

# QUARANTINE NOTES

Novi Sad, 2020

## **Quarantine Notes**

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Publisher:

...IZ KRUGA - VOJVODINA,  
Organization Providing Support to Women with Disabilities

For the publisher:

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Translation from Serbian:

Marina Iles

Proofreading:

...IZ KRUGA – VOJVODINA

Cover design:

Aleksandra Erdeljan

Layout:

Nenad Samardzija

Printing:

PROMO S, Novi Sad

Circulation:

500

ISBN-978-86-88141-05-5

Distribution: ...IZ KRUGA - VOJVODINA,  
67, Bulevar vojvode Stepe St, Novi Sad, +381 21 633 4584,  
[www.izkrugavojvodina.org](http://www.izkrugavojvodina.org), [www.portaloinvalidnosti.net](http://www.portaloinvalidnosti.net)

Published with the support of the foundations: Mama Cash and the Reconstruction Women's Fund.

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RECONSTRUCTION  
WOMEN'S FUND

The opinions expressed in this publication do not necessarily represent the views of donors.

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## ***INSTEAD OF A FOREWORD***

### ***A time when the entire society can learn from the experiences of women with disabilities***

While everyone fears the coronavirus COVID-19 infection to a greater or lesser extent, women with disabilities do not only fear the health-related risks, but also the risks that come with living in a discriminatory society. Healthcare is already largely inaccessible to women with disabilities, a reality that has intensified in the circumstances of the pandemic. Hospitals and collective centers are not adapted to persons with disabilities and do not allow personal assistants, sign language interpreters, and informal caregivers to participate in the therapeutic process. The conditions that women with disabilities would be exposed to in case of infection are at least as horrifying as the virus itself. Prescribed protection measures are unattainable to many persons with disabilities: women that use personal assistance services cannot isolate themselves completely; some women, because of the nature of their disability, cannot practice the recommended stricter hygiene measures. At a time of shortages of disinfectants, many do not have the means to disinfect the assistive technologies they use. Women living with respiratory difficulties often have difficulties to differentiate between their usual symptoms and COVID-19 symptoms, which leads to additional anxiety... Women with disabilities are systematically denied freedom of movement. Many are accustomed to living in isolation, and now are faced with the fact that all those things they were told were *impossible* to provide for them, are now available in alternative forms to serve the general population in quarantine (online jobs, online schools, home delivery, virtual cultural programmes), emphasizing to them their marginalised position. There are also disruptions to communication. For example, persons with hearing impairments cannot read lips in

an environment where everyone is wearing masks. See-through masks are available only on individual initiatives. These masks are known as *masks for persons with hearing impairments*, even though we should all wear them as universal-design masks. Additional support systems, such as voluntary and humanitarian organizations, exist and are being developed, but do not provide any support for women with disabilities. In short, the pandemic has uncovered and reinforced the deeply rooted marginalization of women at all levels.

The media keeps announcing that older persons and persons with chronic conditions are under increased risk, while persons with disabilities remain invisible. The women with disabilities we spoke to agreed that all the measures taken since the pandemic was announced, have been directed at assisting and supporting elderly people, while they, and persons with disabilities in general, have remained invisible. First of all, we mean humanitarian packages, the support of volunteer organizations in the delivery of food and medicine, as well as online mental health centers, which are usually not familiar with the specifics of the position of women with disabilities. The initiative for allowing the movement of personal assistants was adopted later, with the ban of urban and suburban transportation making their functioning more difficult. Due to lack of support, some women testify to being overburdened in this new situation with work and family care. As a result, they put their needs last, which will certainly affect their health. For many women, the pandemic is invoking memories of periods of isolation they were exposed to during hospital treatments or in other traumatic situations. Among women who have struggled to acquire the right to independent living, the fear of the abolition of basic rights is ubiquitous and justified. Women with disabilities living in violence are in a particularly risk position, as they are now continually exposed to violent partners or family members. Their right to privacy is threatened, and thus the possibility to seek support. Some women report being more exposed to digital

violence, to the point that, even though social networks are the only means to contact their loved ones, they remove their profiles. No one is even talking about women in residential institutions, who are written off once again.

Since the state of emergency has been in place, the operating hours of the majority of services have changed, such as the centres for social welfare, courts, and medical institutions, presenting an additional obstacle to accessing information. Women with disabilities most often want to know how to get permits for the movement of their personal assistants and informal caregivers during curfew. Also, women often ask the *SOS service of ...IZ KRUGA - VOJVODINA* about their rights when it comes to the enforcement of court decisions regulating custody arrangements between minors and fathers that do not live with the children, especially during weekend curfews, when this measure lasts for 24 hours. It is expected that parents make their own arrangements and organize visits in the period when movement is allowed, but when there is history of domestic violence, coming to an agreement in line with the court ordered dynamics of visits, is considerably more difficult. Self-isolation and restrictive social contacts enable increased control over women with disabilities by violent partners, family members or caregivers, also denying them the opportunity to seek support, especially in the period when everything else is overshadowed by the pandemic.

After the state of emergency in Serbia was declared on March 15, 2020, we agreed to get in touch with women with disabilities, our associates and beneficiaries, and ask them: how do they react to the new situation, do they need urgent support, do they have assistance, how will they obtain basic groceries... The majority of women said that they organized themselves and had the support of parents, friends or neighbours, but it meant to them that they could count on the support of *...IZ KRUGA - VOJVODINA*. Many women say that they are used to living in isolation; emergency

measures are business as usual for them. Still, the new situation has brought up anxiety, depression, fear for the future, as well as fear of escalating violence, which is why the psychological support we provide is very important to them. We use our *Disability Portal* to publish up-to-date information on the impact of the pandemic on the community of people with disabilities, as well as updated contact information of organizations providing support.

We found important that there is a virtual space contributing to the visibility of women with disabilities and showing diverse experiences, because the pandemic does not affect everyone equally. That was the reason why we launched an instant section *Quarantine Notes* on the *Disability Portal*, within which we published personal experiences of women with disabilities, their authentic testimonies about everyday life during the pandemic, current challenges and points of support they find in the new situation.

*Disability Portal* journalist Marijana Canak asked women with disabilities what their daily life looks like during the state of *emergency*. What they go through from morning to evening, what activities keep them busy, what they talk about with themselves or other members of the household, what changed in their daily routine, what their greatest obstacles under the new circumstances are and how they overcome them, what aspects of their character help them or make it more difficult to cope with the situation, what their sources of support are, if there is a good side to what is going on, what new things they have discovered about themselves during the state of emergency, how isolation affects their relations with others, what makes them angry, are their days in isolation too long or too short, what is the first thing they will do when this is over... The women with disabilities who shared their experiences in the *Quarantine Notes* said that it was important to them that their voice be heard, and the readers of the *Disability Portal* experienced their testimonies as mutual encouragement. That is why we decided to make their stories available to the public in the form of a publication too.



This is a time when the entire society can learn from the experiences of women with disabilities, because the majority of them regularly face the challenges brought by this state of emergency to the general population. The impact of the pandemic is a clear illustration of the social model of disability: we are not limited by disability, but by society not respecting diversity as a main human characteristic.

The pandemic has served as a litmus test, clearly and undoubtedly showing the deeply rooted marginalization and the spectrum of daily challenges faced by women with disabilities. The state of emergency will end, but will women with disabilities remain in isolation? It is the responsibility of us all not to let this happen.

Svjetlana Timotic,  
Executive Director of ...IZ KRUGA – VOJVODINA  
In Novi Sad, May 3, 2020



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**Tatjana Stojsic Petkovic**, psychologist, laughter yoga leader, activist for the rights of persons with disabilities, psychological workshop facilitator and provider of individual support to women with disabilities exposed to violence and discrimination in the ...IZ KRUGA - VOJVODINA Organization.

### ***The pandemic confronts us with questions about ourselves***

Every long-term stress situation, along with uncertainty about how long it will last, brings a specific type of unrest, by nature we all want to know some timeframe for things. In this situation we don't have a timeframe, nor do we know the outcome, so we guess and make different assumptions. Women with disabilities I work with react in different ways, depending on the person's temperament, circumstances they are exposed to. When the state of emergency was declared, the reactions were mostly: – *All right, I can handle this. I organized everything. I live alone but I have my neighbors' support.*

In a very short time, some ten days later, the story changed completely: – *This is lasting too long, I don't know how I'll cope!* As a therapist, it was difficult for me not to fall into the trap of confronting them with what they had said a week earlier, because it would make no sense. Searching for the right literature, I remembered a guidebook I used before in work with children in the context of war situations of the nineties, and noticed there is an overlap in the phases that we are going through now: denial, panic, acceptance and raising self-motivation.

