinnitus**. It is a great help; I **regularly have a 'good' day**. On such a day I am able to drive a car, I can go grocery shopping or even drive inland to visit my mom!

This is what the doctors can offer, once you have T and H.

Furthermore you are easily referred to psychiatry, because "it is all in your head". I let myself be admitted into psychiatry from time to time ... for sleep treatment.

The error in my head

There is something very wrong in my head! I constantly hear that **deafening 'beep'** at 9000 Hz and I **react very sensitively to noise**. But there is more: I regularly feel something that I describe as electric shocks. From the inside my head always feels hot and full. I can't remember anything anymore. "Iris is my external memory", I tell my doctor. If my stories no longer make sense, she will fill in the gaps. I can't describe it other than that my hard disk is full and has come to a point that it can crash at any moment. I said so often: "I forget about everything except the tinnitus."

We keep searching. Different MRIs do not provide a definite answer. Some doctors think my brain scan 'doesn't look good', but remain rather vague. They do not make a diagnosis and only want to stuff me with all kinds of **medicines**. My 'beep'? He does not like that and he makes it clear to me. Once again I get the suggestion to go to a psychiatrist.

Losing things, bit by bit

You know, I did not say goodbye to this beautiful life on 12 June last year. **Saying farewell, I did it bit by bit, for 11 years**. Like this:

Goodbye job

Right. One day you go to work, and the next day you don't work anymore. I was always so tired and I had **vertigo** spells due to the hyperacusis. Career gone. We stay at home.

Goodbye bicycle.

I was so happy driving my bicycle! When I responded so well to that TRT, I had treated myself to a new bike: my purple grandma bike, I was so happy with it.

One day I have to admit to myself that I can't ride anymore. I have no energy and feel **insecure**. Iris is suggesting a fluorescent vest, with the text 'beware, swerves' on my back. Such **humour among fellow sufferers**? That's often liberating.

Goodbye dog

I had a dog, a French bulldog. Oh, how I loved my dear Tyco.

Because I rarely get outside, I feel so **guilty**, that I rehomed him with friends. I miss him a lot these last years, but I'm glad he finds a new and warm home thanks to 2 lovely people who have a garden where he can run or just take a sunbath, his favourite.

Goodbye friends - Hello loneliness

I lost friends as well. For years I have tried to explain to them what I had, but that is not easy if you suffer from an **invisible illness**. If you are not chronically ill yourself, then you have no idea how that feels.

And then, one day, you notice that friends **drop out**, 'because you are **antisocial**'. They ask you out and you always say 'no, I can't come. In the beginning I sometimes say 'yes', to cancel their invitation at the last moment.

Even worse is when you have to lie down when someone comes to visit you. Or if you are in bed, hear the bell and don't have the energy to open the door. Then people stay away and **loneliness** strikes hard. But I don't want to end up ill and alone; then I don't want to be here no more!

When my mother died, I wasn't even sure if I could go to her funeral. Iris said: "You have to go to that funeral; it is part of the grieving process ". She was right. I had not seen my mom for a while, and her death was so unreal. So Iris brought me to the crematorium by car. It snowed and there was a lot of wind. I barely understood a word from the service. I had chosen the music together with my nephew, but I hardly heard that either. Attending the coffee

table? Not an option in my situation: 4 tables with people talking through each other; coffee spoons stirring, knives laid down on plates. That is hell for me. So after the service Iris just drove me to a quiet spot to get some rest, and then we drove back for the scattering of the ashes.

The funeral in the presence of my family? A reality check!

I hardly know how I got through that day.

Goodbye dancing, goodbye music

I love music. I loved music. When I used to go out, I liked to dance. It still itches when I hear the sultry voice of Barry White singing 'you're the first my last', but my body no longer wants to. My head refuses as well. Anyway, I love music and even though it became more and more difficult to enjoy music, I always kept listening. My iPod is full of both old and new tunes. Agnes Obel has been my faithful companion during the long, sleepless nights.

Goodbye books

I also like books. Oh how I loved to read books!

