

A NON-SCARY BOOK

ON LIFE, DEATH, AND EVERYTHING IN-BETWEEN

TABLE OF CONTENTS

Where did this book come from?

Whom is this book meant for, and how to use it?

How does the book help to fight monsters?

How and why is it so unusually made up?

A story about Grandpa Vitaliy, who loved to plant his vegetable garden

A Story about a Teenage Girl Liuda, her Grandma, and a bouquet of Asters

To undergo treatment till the very end or simply to live?

A story about Anastasiya, the apartment deposit, a cancer diagnosis, and a lesson in making decisions

A story about Grandma Rosa and how her entire family “got sick”

A story of Suse and her leadership

A story of Tatyana, the news in the envelope and the plan

A story about Milia, a favorite doctor who refused therapy

A story about Anya, a mother, and how important it is to find competent specialists and to be close by

A story of Viktor, chemotherapy, and his trip to Venice

A story of Maria’s mother and treatment dilemmas

A story about Gavr and how “we tried so hard”

A story about Anna’s mother and her “oncologic cells”

A story about Natalie, who dug up burdock roots for her sick mother

To live in the here and now

A story of Dmytro and an influential patient organization

A story about Irina and her wish list

A story of tango-loving Viktor and his swimming fins.

A story of Yuri, who dreamed of winter swimming while lying in his hospital bed

A story about a Dad named Alexander, who outsmarted death for two of the happiest months of his life.

How to survive bad news?

Fear as the greatest enemy

What can you expect from the healthcare staff?

A story about little Maxim and his mother, who informed herself about his death

Stages of grief

A story about Katya and using meditation as a way to cope

A story about Manya, who wasn't afraid to tell it like it is, and to be close at hand
A Dialogue about sadness and about being true to yourself
Diary and writing exercises as a tool for self-help

A simple recipe to counter panic

What should one talk about, and how should one do it?

Silence as a form of defense

A story about Julia's father and inappropriate haste

Five recommendations about how to talk to a sick person

Four things that matter most

The correct phrasing is important: what should one pay attention to?

A story about a wake and about tact

A story about Kristina and the importance of hugs instead of words

Is it important to discuss the funeral and which questions should one pay particular attention to?

A story of a man facing complicated surgery who was brave enough to share business details with his wife

A story about Leonid, who asked us to arrange a celebration of his life instead of a funeral

To stay at home or go to the hospital?

How should one organize palliative care for someone at home?

A story of Rufina, for whom taking care of her mother turned out to be a blessing

The person's room: how to preserve the space they're used to and to arrange for connection

Mobility: minor inconveniences shouldn't be a barrier to experiencing great happiness

Bed, and body positioning: how to minimize the risks of limited mobility?

Hygiene and safety in the bathroom

Specifics of nutrition

What you should Google about taking care of someone, personal care items, and adaptive equipment

Pain and Its Management

A story about the internal medicine doctor, "playing with pain medication", myths about morphine, and the victory of a persistent daughter

Taking care of someone, burnout, and the support team

A story of Uncle Zhenya and the teamwork of the "Young Falcons" dance group in his last weeks

A story of Nastya, who made it through burnout and learned how to take care of herself

A story of Grandma Lida and correctly sliced potatoes

A story of Maria and her right to life, joy, and tears

A story about the fact that it also “takes a whole village” to take care of a sick person

If “it” happens at home, where should one run to and what should one do?

A story of Veronika and her final 2 weeks with her mother

A story of grandma Ulyana and the blue shoes

A story about Katya, a raccoon, and a Dalmatian

What if “it” happens in the intensive care unit or in the hospice?

A story about an old man who was scared

A story of Pasha and “I am letting you go”

A story about hospice, saying good-bye, and the family razor

A story of Nataly’s dad and his last sunny day

A story about Vova and his wisdom, “Mom, I love you, let me go”

Children and death

How should one talk about death with children and what should one do during the funeral?

A story of a little boy who doesn’t have any grandpas

A story of little Roman and a peaceful farewell in the bosom of his family in a remote village surrounded by pine trees.

A story about the wisdom of 3-year old Danya and about meeting one’s deceased parents

A story of a teenager Anna, who coped with her loss 20 years later

How to help a child cope with the loss of a sibling?

A story of big brother Max, who was there and helped his mom during Andrei’s last month of life

How can one use art therapy in working with children?

A story of Mia, who wrote letters to granny Nadya up in heaven

How to answer the difficult questions about death, which children of various ages ask?

How to live afterward?