The way we cope with the current situation greatly depends on the relationship with persons we live with. For someone who has lived in a relationship of trust or of good cooperation, this is a time for developing deeper bonding through long and quality conversations. If someone is in a bad partner relationship or in a bad relationship with those in their immediate environment, the



situation has only become worse. The situation of women who live in a violent relationship, has become worse. Mothers of children with disabilities now feel marginalization more intensively. Some have gone to their holiday homes, to be alone with their children, because other household members can't bear to be together in the new situation. For me this is devastating, as I find it very difficult to stay supportive and not say: – *This is a situation in which you should think about whether you accept the given circumstances at all.*

The support system has completely changed, we can't apply some of the principles we generally apply. For example, in the therapy process, the clients always face their own responsibility and the things they can do on their own. Women victims of sexual violence are an exception, because they hold no responsibility for what was done to them. In the current situation, this applies to the majority: a client can't take responsibility for the state of emergency and all that it implies. Generally, we now don't have support where we once had it, the focus has shifted. We all say that we now have more time for ourselves and our family, but family dynamics have substantively changed. To some of my clients I suggested writing instead of having online conversations, because this is now the only way they can have privacy.

Moreover, women with disabilities feel an additional dose of bitterness, disappointment and anger, which are not emotions that are easy to deal with. Everyone is complaining about restrictions of movement and isolation today, and that has been, for a lot of women with disabilities, a reality for many years. Their spontaneous reaction is: – *Let them see how it is! I haven't been able to go out for twenty years!* This is not a reaction with bad intentions, but it rather shows that women are aware of all the things they've overcome, the things they gave up, the things they've learned to live with. Now, when someone else is telling them about it, they think: – *You see how it is for me, and nobody thinks about it.*

If women are focused on informative programs and television, that represents a pathway towards depression. Fear is inevitable,

and once we get out of the situation, you can't just *rub* different fears *out like with a rubber*. Once fears appear, the question is how we are going to deal with them later on. The key fear in this situation is the fear of death, fear or helplessness, fear that things will turn bad for me and for those I rely on. We don't usually face these fears so often and so intensely. Women with disabilities fear being placed in collective centers like the fair, because nobody considers how someone who moves with difficulty, who has a sight or hearing impairment would function in these centers. It would seem we are increasing the level of humaneness and we are developing additional support systems, but paradoxically it is becoming evident that marginalized groups are now even more marginalized. I contacted several voluntary organizations to check how they are providing support to persons with disabilities. They told me they hadn't even thought about it. We have to think about marginalized persons and provide support to them in an appropriate way.

If in the newly-occurred situation we live with someone we don't know very well; the process of learning and adapting is inevitable. Some women with disabilities now rely on someone that did not help them before or they had personal assistance at one point, but are using it now only at home. It is necessary to establish a different way of communication. We all get upset more easily now, because fear and uncertainty are omnipresent: we don't know what announcements there will be by noon or by the end of the day, whether the quarantine will be extended to 24 hours or similar. As our relationships get more and more complicated, it is important to recognize the things we can do something about, and those we can't. We can try to be all right with ourselves and be patient with ourselves and others. Differences now become stronger and more evident in relationships. Let's say a household member refuses to wear a mask or wash hands; or that they believe this is biological warfare, while others have their own theories. Someone will feel cast off by their own family because of these views. People now rely more on each other; they need to communicate and make decisions about daily activities and use of common space. Previously, people in many families met only briefly during the day. How



can we work on patience if we are annoyed by everything? It's important to focus on the fact that this can't last forever, and use this as a starting point for setting personal tasks and goals.

The consumption of sedatives is high, which I consider detrimental, because medicine and other substances should not be something we turn to as a first option. Alcoholism is also increasing, because many people are using this situation to justify excessive drinking. Avoiding the situation will not make it go away. Having a routine is important. It is common that when we think we have plenty of free time, that's just when we don't manage to get anything done. That is why I recommend a daily schedule: – *What can I do and when?* It doesn't need to be a long-term plan, it can cover the following several days. It is important to set aside time on a daily basis for activities we like. Breathing techniques are extremely beneficial, accessible to all and everyone can do them. Laughter yoga classes can help us *take a break* from everyday events. Many beneficial techniques are easily accessible and simple to do. In my work with clients I use laughter yoga, breathing techniques, meditation and *EFT (Emotional Freedom Techniques)*, a technique that can be used in all conditions and regarding any topic.

I've been in self-isolation since March 15<sup>th</sup> and I have to admit I was in a quite rebellious mood during the first several days: – *Nobody is going to forbid me from going out!* But then I accepted that this is a way of protecting myself and others. As a wheelchair user, I inevitably touch numerous surfaces entering or exiting my building, entering the elevator, while moving generally. Based on a conversation with a friend, a doctor and someone I trust, I concluded it's best for me to stop going out, no matter how much that clashes with my temperament. I informed my clients that I was working online in the new situation and I really have a lot of work. When all the therapy-related conversations are over, I need to deal with my own mental hygiene. I am in contact with a lot of people, who react from panic and exaggeration to the negation of the situation. All that affects me. For me to stay me and prevent



other people's thoughts to intrude mine, I need to do something for myself. As I am not the kind of person who looks for a *shoulder to cry on*, nor is there currently a person I would put into that role, I started drawing fractals and using colors that bring me a feeling of harmony, health and happiness. This helps me immensely.

Otherwise, I use the method of fractal drawing in my work with clients, but it is difficult to implement it in online communication.

The greatest challenge for me during these days is supporting other household members in a way that I do not lose myself, because I have the impression that they are processing this situation differently than I am. Besides drawing fractals, I started riding an indoor bicycle for which, allegedly, I did not have time before. During the thirty-minute training, I let household members organize themselves completely on their own, to get out of the inconvenient role I took over. I am learning not to be there for everyone, but to be there, above all, for myself, so that my health would be all right, as I belong to a high-risk group. I was in bed with the flu four years ago and I was told the next flu would not be without serious consequences. I was in hospital for three weeks; it really took a toll on my body and there are still some consequences. I was not afraid only of the infection, but of the circumstances I would find myself in case I fell ill. In those situations, people are alone, relying only on medical workers. I had to work on that fear for a long time, to prevent myself from constantly thinking about this situation. Laughter yoga helped me fight the fear.

It is good that we all have to ask ourselves what our purpose is, why we are here, what we can do for our life and other people important to us. I believe we are all asking some philosophical questions we did not ask before.

In Novi Sad, April 1, 2020

**Olivera Ilkic**, activist for rights of persons with disabilities, with two-decades-long experience in provision of support to women with or without disabilities exposed to violence and discrimination.

## *You can do anything, but you won't right now, because you're smart*

I am already up at around seven. First, I read the news on my phone, see what's new, I check Facebook to see what's going on, then I get up. I get dressed, tidy up around the house, I exchange messages with my sister to see how she got to work (she works at a private textile factory, they are currently sewing masks). When I finish that, I turn the TV on, often just to have some sound in the house. Sometimes I watch the program, film channels most often, crime series, animated films for children cheer me up too. I communicate with my cousins, friends through the internet, sometimes we talk on the phone, I check how they are coping in isolation, how they organize grocery shopping if they have disabilities. When my sister gets back from work, we have coffee together, we eat, tidy up, talk about how our day was, we watch the news and sometimes a movie, and the day is done.

I tell myself this is not the first time I'm in a situation requiring caution, that it will not last forever and that I have to be calm and patient. My sister and I talk about how we spent the day, how much money we have left for everyday life until the next pay, about new information concerning the curfew, because she works until 3 p.m., which is also until when the shops work, so she rushes to get there before closing time. The hardest thing for me is to see how tired she is when she gets back from work, where she really works hard, and her work is undervalued even under these



circumstances. She is careful, she wears a mask she sewed herself and the gloves she got at work, we follow doctors' instructions and we have no fear of getting infected.

In regular circumstances, I live alone, and I have an elder care home assistant who comes for two hours every day, from 7 to 9 in the morning. She does the shopping, pays the bills, helps me with the cleaning, I have my morning coffee with her. I moved in with my sister temporarily, as my home assistant can only bring me bread and milk, without entering the flat. No matter how close my sister and I are, we are both used to living alone, so we are now getting used to living together again. We're lucky because we're both tolerant. We miss direct contact with people, as the only contact with other people we have is over the phone or the internet.