I was a loyal visitor to the library, but in the end I also had to give up 'reading' as an activity. I can't process the words anymore! My head is full. I can no longer follow the story lines. I sent my last books by registered mail to the library.

Fortunately, we have internet and digital television. Television replaces my books, but often I just see the images pass but the story does not get through. I watch 'De Mol' but can't remember anything. I love Flemish series, such as 'Red Sonja', 'Eigen kweek' and 'Bevergem', but also English comedy drama series. My last discovery? 'Starlings'. With the decoder I always record a complete series, because I forget everything, sometimes I even forget to watch!

Because of those recordings I can press pause once, if I have lost the storyline again.

My last contact with the outside world

I keep in touch with the outside world through social media. From my seat I follow the daily life of my contacts. Through Messenger I try to **chat** with someone on a daily basis, but in the end I can't sit straight for long and all conversations end with: "I have to lie down because my head no longer wants to."

It is different with Iris. I have a constant line with her. If there is something to tell or to remember, we use Messenger; we text each other for urgent matters.

I can't make phone calls. **My ears won't allow.** If I have to have to make a phone call, it gives me so much stress that someone else has to continue the conversation; or I just hang up. I also don't answer the phone when it rings. I can't do that anymore.

Shopping? No way!

I buy clothes and shoes online. That way I don't have to bother anyone. I do not want that. I do not want to be a burden!

And finally, you have to cry for help

I have always had trouble asking for help. I once made **a call for help on Facebook**. A few people responded and asked what they could do for me. I could not explain it: "Well, I do not know where to start. The holidays are coming; that gives me fear and stress. Can someone come over? Or do some shopping? I need people I can count on. "

In the end I decide that I needed professional help. In the meantime I am back in my apartment in Ostend and **I can no longer take care of myself**. I want to feel at home again at my apartment and I can't do that alone. Cleaning assistance is arranged. And once a week a nurse comes to help me to take a shower and helps me fill my pillboxes. Home care is called in to run the household. The GP visits home every Wednesday and the physiotherapist also comes over twice a week. My therapist is now also coming to the house. And Iris comes over 2 days a week.

Misjudged

This was the situation during my last 6 months. In that period the misunderstanding reaches a peak. It is 2017. **I am 58. It has been enough.**

The person in charge of home care planning decides- after an intake interview- that someone can come over for **home care** twice a week only for two hours. Did I forget to tell certain things during that intake? That is hardly possible, because 'my external memory' was there and she has outlined the situation very clearly ...

They need time for grocery shopping and they have to cook, because the caterer's hot meals are no longer an option. My blood pressure is too high and we find no medication to control it. That is why I have to eat healthy and salt-free. But my sense of hunger is gone and I do not eat enough. That's why the doctor is insisting on nutritious meals.

The garbage must be put outside. The waste must be sorted and sent to the container park. And then there is the dirty laundry and the changing of my sheets. And above all? **Above all I can use some company.**

The stress it gives me, makes my blood pressure peak and I get sicker. I pass my days while lying down and go back and forth between my bed and the couch. Sitting in front of my laptop for more than fifteen minutes is no longer possible.

Back to square one

Because I live in the centre of town and there are barely free parking spaces in a tourist region, I don't get a **regular health care professional**, but they always assign me someone from the backup or mobile team. How sweet, understanding and deserving most caretakers are ... 2 x 2 hours a week is not enough for all the groceries and the 7 hot meals that I need.

After each visit, they bring to their supervisor the message that I need more help. The answer is always: **"But Iris is there anyway."**

And Iris is there indeed. Although she usually comes on days when there is no carer - so that I see someone at least for most days - she has come up with a system with a list, on which caretakers note which groceries are needed and what is on the menu every day. This fantastic cooperation ensures that sufficient meals and snacks are always available in the fridge and the freezer.