A story of Olha, her mom, and her feelings of guilt

A story of Rufina, who has discovered she has additional stages of grief and why it’s important to “process” the loss completely.

A story of Lara’s mom, her ten-day-long agony, and the long path ahead

About religion, faith, and the search for meaning

How can one support a religious person?

What kind of support can medical chaplains provide?

Book about life

Instead of the afterword: the story of little Fedya, who loves to swim

What is palliative care?

The World Health Organization Definition of the palliative care for children

Who and where can one get palliative care?

What can you read about the topic?

What films on these topics can you watch?

How can you support the development of palliative care?

SELECTED STORIES

The story of tango-loving Victor and his swimming fins. Viktor Kremen

The gear turned out to be really well made: having spent two years in the dark corner of the attic, the swimming mask, fins and snorkel were in excellent condition. My diving skills, however, got a bit rusty – it's still quite scary to have confidence in my detrained body and lungs. Like, yesterday I went into a crevice between two rocks, and it wasn't as deep as it seemed. Felt like I would start rubbing the walls with my belly. That is when underwater claustrophobia kicked in – sheer panic!

Down there you see a display as rich as a seafood stall in a posh supermarket – apart from salmon or sturgeon. However, there's a lot of exotic creatures, like baby octopi.

Warmest greetings from Korfu.

.....

One of the lungs is essentially fine, roughly speaking; the other still has some of it remaining: even the all-pervasive eye of PET scan can't see where is the rest of the tumor, and where is the remaining part of the lung. The bronchus is partially blocked, but I hope it heals well, so this part of the lung will regain strength and get back to shape. Last year on Korfu I've been diving and breathing with a snorkel.

This season I have bought a new mask, a full-face one, Navy Seals-type.

My achievements yesterday and today might seem minuscule to a healthy person, but they're quite significant in my personal context. Yesterday I managed to swim 50 meters in fins. It took two attempts though.

It's not because I was physically unwell, it's the damned panic, which ambushes, crushes and dissolves me. With the mask so far I managed to only dip my face in the water, that was it.

It's really obvious, that one lung is enough to breath in a full-face mask. But the subconscious overrides the controls, and you start spastically kicking your fins, trying to breathe in and out, and the panic instantly drowns the body and takes full control of it.

The most important thing here is to look into its eyes – yeah, it's scary, it's very scary, but not scarier than... you know. Let's go again. And again.

Actually I am a sporty person, with good athletic discipline. Throughout last year, my Kittie had been regularly talking about the need to take care and to replenish physical resource. Now I felt that she was right, and that she had grasped way earlier the things I missed being so stubborn.

Yes, the resource should be cherished and replenished.

If you can't lift the dumbbells – do the plank.

If you can't do krav maga fighting – do the breathing.

Don't wait for summer and the seaside – grab your fins and your mask and go to the swimming pool.

Walk your dog – towards your dreams.

If you can't dance all the milonga through – come anyway for at least one or two tanda rounds.

And the most important: don't drown in the feeling of personal unworthiness and guilt, if you're weak so far. You did 50 meters in fins, so be proud, drink wine and celebrate!

A simple recipe to counter panic. Anastasiia Rubtsova

If you feel really bad, bitter, powerless and in panic, and you want to lie down and die right there – keep your feet warm.

Come on, take your warmest, dearest, softest socks and put them on. If you don't have your favourite socks, get a pair, everyone should have one: so soft and fluffy that you want to keep rubbing them, like your favourite spaniel. This is going to be your first aid, like a lungs ventilator.

Check if your feet are warm. As the body is sending the most ancient signal «i'm safe», and the mind is reading it loud and clear.

The second advice: make cookies.

I've learned it from the experience of hospice workers. When you spend all the time on the frontline of pain and chaos, and there's god knows what behind the line, you want to hold on to something, so that you would not slip away. In some hospices they make cookies every evening. Every evening. It's a tradition. And it doesn't matter if someone is not eating it, and someone can't eat it anymore.

The smell of cookies, sweet, hot, vanilla, festive cookie – it's concentrated life. And it's ancient like fire in the hearth. It's the painkiller, the consolation, it's guiding into the darkness and welcomes back from the darkness.

When your house smells with cinnamon cookies or a plum tart, it just becomes different, and nobody knows why, it's pure magic. It becomes a cuddly house. This is how the scarred mind gets another signal that life goes on, that somewhere deep the current is calm, and you can swim and swim and get to a good place, while all the rush on the surface is nothing but a bad dream.

You know what? I'm gonna bake a plum tart now.