I focus my energy on searching for information about who persons with disabilities can turn to for support during the state of emergency. In that sense, I am glad the organization *FemPlatz* thought of me and some of my friends who I cooperated with before, who were also thinking about the same topic. When this whole thing started, I first called a friend who I knew had no support and organized for some mutual friends to get her all she needs to last her for at least a month. I am thankful to all who are ready to help in any way. I remind people who have decided to volunteer and who are connecting through different Facebook groups not to forget about persons with disabilities. Many were shocked when they realized that the support of the Red Cross and volunteers organized by the state was not directed towards us at the moment. They thought this was implied.

Friends without disabilities are important to me, for whom this may be the first time facing isolation and spending time in closed space. I understand them, as I am often in isolation during winter and I have experience with this, I try to show them I am there for them and that they can write and call for whatever they may need.

I didn't discover much about myself that I didn't already know, the only evidently different thing is that I don't have enough concentration to read as much as before and I am very sorry about this. I hope this is only temporary. I am lucky that I am very calm, rational and composed in crisis situations. That's how it was during the great economic crisis, wars in the early nineties and bombardment which I spent and survived in Rakovica, a part of Belgrade that was bombarded daily. These characteristics are important to me generally, as I worked for a long time on the SOS helpline for women with disabilities who survived violence. I feel better when I control my own emotions and when I don't let them control me. Every emotion is okay, but for me it is important to express it when I assess that this is safe, both for me and for others. I don't respond to restrictions well. Before, when they told me I wasn't allowed to do something, I would usually do everything to prove the opposite, which even helped me, because it often meant pushing my own boundaries and getting out of my comfort zone. Now I tell myself: - *You can do anything, but you won't right now, because you're smart!* Of course I am not allowed to and I know this, but at this moment I need to believe that it is my own decision, so that I have a sense of control over my life in this chaos in which we know close to nothing.

One good thing about this situation is civic solidarity. It was present before, in all crises we found ourselves in. When everything around us seems to be in chaos, uncertain, poorly organized in the sense of the response of state institutions to how this affects the lives of ordinary people, those with the least social power, I think civic solidarity is omnipresent and invaluable. Somehow, we see each other more clearly, we are ready to share our energy, emotions, and all other resources, to help those around us. Many friends without disabilities called me to check if I needed help with getting groceries, if I knew anyone in need of psychological support... They want to help. Some of them are feminists. A lot of them, before becoming friends with me and my feminist friends



with disabilities, did not even think about this. This is important to me because it means that women with disabilities succeeded in becoming visible in the feminist movement and this makes me proud!

What makes me angry is that I didn't notice that traditional associations of persons with disabilities did anything to inform their members about sources of support. There are positive examples too, of the traditional organizations the only I know is the *Association of Cerebral and Child Palsy* from Užice, others that I know that are doing everything they can and provide active support are: ...IZ KRUGA - VOJVODINA, ...IZ KRUGA – Beograd, *Beli stap* (Eng. *White Stick*), ...IZ KRUGA – Nis, USH (Union of Students with Disabilities) which provides support to youth with disabilities, *MDRI and FemPlatz* providing support to women living in institutions.

I get furious when I hear politicians treat some groups differently than others in these circumstances. They ask us to respect doctors' recommendations, others send volunteers and support, or they scold, they treat us like naughty children, they publicly show their frustrations, they ask us to praise them for the job they're paid to do. For them, some citizens don't exist even under these circumstances. I didn't hear them mentioning homes for permanent stay of persons with disabilities when they talked about the situation in homes for the elderly. They don't mention people living with chronic respiratory disease, rare diseases, people suffering from cancer, people whose lives are endangered every day even without this virus. They don't send volunteers to support parents with children with disabilities, though for many of these children even a mild form of infection could be a life endangering condition.

They talk about the importance of personal hygiene and isolation and about the prevention of infection, but they don't mention



how this could be achieved by persons living in unhygienic settlements, homeless people living in the streets, while public toilets and drinking fountains are not operating. How do they expect persons with disabilities to do this, who live alone and don't have personal assistance now? Not to me misunderstood, of course it's important to help senior citizens, but I believe it is important to know we are all in this together and that each of us can be vulnerable.

When this is all over, I will go back home and try to see as many of my friends as possible, with some of them I will go to an outside café, some I will invite over to my home, and I will go to the hairdresser's.

In Belgrade, April 6, 2020

**Irena Stojiljkovic**, graduate defectologist and psychotherapist under supervision, trained for work with children and adults with disabilities and their families.

## ***Let's not pretend we are stronger than we are***

I am very busy, I go to work every morning, I work in the health-care sector and I am in contact with a lot of people. Everything that is happening does affect me, I am worried, but I am doing everything to protect myself and protect others from myself. It is normal to be scared, to be confused, nervous and irritable. We shouldn't blame ourselves for feeling the way we do or pretend we're *stronger* than we really are. Feelings like sadness, fear and pain go away faster if we let ourselves feel them and if we work on them. When we keep these feelings in, ignore or suppress them, they can cause problems. We can all take care of ourselves and our health, as well as the health of others. I've learnt to recognize what I can control and what I can't. I focus my attention on the things I can do something about and respect all the prescribed protection measures.

I've made a clear daily structure that supports my physical and mental health. I follow my interests and I do what relaxes me. I am a member of a family of three, with my husband and ten-year-old child. We divided household chores among the three of us. We spend our time together during the evenings: we play board games, talk, we watch interesting shows on television or funny videos on Youtube. Every other day from nine to eleven in the evening, I volunteer as a psychotherapist and provide psychotherapeutic support via text messages and e-mail.

I have a hearing impairment; I communicate by speaking and lipreading. My greatest challenge in the current situation is



communication with people wearing a mask, because I can't read from their lips. I don't know sign language, so all I'm left with is written communication. It's also difficult for me to follow online group psychotherapy trainings. This frustrated me at first, but I got used to it now and found a way to communicate with others. People I've encountered so far, were always ready and willing to help. They usually have patience and communicate with me through writing. During the psychotherapy training, if I didn't understand a part or I didn't manage to lipread, other students send me messages using Viber. I have all the support I need. There is an alternative way for everything. This is a state of emergency, but it will pass.

In Novi Sad, April 8, 2020





**Dragana Markovic**, an English teacher, activist for the rights of persons with disabilities and one of the coordinators of the *Translators' Heart* group.

## *I'm a bit jealous of people who complain they have too much free time*

If you're an online English teacher, your life doesn't change much during a pandemic and isolation, except that you: don't go out, you've got a bit more work than usual, you don't have time to follow different culture and art events that are now available online and maybe you're even a bit jealous of people who complain they have too much free time and not enough ideas about how to spend it. So far, I've watched one play and no movies. I find time for books.

Several days ago, I arranged to have two lessons with four different people – and these are individual classes. By some miracle, two hours before the lessons I realized I had more students and a lack of class time. An old student of mine called me after a two-year pause. She says: – *Please, let's have some lessons, I need to do something otherwise I'll go crazy!* Another one says we can have lessons every day, at any time. The third tells me her days go by from one English lesson to the other. In the introductory part of lessons, during conversation practice, we talk about the situation in the different countries my pupils are from, about how people behave and react, we learn the current terminology, such as state of emergency, police curfew, isolation... and then we go back to standard teaching activities.

I look out the window during my afternoon lessons, in between verbs and adjectives, formal and informal letters, phrasal verbs, and idioms, and see there's not a soul in the street. It's the police

curfew. I am so angry, yes, angry with the people who are walking in the morning like they've never had a walk in their life. I am angry with those that discuss conspiracy theories, our government and justification of introduced measures. Isn't 1,000 deaths in a day in one country reason enough to stay at home? It is for me.

There are those of us that can't isolate ourselves completely, even if we wanted to. Personal assistants can't stop coming. Life in the street maybe can stop, but not life at home. Assistants are at risk, and persons with disabilities, as well as their family members. We need to cope with this as best as we can. In addition to this, assistants need to have permits issued for being outside during the police curfew, this is clear, but not even that could be handled smoothly or without unnecessary stress. And no, I am not afraid of the very disease, I am afraid of the situation where I would be completely isolated, and I absolutely cannot function without assistance. I am afraid that someone might need medical help for some reason, and this is not a time to go to the clinic or hospital.

There are days when I am completely calm and rational, positive, careful and solution oriented, recognizing the importance of raising awareness about the entire situation. I am ready to be supportive. And then there are days when panic and madness take over. I get a sore throat and I immediately see myself getting tested, the only thing that comforts me is that one of the so-called covid clinics is right here in my neighborhood. Then I realize I am not the only one and that some other dear people have almost the same outbursts of insanity, so we laugh together. During such days, a Facebook chat nonetheless comes to the rescue, it has existed for years, but during these times it's better than gold. Us four coordinators of the *Translators' Heart*, with another additional member, are available to each other 24/7 and all the outbursts of insanity or panic attacks can't do anything to us as long as we have each other. I won't write about the *techniques* we

apply, but I will say that without them I would've packed for the fair a long time ago (that is our code for *it's over, that's it, it's time for a break*), that without them I wouldn't know what to do and that I can't remember the last time I had such fun and laughed so hard. It's a good thing that crises don't hit us all at once and not equally intensely.