Grateful and angry

I am grateful, but let it all pass by. When I think of the lack of understanding of those responsible, I become so angry. But because I lack energy, I can't get away with that feeling. And then there is also that immense feeling of guilt, that I am a burden to everyone. **Asking for help is difficult, getting help is also not easy.**

There are a few outstanding professional caretakers. I hope that I have shown my gratitude to them sufficiently. Beautiful people who ensure that the kitchen door is always closed; who are careful with pots and pans. Who tell me before they start the mixer ... I know they listened to me. They understood my situation and that always gave me a good and warm feeling. "How are you doing?" When they arrived and asked me that question, they also wanted to know sincerely how I was doing.

There are also a few who do not belong in the **healthcare sector** at all! I don't expect compassion, but I should at least count on understanding, don't I? There was often one who made a lot of noise here. If you visit someone who can't stand noise and asks if you can keep it quiet, then you will not come wearing high heels there surely? Every step '**sounded**' very painful and my head really could not handle this. The first time I retired to my bedroom. The second time I talked to her about it. The third time I told her to get rid of her shoes and I lent her a pair of my slippers. I already had so much stress when I saw her name on the schedule, that we simply reported that she should not come again.

And then there was the one who talked all the time and suddenly came to me by my bed and said: "**Actually, I want to change places with you; I also want to take a nap.** "

It is my LEIF

'It's my LEIF' means 'It's my body'. But LEIF is also an organization where you can go to ask for euthanasia. The procedure for **euthanasia** has been going on for six months at the moment that the home care is started.

I would like to share that with people I still have online contact with. **Without using the big word**, but rather something along the lines of: "In the past year, I have much more trouble with my head and exhaustion. I'm worn out. That is why I made an appointment at the Levenshuis in Bruges. Look it up, if you have time, they have a website. Then you will understand what I am talking about. "

During a later chat session I will check if they have already googled it. The website is mainly about end of life, but here and there you also read the word 'euthanasia'.

I do not use the word too often in further conversations. "Have you checked it out yet?" "No, I have made an application and they are now sorting it out; for this I have to consult with different doctors."

And I also communicate that way towards the end. "The 29th I finally know the answer from LEIF It now takes almost a year. The end is near. ♥ "

Gradually my social network gets even smaller. If I have informed 15 people of my plans, there are not more than 5 who still sympathize with me on the 29th. People stay away.

It's a YES

And then it is **May 29**: early afternoon we have an appointment with my LEIF doctor. He received a **positive advice** from two different doctors. After a procedure of almost a year I finally know with **certainty** that I will get the chance at a **worthy end of life!**

From that moment on, the decision is entirely up to me: I can have the euthanasia performed, or not. But this is **my victory**; I waited so long for this. I could have put an end to it for a long time, but I don't want that. I want to die with dignity.

That positive advice actually says **that it is not in my head**, that I suffer from a **real condition**. That I have done everything to heal. That I have suffered enough. That I really deserve that rest now. This is the only way!

And then someone asks me if I have peace now. "Yes, it's a roller coaster of emotions, but I'm worn out, I can't go on. I've been working on that procedure for a whole year, so then you are sure. "

"**What I miss the most is a partner; someone who helps me to carry this burden**, someone to grow old with, to push each other's wheelchair and cut each other's meat ... "

No more waiting, this is it

We leave the LEIF doctor's office. With a deep sigh we get into the car. "We have a YES", says Iris. And not just that 'yes'. I had also set a date. **My date: June 12.**

When I hear that 'yes' I am just happy and relieved. I look at Iris and see the tears rolling down her cheeks. She is also happy and relieved for me, but for the first time I am very aware that this also releases other **emotions**.

The doctor said that the decision was entirely up to me now. And I expressed enthusiasm that I was very sure that I want euthanasia. He asked me what timing I envisioned for this and I said: "**This does not have to go on for too long**. I am now fleeing from the noise of the renovations next to my door; I can't keep running. I want to do this before summer vacations! "

When the doctor took his agenda, **reality struck**. What did he want from me now? Did I really have to pick a date for my death? I can't do that! And then I heard Iris's voice: "**Sweetie, from now on you are in charge**. You make the decisions now. "

The following week we often laugh about that strange moment. Yes, **we laugh**, because the humour makes it all more bearable. "How did you think it would happen? Do you think you could just call the doctor one evening and say: come on over, I've had it? Or would you rather not know in advance and want the doctor to suddenly charge at you on the street with a syringe? Gotcha! "

OK. With my mind blank, it was a practical decision to focus on my death date. I book a holiday house in De Haan for a fortnight. Then what? We will go home on Friday. What else do I want? Do I go on? I do not like the idea of starting up all that home care again. And then those renovations next door. Do I say goodbye during the weekend, on Saturday or Sunday? I like the idea of enjoying my apartment for a little while longer.