I don't miss people, people are here. In our time, at least it's not difficult to be close to someone who physically distant. Unless the internet's shut down, like today, for example. Then you're left with your inner world, which, if you hadn't built by now, will be difficult to develop. This situation hasn't taught me anything about myself I hadn't already known, at least not yet. And I'm not sure I need it in order to become better. There are those of us who do good things during peaceful times, we change our little microcosms, and then the world. I am not bored at home. I miss nature. I miss the normal way of things, life without being careful and worrying about those more and less close. Still, one encounter can change everything. Now more than ever. And that is why, for the sake of future encounters and memories yet to be made, we should stay at home.

In Novi Sad, April 11, 2020

**Dusanka Vukelic**, retired nurse, a war veteran with disabilities, she is involved in shooting and is an active member of several associations.

## *This is also a fight against alienation*

The news about the new corona virus on television starts in March of the 2020 leap year. My husband and his brothers have gone to our home region Lika for ten days or so, soon to return, so I video call them to warn them about the fast-spreading virus. The story is intensifying, more and more countries are facing this, as it seems, already a global problem: *China fighting against an invisible menace, terrifying reports from Italy, the number of infected is rising, mortality is increasing.* There are patients who recovered, but significantly less (usually it is those with milder symptoms and a stronger immune system). This situation found my household members and me amid having the walls painted, also the house painter had an accident, he hurt his leg coming down the ladder, so the painting work was prolonged. We clean and wash every day, we tidy. My husband returns home, in disbelief of what is going on in the world. He just came back from a clean environment with beautiful nature. The three of them, nearly completely alone in an abandoned village, working far away from civilization, but they have internet, they heard something, they don't listen to the news and it all seems a bit unbelievable to them. They are surprised and can't believe it, while I am the total opposite of this. I understand how serious all this is, probably because of my profession. I am a nurse, so I know that what is invisible can be lethal.

On Friday morning I had a video call from my brother-in-law in Novi Sad. He called from the market with mask and gloves on, showing me the disinfectant he uses to clean his stall. – *The corona has arrived in our country, there are infected people in Novi*



*Sad and Belgrade* – he worryingly reports on the gravity of the situation. After talking to him, I grab a cloth and cleaning liquid. I scrub down all work surfaces in the kitchen and dining room, everything I could reach by hand. The final step is disinfection of all surfaces and handles with alcohol, and that's how it goes all day. All household members are involved in cleaning and disinfecting. My daughter-in-law and son have taken care of their space on the upper floor and loft, they are making some changes, because they're preparing for their third baby, due to arrive with a C-section at the beginning of July.

The house now smells of Domestos and alcohol. As he goes into the bathroom, my husband says: - *Smells like a hospital*. People are gradually starting to understand how serious the situation is. Several days ago, we were watching the news after dinner, and I remember well, I was eating a spinach pie, and I could only eat half of it. Watching the images of the horrors in Italy, the numerous coffins, I felt a chill creeping up along my spine, all the way to the top of my head. – *Not again!* – I thought. It took me back to the war period, back to 1991, when I was injured by shrapnel from a mine while performing my duties as a nurse, and went through true hell. Discomfort, nausea, and returning to the past; I feel I could let this amount of stress out. I slowly get up to go to the bathroom, but I don't make it, It comes out. I haven't vomited like that since I was pregnant. I measure my blood pressure, it jumped to 133/84. It is high, normally it's 90/60, sometimes 110/70. I am assessing myself: – *Maybe it's a subconscious fear of danger and death* - but that is a question for an expert.

Again, like many times before, I look for salvation in work. Before all this, I started a needlepoint for my granddaughter Tijana. Needlepoint is therapy for my right shoulder that I injured, which is why I am making a pause in shooting practice, but it is also therapy for my soul. I have a painful period behind me, involving the loss of my parents.

I'm come over with worry for my colleagues, medical workers at the frontline of the pandemic, so my prayers go to them, to be protected from the virus, to be strong and endure and overcome this menace. I am sorry I can't do this job anymore, but we can help by respecting emergency measures, not just by applauding them, but by protecting ourselves and others from the further spread of the virus. This is the only way we can win this pandemic: total disinfection and immediate temporary reduction of all physical contact. Keeping a distance of one to two meters, masks, gloves – these are efficient weapons in the fight against the invisible enemy. It will pass, of course, but with many victims.

The state of emergency can be used for all those activities we didn't manage to dedicate our attention to because of work, rushing around, different obligations. Now we can dedicate our time to that which gives us pleasure and makes us happy. To be honest, being a bit slower, the workday is too short for everything I have planned. I worked on the needlepoint four-five hours a day, I walked, exercised a bit, as much as I could at home (I recommend doing easy exercises for activating the lymphatic system to everyone). It's a great advantage that we have a house and lot, a garden where we can have our coffee in peace when the weather is nice. We have a greenhouse, our home-grown fruit and vegetables, not sprayed and healthy. There's plenty of work with that.

Besides all these activities, we now have more time to play and spend time with our grandchildren. On a workday, my grandson Filip follows his classes on television. In addition to that, he gets his homework through e-mail and Viber, and sends the completed work back to his teacher. It seems they handled the new situation well, though parents need to get more engaged around school activities. My granddaughter Tijana and I use this time to play. We both enjoy it, we let our imagination lead us and we never get bored, every day is a different game. A couple of days ago my clever little girl says: – *Grandma, I wish you were never injured!*

When I asked her why, she told me: – *We could have even more fun, you could run after me, we could chase each other, we could go to the store just the two of us!* I told her: – *Darling, when this is all over, we will go wherever you want!*

Several years ago, I started writing about my life, just for myself. I should continue, I hope I will get down to it and use this time to write. I usually have the inspiration and time only while there's snow outside, but I could write...

The isolation and state of emergency are for our own good, with the purpose of saving and preserving people's lives. I don't see any burden in this, in these modern times, when there are other ways of communication, so we can use video calls to see and hear all the people we want. I regularly communicate this way with my uncle in the USA and my aunt who lives in Croatia. I regularly talk on the phone with my aunt in Belgrade, she is a big support: that's how it was when I was injured, and that's how it is now when my parents have passed away.

When I was injured, I lay immobile in hospital and I couldn't talk to nor see my parents or brother, who lived 600 kilometers away, in a war-affected area. If we had had mobile phones then, it would have saved me from additional stress, and I would have worried less. That's why I don't understand why people are complaining now, why they are dissatisfied, when they have all the conditions in their homes and can dedicate their time to their children and spouses, to get to know them better and get close to them again, because we are so alienated from each other because of rushing, obligations and running after a pay.

This is also a fight against alienation. Look at it that way and it will be easier. The family is together again, we spend our time together, we have lunch together. In this situation, the only thing that makes me lose my temper is when some people are spoilt and

arrogant, but they will find a solution for them. I am thinking of people on social networks who are calling people to go out in the street and protest, which is inconceivable for me in this situation resembling biological warfare.

Last night, I saw via Skype a cousin who is a doctor at a heart and lungs clinic in the center of London. When all this started, not even England responded well. As they had no protection, this resulted in many infected healthcare workers. Unfortunately, she also has some Covid-19 symptoms, fatigue, sore throat and pain in her ears, temperature lower than average, she is cold and has been removed from work for seven days to rest, while they monitor her condition. They expect the queen to address the people, they are building a hospital with 4,000 beds. The fight goes on, we're hoping the situation will improve. Only iron discipline, patience and mutual understanding can bring us the best possible outcome for all.

In Smederevo, April 13, 2020





**Svetlana Jankovic Beljanski**, activist for rights of persons with disabilities and former Assistant Mayor for Social Issues of the City of Valjevo. She is involved in acting and is the initiator of the *Drama Creativity of Persons with Disabilities* Festival, an inclusive theater in every sense of the term.

## *It's important to survive and stay yourself*

Mornings are standard, since I retired, I wake up a little earlier than before, around nine, and it's like that now too. The person who gets up first boils the water for coffee. Mikica and I have coffee, Marija drinks *Nesquik*. After that we have breakfast, and then do the dishes. If Marija is visiting her grandparents I prepare what she needs to take them, and I put her mask on. In the meantime, I hang out clothes to dry, tidy up and I go grocery shopping every second or third day, also to the pharmacy, maybe visit the bank. To my luck, everything is near the apartment, in the city center. Of course, I regularly wear a mask and gloves, when I return to the apartment I disinfect my shoes and bag with alcohol, throw away the gloves and plastic bags I brought, wash my hands and the cotton face mask (first with hot water and detergent, than a high temperature cycle in the machine). Based on my instructions, my mother made several masks, so I have them for this *procedure*.

Then it's already lunch time. Besides a cooked main meal, we always have soup or stew for lunch, this has become a routine in my cooking, but when it comes to the main meal I am in trouble, because Marija mainly only eats meals with chicken or minced meat. Then we have this cooked meal for two days. I usually buy my vegetables at the market, so I am not used to buying vegetables in a supermarket. Several days ago, my mother sent me fresh cabbage



my sister had bought somewhere, so I cooked it with chopped beef. After lunch it's time to do the dishes again, and then I usually do some housework, vacuuming, cleaning floors, tidying the closets. There is always work like that around the house. I clean the bathroom daily, that is, I disinfect it with alcohol.

These days I always make us tea, one in the morning and one in the afternoon. I used to drink tea or coffee with lemonade in the evenings, with two neighbors from the building. Now we only talk on the phone, or if someone really needs something, we see each other at the front door and just hand over the bags. We miss being together, especially me, because this was an opportunity to sit and relax, listening to jokes and talking with the two of them.

At seven in the evening, I usually watch *Slagalica* (Eng. *Puzzle - Serbian quiz show*). I put the ironing board in front of the tv, and I am ironing the laundry while watching and listening to something that I am interested in. They criticized me for a while for ironing everything, so I just folded some of the things, but I am back to old-school ironing, and so I iron everything except maybe socks. That is, as my grandmother and mother used to say, the most efficient way of killing viruses and bacteria.

When it's dinner time, I usually make gibanica (layered pastry with cheese), burek, projarica (corn flower dish), and mini pizzas or bake frozen pastry. This is good, because we have the leftovers for breakfast the next day and I can also make them for my parents. Sometimes Marija and Mikica eat chocolate-hazelnut wheat flakes, and that's an opportunity for me to skip dinner. Since I turn the washing machine on when I can use the cheaper electricity rate, I put the dirty laundry in the machine and turn it on before taking a shower and going to bed. Besides all this, I work with Marija, when I need to show her something, especially now when there are no regular classes.

If I have the time, I read a book or do something creative, this maybe decoupage (I decorate flower pots, glasses, jars), or cross-words, I do puzzles or play other games on Facebook. If we had more room in the apartment and a sewing machine, I would sew masks, but this is, unfortunately, impossible. A few days ago, we put together a glass cupboard we got just before the announcement of the state of emergency. We struggled, but we did it. We also painted the wall and rearranged the furniture in the living room. A little change is always good.

When I go through the news on the internet, to stay informed, I get worried, and catch myself thinking: – *Did I by chance get infected somewhere?* I have no official symptoms, but Mikica and I have difficulties breathing, because we had pneumonia, and because of the spasm and involuntary movements I sometimes feel pain in my chest, my sinuses are problematic nowadays, while Mikica sometimes coughs and sneezes. We make sure that we measure our temperature in these moments. When I see the temperature is 36.4, I calm down a bit.

It's difficult that for some tasks, those that require getting down on one's knees, squatting or pushing, I can't call anyone to help, so I have to do as much as I can by myself. I see that at these difficult times, an even greater marginalization of persons with disabilities is starting to surface, but I don't think about this too much, it's not the right moment now. It's important to hold on, to survive, and remain yourself.

I communicate with people from my acting group; we send each other messages through Viber. I occasionally talk to people from neighboring countries, cousins and friends. Of course, I talk to my sister and mother daily. I often tell myself how lucky I am to have a sister, so we can always lean on and support each other. My niece sends me a good night message in the evening, and it fills my heart with joy.

I remembered how, during the flood, I was in position of Assistant Mayor, and called persons with disabilities in endangered zones and arranged help if they needed anything. Some people remembered that now and called me. But I am aware that the current situation is completely different. It is in these times that true friends, goodness, humaneness are revealed... The family is in primary place, which I always talked about, it's where everything starts and ends.

All three of us sometimes feel depressed, but each of us reacts in a different way, so we are each other's support. Marija and I sometimes start crying, but we quickly snap out of it, Mikica reacts rebelliously, so we need to calm him down, sometimes I even have to yell to make him stop. It's even harder on him and he is often overcome with dark thoughts, because he spends most days lying in front of the television, so he hears and sees a lot of things. It was good for him that he assembled the glass cupboard and painted part of the living room walls, because he feels better if he's engaged somehow. My Marija often jokes around which also lightens my mood. Life is most valuable because of her. Otherwise, I am not a panicky person, when I'm in trouble I try to solve the problem or adjust to the situation, and I react when it's all over. That's how it is this time too, at least for now.

As usual, what makes me angry is that I have to do everything, no matter how exhausted I am, because I have only my daughter to help me. Thinking about the situation in my city also makes me angry, because I remember where we've come to from the Valjevo that was once the industrial heart of Yugoslavia and a city to be proud of. I am irritated how the situation is politicized in Serbia, and it seems all over the world, but I try not to react to this or avoid this type of information. I feel sad and disappointed when I hear people dear to me got infected. I often think about my friends who are medical professionals, about doctors and nurses, I wonder if they are all right, how they are coping with the burden

and responsibility at work.

When all this is over, I will most certainly dedicate time to myself. I will go to treatments that I kept postponing. We will go together to Novi Sad for a longer time if the conditions allow it. I will make sure I walk more and stay in nature. All in all, I lead a common life, it's just that there is more worrying about myself and my loved ones and there is more tension around.

In Valjevo, April 15, 2020



**Milica Jankovic**, author of the blog *Balkanski mali dnevnik slepih i slabovidih* (Eng. Little Balkans Diary of Persons with Visual Impairments). Milica has been writing from an early age and is dedicated to advocating for social justice and changing perceptions about persons with disabilities.

## *I am planning a survival party*

During the pandemic that has shaken the entire world, I am often thinking about how people are coping with the new situation. Among friends I am often in the role of Dr. Phil and this has not changed even now. I try to make these days a bit easier, more interesting, simpler, for others and for myself... I send funny clips to my friends, and we talk, sometimes for hours.

I try to do things I didn't have time for before. I am learning to cook and bake. I read books, I write something here and there. I've been in isolation since March 12 and so far, I've completed two online courses and signed up for a third one. I am preparing some tutorials for different applications. I play the *Puzzle* (game based on the television quiz show) and quizzes. I try to follow as many online tours as I can organized by museums of the world and see online plays that theaters made available online.

I keep reminding myself that though I am immunocompromised, I am not in the worst position. This isolation is certainly something that I was bound to face at least once in my life. I've known this for a long time. I am, based on my health, at risk, I am completely isolated from the entire world, even household members, but I was not left without a job, because I didn't have one. It's also very important that I didn't lose anyone I know or love to covid. – *A lot of people weren't so lucky!* – I often tell myself. En-



tire economies of big countries are falling apart. Companies are shutting down. People are literally losing their basic life income. People are also dying all over the world. They struggle and they don't make it. They are lost to their loved ones. These are terrible things. A lot of companies in the USA, where people from our regions were working, simply closed overnight. People were left without their jobs, with no security, even without basic life necessities. It also sometimes happens that those who were in hospital are sent home and household members try to look after them as best as they can, but that is not enough. If they could, if they had the conditions and knowledge, they wouldn't even need hospitals.

A change in my daily routine is that I don't travel, I had to cancel some things, miss some parties and not get to meet my friends, until further notice. However, my whole world hasn't changed compared to the people mentioned earlier. We are all here, we all have a roof over our heads, flour, oil, paper, bread and salami. We are alive and we are getting on – and supporting each other. We are functioning. That's the most important thing. I will be brutally honest and say that for most persons with disabilities nothing has drastically changed. It's well known that persons with disabilities are not sufficiently physically active, in reality, at least seventy percent of people are not physically active or go outside as they don't have conditions for this, training, lifts, or are simply not motivated or encouraged. When it comes to jobs, I think that ninety percent of persons with disabilities are not employed, so there is no drastic financial decrease. I often say we are *all equal* in this, but this may not be the truth. In these circumstances it's even easier for persons with disabilities as they don't have that much to lose compared to others.

My greatest challenge currently is the question: – *What useful things can I do?* I try to answer this question every day and do something new for the community, friends, and myself. I have been writing and will continue to write. That's somehow what



I'm best at. I wish I could volunteer, I am currently trying to find something online that I could do as volunteer work.