That's how I did it, that's how I chose my date.

A fortnight of quality time

There we were: a sun-drenched day at the end of May 2017, on a roller coaster of emotions, with a fully loaded car ... **on the run for the noise** of major renovation work next door. And yet, it seemed like a holiday!

Iris stayed at my side for these last two weeks. We have wept, but also laughed a lot. Ah, what else is there to do?

That house was meant for us: when we came in, we immediately noticed the luzzu with brackets, to hang the keys. A luzzu is a small Maltese fishing boat. We had been on vacation there three years earlier! In the house were paintings of boats and there were various scale models. My deceased partner was crazy about boats! In my bedroom was a painting with poppies ... A picture with a field with poppies has been my cover photo on Facebook for years! That house seemed specially designed for us.

I think: this is exactly what I need now: it is quiet here. There are 2 sun loungers in the garden and the sun is a blessing. Strange as it sounds, it does feel a **little 'vacation'** anyway. Iris does the shopping and takes care of food. She cooks, but also discovered a nice Italian restaurant, where we can pick up goodies.

Humour and hilarity

I take a look at the menu and see lots of goodies. Because I love to eat shrimp, I immediately notice the fresh shrimp croquettes. "But look at the price of those croquettes!" "Afraid that you are not going to make it to the end of the month?" My doctor assured me that I should enjoy and do everything I want. The shrimp croquettes are delicious!

And then that bruschetta. Iris tries to cut them neatly in half, but in an attempt to get the last pieces of tomato on my part of the bruschetta, she suddenly sways dangerously with a knife. Because it didn't go fast enough, she had reversed the knife in her hand to use her fingers. "Hey," I call out, "**I'm not tired of my life yet**". We both take a fright and for a second it is very quiet, then we both start to laugh. Humour has often helped us through

difficult moments. Once we stopped laughing and dried our tears, I say seriously ... "I am not tired of my life, I am tired of the tinnitus and the hyperacusis!".

In front of the house is a little stream. One night I hear a croaking or something. "A frog", says Iris, the next morning. "Fortunately, it is only one. Maybe a prince?" In the afternoon I walked with the walking stick of my grandmother to the brook, looking through the reeds. I did not find the frog, so I did not kiss him either. The next night it was quiet again.

We are both in the sun with our own thoughts. "Oeoeeee oe"

"There is a cuckoo here; I hear them everyday since I've been here. "

"That's a turtledove, Sweetie."

Bent double with laughter, we were.

Peep said the mouse

During the day I did not eat much, but in the evening and at night it was different. I always say it is due to the combination of sleep medication I take, but perhaps it is just a bad habit that I have taught myself. I call it 'my little hunger'.

Iris responded to that and puts small portions with things that I liked, ready for use in the fridge. The next day she said: "There was a mouse in the kitchen again last night; only packaging and crumbs left; I have heard the refrigerator door beep ". But every evening she lays out goodies, to satisfy 'my little hunger'.

"That way I want to continue for a while, in a quiet place, in good company, with someone who takes care of me." With a partner my life might look very different. But there wasn't one anymore.

It is what it is! Iris has taught me that.

How often have we said this to each other, that last half year.

After death

If you die, you need to be buried. I had already thought about that. But reality hits hard when Iris said: "Sweetie, I would like your funeral to go as you want it, but then you will have to arrange something yourself, because I do not have the authority to do that. ". "Do I really have to **arrange my own funeral?**", I shouted. "It depends on how important you think that is."

And that's why we invited an undertaker. He understood our black humour real fast and wanted to make sure that all my wishes were arranged in advance.