My greatest support are my friends, who I talk to. These conversations fill me with positive energy. Also, what supports me is the knowledge that I've survived in quarantine for almost a month and that this will be over! Just thinking about a nice little beach, just waiting for me to get there if I manage to survive, makes me push on. Literally.

A good thing in what is happening is that museums and theatres have enriched their online programs. At the same time, I think we are slowly becoming more aware of each other. At least I think this is the case! Sometimes the days are too long, sometimes too short. It depends on whether I *got out of bed on the wrong side* or not. I think everybody can be in a bad mood sometimes, but this passes.

When all this is over, the first thing I am going to do is to give all the people I love and respect a big, strong hug. I really miss simple physical contact like hugging. I plan to host a *survival party* and get all my friends together so that we can dance, sing, laugh and hug while we listen to some loud and hard folk music! After that I will see a friend who promised me even before all of this that he will throw a party for me. He makes the best house parties and I can't wait for that weekend, so I can give those people there a big hug too. When I recover from those parties, I will start planning a summer vacation. I would like to visit Ohrid Lake again and on a boat trip to St.Naum spread my arms and yell: – *It's over, darn it! It's over!* Everything passes, and this will also slowly become a mere shadow of the past. A collection of positive and negative memories.

In Mladenovac, April 17, 2020





**Milesa Milinkovic**, director of the Film Festival *Uhvati film* (Eng. Catch the film), activist for human rights of persons with disabilities and theoretician of gender and disability.

## ***What can I do as an individual, so we don't end up like Gilead from the Handmaid's Tale?***

It's strange... It's not like I hung outside a lot even before all of this. It happened just around the time the *Festival* and *Caravan* were over, more or less immediately after the holidays, we started the first phase of implementing seminars on rights of women with disabilities for representatives of institutions, and then continued with the cycle of writing project proposals for open calls. You could say I almost didn't leave the house/office, and going to the shop or meeting Love does not count as hanging out outside. Still, I totally feel, as my late father would say, *like I fell out of the right angle*.

It seems like the very same time I had before, is not *that* time. Like there is more of it. Or there is less of me. Perhaps because things keep changing constantly: rules, time and spaces of freedom, possibilities.

I don't even go grocery shopping. I belong to the risk group. Self-responsibly, I withdrew. Like the signs of the *Roads Public Company* on the motorway: – *(I) drive carefully, somebody loves me*. Sometimes I catch some sun during my walk around the block. In a mask, of course. Because when you're short, if someone coughs or sneezes passing you, it goes straight to your face. And as I said, *I drive carefully*, because...

Somebody loves me. And that somebody is sleeping without me these days. And this is something that is most difficult for me personally. A couple of days ago I saw this funny post on Facebook:



- *Relationship status: 1. single; 2. in a relationship; 3. the state doesn't let me.* Love and I laughed about the third option. Laughed in agony.

... I started coloring fractals, the handbook with examples and color pencils have been waiting for me since the Festival. I downloaded a bunch of scientific texts about women with disabilities, science has been waiting for a long time. Also some high shelves, out of arm's reach, have also been waiting for a long time for me to dust them. But I'm not scrubbing the house like crazy. I clean during the weekends, as always. I don't touch the high shelves, because if I climb on a chair and, according to Murphy's law, fall and get injured during the police curfew, I really wouldn't like anyone to break the law by rushing over to help me. I rarely color. Science waits in my computer.

Actually, my anti-stress mechanism told me at one moment that it's better for me to keep my everyday life as similar as possible to what it was like before. To do the things that make me the happiest at that moment (without a guilty conscience). To do the things I would otherwise do this time of the year (project writing time is generally over, the current work-related tasks are preparations for the Festival). And it really helps me. This is why I read, cook, do housework, just as before, work a little bit on the Festival (generally speaking). I do a little bit of sewing (I'm just fixing holes and making alterations really). The only difference is that I have to keep dancing instead of my exercises and walking, so the little muscle mass I have left doesn't atrophy completely.

In truth, regardless of efforts to live the same as before, my thoughts are not the same.

... I am thinking about the consequences of all this. Local and global.

Will the state withdraw funds for culture and reallocate them for other purposes linked directly to covid? Will we have funds



to implement the 18<sup>th</sup> Festival just as we planned? Will we lose human rights and freedoms? Will we become Gilead from the *Handmaid's Tale*, using the fight against the virus as an argument? Will we get smarter and start treating our planet and other human beings, with love? Will we realize that we are not superior just because we are human and that it is high time we stopped exploiting people, animals, and plants?

Will we learn the lesson of responsibility, or will we be convinced *someone very tough* is looking after us?

How do other persons with disabilities cope? I think of some elderly ladies. I think of those who live alone, like me. I ask them if they have a support system. I can't help thinking about different groups and how they are affected by all this.

My sister worries about her income, and I worry about her safety, because she works with people. Since all this started, I talk to my mom several times a day. She's alone too. And I know she's also worried about my sister and me, who are hundreds and thousands of kilometers away. I am only glad that she had a village she could withdraw to, where she keeps busy in the garden.

I keep repeating the question: – What can I do as an individual, so we don't end up like (not even close to!) Gilead, where guards stand in front of houses, and children grow up with the conviction that these are their guardians from enemies, while they are really prison guards?

I am thinking about the independence I suddenly lost. That nothing should be taken for granted. For example, it shouldn't be taken for granted that you will always be able to sleep next to Love just because there is a mutual wish, that you will be able to do what you love, that you will see the people you love. That you will go to a shop on your own.



How easy it is to lose freedom; to give (sell) it away.

I have become aware of several things about myself. Some childhood wounds never heal. I am five. I am at the Banjica hospital, in bed with a plaster cast on my legs. My mom is here for a visit, but she looks at me through glass. They don't let her come in. The bed has bars. The balcony door through which my mom is looking and waving at me also has bars. The first quarantine I remember.

No matter how aware and wise I thought I was, I needed some time to realize how heartless it was to lock up people above 65 in their house, and how no one, not even I, spoke out against it. I remembered the poem *First they came...* attributed to pastor Martin Niemöller (1892–1984).

*First they came for the Communists;  
And I did not speak out;  
Because I was not a Communist.  
Then they came for the Socialists;  
And I did not speak out;  
Because I was not a Socialist.  
Then they came for the trade unionists;  
And I did not speak out;  
Because I was not a trade unionist.  
Then they came for me;  
And there was no one left;  
To speak out for me.*

More than ever I think about what I'm thankful for. I am thankful for my own space. For good immunity. I am thankful for everyone around me and my loved ones being healthy. I am thankful for stable sources of income, no matter the amount. For access to the internet. I am thankful for friends who care and who are here, and who are there for me also under normal conditions. I am thankful for the possibility to call people who are dear to

me. I am thankful that I have interests, a job, hobbies, and that I don't have to force myself to do something to *kill time* (I have, otherwise, never been bored). That I enjoy my own company (*If a person can't be alone in silence, that is a sign of spiritual emptiness*, a Native-American proverb says). I am thankful for the human being who loves me, cares for me, comes over for even only two minutes just to see me, a being valuable in their own right, who can be alone with themselves, asking the same questions as me, thankful that during the hours together we can talk about our insights. I am thankful for our two furry friends, sidekicks, two small, natural serotonins.

I am thankful for all insights.

Still, I can't wait for all this to be over. To again have the choice of whether and when I can do what I want. To make big changes on election day. To never let anyone drive us inside our homes, to be wiser in the choices, decisions, we make. I can't wait for the first night of freedom in which I will fall asleep hugging the universe.

And then I'll go get my hair cut. ;-)

In Novi Sad, April 20, 2020



**Marija Vrebalov Djordjevic**, interior designer according to the principles of feng shui and universal design, an activist for the rights of persons with disabilities, member of the permanent working body for persons with disabilities in the Assembly of the City of Novi Sad.

## *Life is to be lived, even in unimaginably complicated circumstances*

I taught myself a long time ago not to think thoughts that are not constructive, productive, which are damaging, that make my heartrate go up and leave me short of breath. I thought I had taught myself well, but recently I realized I didn't. Everything went down into the deepest ocean of the unknown, the terrible, when, because of the news and information about covid, I realized my life would be endangered if they introduced the police curfew. Life within four walls can be organized well if we have all the necessary logistics, helpers, sufficient funds and a life that is not too challenging in itself. Who will help me and how will I manage to do basic physiological needs, going to the toilet, getting dressed, getting up... All the way to what am I going to eat, is there enough Prolom mineral water, gloves, disinfectants for the person coming, who will help me in the evenings if the police curfew starts earlier in the afternoon. My thoughts were spiraling, upsetting me, I couldn't breathe, I kept thinking about all the things I am afraid of and all that I am deprived of in this already restrictive bodily state. Enough. Enough! I managed to stop myself from thinking these worthless, horrible thoughts, blocking and paralyzing me. I gave myself the task to create a realistic plan for the morning in new circumstances.