They have called me 'cowardly' and 'weak', but if you choose your own coffin and sign your own cremation form, then you have to be extraordinarily strong? Don't you think?

I also thought it was a morbid thought to see my obituary, but when the design was finished, I wanted to see that result. Iris enlarged the document on a big screen, so that I only saw a piece at a time; it was only when I had read everything that I could view it in its entirety. So beautiful.

The undertaker had chosen his words well; he had clearly listened to me!

*Death. Have no fear. Don't hold back at my door. Come on in.
Read my books. You're a character in most of them. You are no
stranger.*

*Do not fool me with ailments of which nobody dares to mention
the names. Do not put me in a bed between drooling children who
do not know what they say of old age. Do not ask me money for
useless hours in fancy clinics.*

Wipe your feet and be welcome.

"Jenny"

A load fell off my shoulders.
Arranging your own funeral **feels good**.

I have what I want and no one got hurt

I was caught up in the series 'Starlings'. In a certain episode there is a scene at the cemetery. A beautiful text is read there, which I like a lot.

I showed the scene to Iris and she knew the poem: **'Death is nothing at all'**, from H.S. Holland. On the internet we found Dutch-language versions, but I also liked the subtitles of the series. So we compared the translations with the subtitles line by line and made my own version. I deleted the few words that refer to a religion. Faith is not for me.

In 'Starlings' it was about a funeral of a veteran. The service ended with a few salute gunshots. Personally, I thought that was a nice accent. Iris said it would sound way too loud in the auditorium of the crematorium. "Not good for your ears; you can get tinnitus or hyperacusis. "So ... the funeral director read the text and at the end Iris said **'pang!' ... I had my 'moment' and nobody got hurt.**

"Do you wish flowers at your funeral? Flowers on your coffin? Or would you rather not; then I'll mention 'no flowers or wreaths' on the obituary. "" Who is going to bring me flowers? ", I thought aloud. "Don't mention flowers; there will be no flowers! "But on the table in the cottage was a bouquet of freesias. I loved that. Perhaps under the spell of that wonderful fragrance, I said to the funeral director "Well yes, you know, put beautiful white flowers on my coffin ... and attach a ribbon " **gift to myself**, "It's well deserved!"

Never forget this

When Iris informed my file manager of the home care that they could take me **off their planning**, she was very shocked.

The application for euthanasia had nevertheless been discussed during the intake interview. But she had never taken it seriously; she never believed that I was so sick that this was an option for me. And then she apologized and admitted that I should have been given a lot more help. Iris insisted that she would never forget 'my story' so that when other people ask for help from now on, she will do everything she can to provide them with the necessary help.

After my euthanasia, many people had to **revise their opinions**. "I never thought she would do it." "We knew she was sick and that she had a hard time, but that it was so bad that she would get permission, that is shocking." "I have never realized that she was so sick".

Well, I'm **very proud of myself**! I know it's ambiguous, that I leave a few people with grief, but I want peace. And I am glad that I could end my life in a nice and quiet way. And I refused to get out of life in a different way, but while the procedure was pending, I asked myself regularly: "**What if** I get a negative advice? Then what?" I also discussed this with Iris and the GP. We have discussed, weighed and weighed all possible ways of suicide. But it always came down to the fact that it was so uncertain that I could end up in psychiatry if there was a failed suicide and I do not belong there!

Yes: I suffer from tinnitus and hyperacusis.

And those disorders make life unbearable for me.

And now? What are you going to do with it?

According to my LEIF doctor, my positive advice for euthanasia for psychological suffering due to a medical cause (being tinnitus & hyperacusis) was a **precedent** for Belgium. When I realized what that meant, I entrusted Iris with the words "I do not want to be in papers and magazines with my picture." Iris joked that we would not just go for the tabloids, but would appeal to well-informed journalists and demand a say in the articles.

A few days later I realized the importance of this precedent for my fellow sufferers. To clarify that, I have to mention **Dietrich**. In 2009 Dietrich Hectors left life, through **suicide**, and published his **farewell letter** on Facebook. He did so to **draw attention** to tinnitus and hyperacusis. The short film 'Ruis' is based on Dietrich's life. **We are now 8 years later and little has changed**; and there is still no serious research into both disorders. And therefore no hope for a cure. Even though the 'Tuut van Tegenwoordig' does a lot of sensibilisation work!