Life is to be lived. Even in unimaginably complicated circumstances. To find something for ourselves, to choose in situations we didn't choose. There is a choice to make, always and in every-



thing, in this case in our new reality, with the pandemic and covid and given restrictions, we can choose reason, peace, quietness, mindfulness, slowness. We can, if we want to. And we can also choose to be angry, upset, to be afraid, to hate. I chose the first. Dad and I are the most at risk in the family. We stopped getting together as a family ever since the beginning of March. We don't want to take any chances. We've all had our times of hardship, different forms of separation, loneliness, dad had the variola epidemic, I had typhoid fever and isolation as a girl, then almost two years of separation from my family, spent at different hospitals after a car accident, in 1998 I had severe pneumonia with pleural empyema and effusion, which is why I was on a ventilator for three months and also in moderate isolation, and the bombardment, during which I was pregnant with complications. I never stayed angry for a long time because of circumstances out of my control. I always quickly understood the given circumstances, from them I learnt what life brought me, learnt to take care of myself, find happiness in the very moment I was in, not to remember bad experiences filling me with indignation, but accept them as a wealth, a storehouse of knowledge, enabling me now to enjoy the little bright parts of the day. And even when I'm not all right, I know it will pass if I don't give myself over to self-pity, anger or criticism.

My life circumstances changed exactly one year ago. Into my single life, my inner silence, peace, general love, entered concrete love. A relationship I was dreaming about almost my whole life. I never thought I would fall in love ever again, nor that I would wish to wake up in the morning even before falling asleep, just so we can be together again, to laugh, to talk, to share the tiniest feelings and wishes. But that's just what happened. Love. Dedication to partnership. Stability. Trust. Humor. Happiness. Fluttering. Tenderness. Passion. All in one person. I let myself go. I gave myself over to life. I realized that things happen just when I am ready for them. Even now, though it's very difficult, individually and

globally, though restrictions in daily activities are huge, I know that the whole world, from my first neighbors to the next city, country, continent, the entire world is going through an enormous transformation and I gave myself over to it. I am enjoying the fact that I am healthy, that I am with my husband, that I have a good assistant, that my family and friends are healthy.

Writing, creativity, very specific isolation due to disability, winter isolation lasting two to three months each year for almost twenty years now, introversion and creation, have represented my daily life for many years. Political engagement, activism in the field of disability and accessibility, writing a book and editing diary entries, all of that shaped me. A lot of love dedicated to, through presenting my difficult personal experiences, making heavy and dark moments brighter, clearer and lighter for those who are going through something similar but don't have anyone to share with. Some things have intensified, some have become quiet, waiting for some other times, during these times I do everything I can, everything that is my personal responsibility, I don't listen to the news, because there are a lot of upsetting things that are out of my control, I spend just several minutes daily on social networks, I read posts selectively, we don't let anything into our personal life that is not part of us, we take care of each other, we work from home and are grateful for the extra time we have just for us.

And I realized that the world isn't here to make me happy, nor are politicians, friends or anyone else, not even my family. I realized they are all here for me to wake up, understand who I am, to know my values and increase them through my dedicated daily routine in prayer, meditation, exercise, discipline which I value greatly otherwise and I don't find it difficult to keep in the new circumstances, because I live that way otherwise. I don't deal too much with what I am not allowed to do, nor do I analyze other people's activities, fears, angers, but I understand the times we are living in, in which I understand the virus itself is not lethal, but



rather the way we treat it, the way we understand our life, health, hygiene, bodily and spiritual. What is lethal is that we don't care about each other. What is lethal is that we don't do everything in our power for ourselves, because that's how we do it when other people are at stake. What is lethal is that we hate the police curfew, but we make ten contacts before it starts, exposing both ourselves and others to danger. What is lethal is that we don't understand that the most important thing for us all is to stay away, quiet, to silence all the noise of the world in our head, it is lethal to think *it will not get to us*, it is lethal for all if we don't realize each of us individually can save the world. With our discipline. Reason. Love. Peace and acceptance. It seems difficult, but it isn't difficult at all.

In Novi Sad, April 23, 2020

**Jelena Rasic**, a graduate economist, she is often in the role of *live book*, who, without a trace of censorship, demystifies various topics regarding the life of young women with disabilities.

## *There'll be plenty of everything*

I wake up slowly, at seven in the morning, as usual. I don't know what day it is. I open my eyes, the dog is already jumping on me wagging his tail, he knows it's time for a walk. He always reminds me that a person should be happy for waking up, for being alive and healthy.

While I am taking care of personal hygiene, I notice I'm all swollen. I stayed up until three in the morning again, those series won't watch themselves, and as my trainer gave me his *Netflix* password and SBB (cable channel provider) unlocked its channels, the choice is almost unlimited, and there is plenty of time. I remember the times when I was a high school pupil, then a university student, when I did similar things, only then I didn't live alone and I didn't have a dog, so I didn't use to get up so early. But I'm not complaining, I am glad that I have him. So, then I guess I'm still not living alone.

It sometimes happens that I forget and I think I overslept, because under normal conditions I usually get up at 5:40 for work, I take the dog out for a walk, I make tea, I put on the clothes prepared the previous evening, I put make-up on and the workday starts... But not now, now I don't even know what day it is, I live a different life now. Life in the time of the corona virus pandemic.

I take my coat, put my sneakers on, from the corner of my eye I see my new olive green suit on the hanger, prepared for work, for which I spent my last dinar from my pay at the end of February,

because it looks phenomenal on me, and it was still the period of sales... My make-up is in its box, unopened. I remembered it the other day, then I cleaned all the brushes, put them away neatly, I made myself up once, just for myself... I will have to do it again soon. I miss these things. I miss a lot of things. But there'll be plenty of everything.

I go out, the dog runs to his special place to mark it and show who's the main dog in the neighborhood, he meets neighbor Albert, barks to justify his nickname The Beast, though his real name is Miliša. I take the morning sunlight in, I enjoy it so much these days, it seems like it never felt so good...Neighbors' greetings bring me back to reality and quickly my main preoccupation becomes the everyday fight against the corona virus. Whenever I go outside, I have a feeling it's all around me: like being in a minefield, but I can't see the mine. My only weapon is a bottle of active oxygen in my pocket, and at every little suspicion I might get infected, I spray down everything. Literally everything.

Today, I decided to go to the supermarket. Luckily, I live in a neighborhood where there are quite a few smaller and bigger stores and I always go to the same one, the one that seems to me the cleanest and safest. That's how I help myself mentally. It's still early, so there is no crowd. The dog waits outside, as usual, I take a shopping basket, I disinfect it myself, and I always wear gloves and have a mask on. Then I sort of smile: – *Hey, there's a shortage of gloves, I need only one, so each pair I have in my stash will last longer!* I try not to think about the fact I don't have many of them. There will be gloves. There'll be plenty of everything.

I take a can of tuna. I already have ten stacked in the fridge. I don't know what it is with cans and our people, it must be those stories from the war during the nineties, that cans were real *life savers*, at least that's what I heard (and many others, I suppose), so now these cans give us some security, for just in case or *in case*



*they shut everything down 24/7.* I also buy two liters of milk, 20 eggs (I always need eggs if I decide to make pastry), macaroni, sour cream, cheese. I look for popcorn, but they haven't had it for days. Probably everyone is eating it now while watching movies. No matter. There'll be some. There'll be plenty of everything. My neighbor says yeast has arrived. I swear, I wanted to scream at that moment, but I got it together, I am adult, responsible, a person needs to be calm in these situations. Or that's how they have to behave, not to spread panic. Nor too much happiness. How can you say you are happy because of plain yeast? I get five sachets, they only got dry yeast. No matter, there are so many recipes, so many things to make.