Exactly one year ago, on June 12, 2017, I died at home in Iris's arms. My last words for my LEIF doctor? "You are a perfect doctor!"

Thank you for reading me 😊.

And now ... celebrate your healthy life. Party!

But do me a favour and be kind to your ears: do not forget your earplugs.

Love, Jenny XXX

June 12, 2018

A word from Dizzy Me

As Dizzy Me, I followed from a distance - through our common friend Iris - Jenny's gripping wait for an OK from the LEIF doctors for euthanasia. After that redeeming 'yes' on May 29, 2017, I also followed the last 2 weeks at the seaside of the two friends. The countdown to the day of farewell: the euthanasia on 12/6. An intense, moving journey.

Jenny left us on a Monday. Only that day she decided to leave this for us. And I agreed to present her story now, one year after the date, through my followers, as a tribute to Jenny, Iris and all of their fellow sufferers, and the doctors and researchers who are already committed to them today. With the right framework. Without 'promoting' euthanasia.

Articles in the media about Tinnitus and Hyperacusis? They are usually told by a celebrity that sustains a sound trauma and can then continue with 'normal life'.

Engaging well-known Flemish people to break a taboo seems attractive. And the media are eager to participate. Because then people will read it, or watch the program. But what image do you present of a disorder? Is that realistic?

* Bart Peeters: not exactly the average story of someone with tinnitus. He continues to make music and stand on a stage. Can Jan with the cap with tinnitus do that?

* Michel Follet writes in his book about hyperacusis exactly how those patients feel ... But he still makes radio. Jenny could never have done that.

Because of ratings and clickbait we only showcase the famous person. Put Jenny, Bart and Michel next to each other in a television program and you get a completely different and nuanced story that is right.

I would like to expand on euthanasia. According to VUB professor Wim Distelmans, whom I consulted about the facts and figures on the first Friday after her death, euthanasia for tinnitus can only be done in Belgium. "There are only 5 countries in the world with a euthanasia law: the Benelux countries, Colombia and recently Canada. But in these last 2 countries euthanasia can only be administered to terminal patients, so certainly not in the case of tinnitus and the like. In Luxembourg people are very reticent about euthanasia and in the Netherlands it has not been performed yet on tinnitus patients," he said. "In Belgium it has happened several times, over several years." Last week I asked him where we are today. His update: "In the meantime, 1 state with a euthanasia law has been added: Victoria State in Australia. But here too only euthanasia for terminal patients." That makes 6 countries with a euthanasia law, but for disorders like tinnitus and hyperacusis it appears that Jenny's choice will have big implications for us. So we can return the favour.

What can we together do for Jenny and her companions?

- The medical world and the healthcare sector:
 - o Understanding the patient and supporting them better.
 - o Invest in more research.
- The (social) media:
 - o Bringing a nuanced story, disregarding the drive for good ratings and the attraction of clickbait

- Each of us:
 - o Review our viewing, click and herd behavior, so that we are presented with the correct information.
 - o Show understanding for her choice for a worthy end of life. Understanding of syndromes, which today are difficult for the average person to grasp. It is too far removed from us. Today, those people with an invisible disability are easy prey for gurus who promise that they can help them learn to live with it. Which minimizes the syndrome once again, causing the misunderstanding to grow and also ... the suicide rate.

Eight years after Dietrich Hector's suicide and his farewell letter on Facebook and despite the short film 'Noise', based on his life, we haven't made a lot of progress. Unfortunately. No one should commit suicide. Every person has the right to a dignified life and end of life.

Jenny was a woman with tons of humour and joy of life, but she was depleted: she needed peace, the peace in her head that she never received. Today we celebrate Jenny and we'll never forget her. Does her letter help us to gain more understanding for choices like hers? Do we recognize that it can be improved? Are we investing in more research?

Spread the word.

Tania