Otherwise, I love cooking, dough always takes time and needs love; though I can already make no yeast breads with different seeds and herbs, rolls, scones, fritters and doughnuts represent a higher level for me and a true art. I get home with two bags. The dog's not thrilled, he still doesn't understand why we are always at home and if we are, why we don't go for walks until our legs start to hurt, then sit at a nice place, have coffee, he gets his water and treat, and then all over again. I enter the apartment, he waits. He looks at me again, confused: – *Why is it taking so long?* We have our routine, besides hand washing, there is disinfectant for door handles, shoe soles and floor. I clean his leash with alcohol. The bags as well. I spray my coat with alcohol and take it out on the terrace. There'll be stains on it. No matter. There'll be plenty of everything. Coats too. Then we wipe each product I bought. He doesn't like the smell, but he still chases after the bag with the cheese. Then I get angry at him, not because of the cheese, but because I am afraid he'll poison himself from all those disinfectants and smells. I can't explain to him that there is a possibility for the same happening to me too, that we need to be careful. I put the groceries in the fridge. My mother's coming over today. She is the only person I see, with all precautionary measures. But she doesn't meet anyone but me. That is all right, I guess.

I have yeast now, I'll make rolls, I'll send some to my brother, this makes me happy. Mother's here, no kisses though. Honestly, I'm not the kissing type, so I don't mind. While I wait for her, I visit social networks, I answer my messages. There are dear people I talk to daily, it's important for me that they're all right. Or I call my friend to see how she is. Or we laugh, send each other funny pictures about the corona virus everyone is sharing these days on social networks. I think this is good. Humor will save the world, and if not, it will make it more bearable. It's good that after years, my father answers the phone when I call him. He didn't want to before all this. That was a big surprise for me, during this time, the period of a virus. I wanted to see if he's all right. And he is. I am glad, as he's in the risk group, those over 65. Now we talk, that is, I talk, he listens. Perhaps I need to tell my father things, it doesn't matter that it's not two-way communication. I don't hold a grudge against him, I've grown up, I forgave everyone everything, life goes on. It's going on now too, though it seems to me we're on a short break, but still it continues.

I can smell the rolls already. I am so proud of my little masterpiece. We drink coffee, mother says a new series started, called *Kalup* (Eng. Mould). Finally, the 3500 dinar package has paid off, now I can really watch tv, and even have the option of rewinding, so we start watching the show. It's not such an interesting topic. Actually it is, but not for the time of corona. All the same, we watch it. When she comes the next time, we will watch the next episode. My mother has to get going at around 3 p.m., the police curfew is from 5 p.m. I pack the rolls, every last bit, I don't want to eat too much dough and put on weight, I look just great to myself now. I miss my training sessions. Physical appearance is just a secondary motive for training, I feel the pain in my shoulders coming back, and I don't have a place to get all that energy out, good or bad. I do exercises at home, but it's not the same, but I do try to stay active.



I take the dog out for the second time, ten minutes, the same routine: short walk, long and detailed disinfection and the same look on the dog asking *what is all this for*.

I followed the news and read comments of experts, politicians, diaspora, other countries, conspiracy theories before... I no longer do that. I don't know if that is good, but I know I am calmer. I read the news ticker when the evening news are on and that's it. I respect all adopted measures, whether they're good or not, I don't know, nor do I consider myself qualified to comment on them. I admit, it was very hard for me when they banned the evening walks for pets between 8 and 9 p.m. Then I decided not to read news comments anymore, I was really surprised to see how people are still glad about the misfortune of others. Even at times like these. I don't know when they'll realize they are just poisoning themselves this way and that if someone is in a bad situation it doesn't mean it will get better for someone else. What's this comparison with elderly citizens for? We're now moving from comparing children and dogs to comparing pensioners and dogs. I will never understand why people make comparisons like that. Everybody is in a difficult situation now, some more, some less, and everyone has their own problems, so why wouldn't we solve some of them, if we can? My dog and I have wonderful neighbors who show solidarity with all: they help elderly people, with the groceries, have understanding for us dog owners. There are always good people around and there is always a solution. We replaced the evening walks with going out into the yard, and we, of course, always clean up any mess we make.

As we've been in a kind of isolation for days now, I admit that, reading news on the internet, I also got interested in work on myself, now that we have time to dedicate to hobbies, reading, inner peace...I cleaned the apartment. I cleaned it before too, but I think now I took more time. I organized the closet, books, smaller items. But I do this regularly too, so I wasn't sure what exactly I

was supposed to do. Then I simply stopped thinking about it, because it made me feel nervous and uncomfortable. I do whatever I feel like doing, if I feel like doing it. This is also some kind of work on myself: letting myself be unburdened and relaxed. I cook, sleep, watch series; currently I am watching season five, episode two of a show about a female prison. Now psychologists would probably say this is a consequence of being in a prison of sorts. Who cares, I don't burden myself with this, the only thing missing is the popcorn. But as I already said, there will be. There'll plenty of everything. I wanted to use the time in quarantine to quit smoking, to do something smart. I didn't. And I say: I don't want to burden myself anymore. With anything. I respect the prescribed measures, I take care of myself and others when it comes to preventing the virus from spreading, but only I decide about what I need or I should do with myself, within my four walls, and in myself. Mostly in myself. In truth, that's how it should be even when the quarantine is over. It's not so bad, on the contrary. We can do anything, as long as it doesn't jeopardize others. That is why I am going to continue with my serial shows, regardless of comments on what we *should be* doing. As I said: there will be plenty of everything, all the things I miss will be there again. Let's stay at home, so that we get to these things soon.

In Novi Sad, April 27, 2020

**Jasna Grizer**, graduated pedagogue, the author of the *Mape u mom umu* blog (Eng. Maps in my mind), engaged in projects of the *Caritas* organization aimed at provision of support to persons with visible and invisible disabilities, as well as education of youth on mental health issues.

## *The art of living in the present*

Several days after I had bought two pairs of shoes for the spring season and was thinking about what clothes I could wear them with walking around our beautiful city with my friends, they announced the state of emergency and police curfew. The reason: the appearance of the Covid virus, dangerous to all humankind. Schools were closed, shopping malls, shops, cafés, libraries, cinemas, theatres... They asked us not to leave the house unless necessary. In Italy and Spain, a hundred people die daily, and we are in danger of facing the same scenario if we don't behave responsibly.

So my family and I got responsible. The children are at home all day long, with only an occasional short walk close to our building, in the morning I take our pug for a walk, buy groceries, and come back home. My father-in-law has lung cancer, so my husband has to go see his parents more often.

I start the day with my morning coffee, this has never changed since I started drinking it. As I have my coffee I make a general plan of my day, which sometimes doesn't turn out the way I plan it in the morning, which happens to me otherwise, because, also a case now, just as before, it doesn't all depend on us, so there's no change in that. The activities I do are the same as before: cleaning, cooking, doing the laundry, with the addition of working from home and distance learning, which is a problem for my younger son, so I have to give him much more support than when he goes



to school regularly. I do a lot of creative work: writing, drawing, making miniatures combining decoupage and plaster, I read... As usual, my day is full, I always need an hour or two more.

I talk to my husband about everything, as I always do, with the difference of adding new topics, victims of this unfortunate pandemic, respirators, people infected, comparing our situation with other places of the world, when the police curfew is, when we are allowed to walk the dog... What I miss the most are activities related to life outside our apartment, because they are a big part of me: walks on the beach, the quay, the city center, enjoying the sun, conversations with my mom, sister and friends while we're having coffee, laughter, a lot of laughter, hugs, their support in everything going on, shopping in second-hand shops, in the *Promenade* shopping mall, the flea market. We talk regularly over the phone, but that's not the same.

Instead of going for a walk, in the evenings I do exercises following an instructor on a CD and I pretend I'm in an aerobics class with my friends. My sense of humor and skill of living in the present make my days easier, and seeing my children smile feeds my soul and prevents me from losing hope. Sometimes I cry because I'm sorry about everything that's happening. I don't see a good side to what has happened to us, not a single one.

I didn't discover anything new about myself, I'm me, we're acquainted. I am as angry as a bull at Covid-19 and it is what makes me mad most easily every day, because it brought such turmoil into our lives, as well as lives of all people. I also find it uneasy that our movement is restricted and that we are socially distanced.

When this is over, I will dip in the Danube and give a big hug to all those I can't hug while this situation is still going on.

In Novi Sad, April 29, 2020



**Jelena Radovic**, a law graduate and president of the *Sunce* (Engl. Sun) Association for Cerebral and Child Palsy of the South-Bačka County in Novi Sad, the author and host of motivational public discussions for support of persons with disabilities.

## *I miss the busy Jelena*

As if in a dream, my world changed overnight. At first, I didn't know what was going on, as I was away from Novi Sad for several days. I was at Kanjiža Spa, where I had therapies, exercise sessions, walking, swimming... We had to leave the spa within two hours because of the *invisible enemy* COVID-19. I didn't know what was going on, my stay at the spa had just begun, when I had to pack my bags again not knowing what to expect when I got home. What was waiting for me there was isolation and fear for my parents who belong to risk groups. I live with my parents. My sisters have their families and only come to the door to bring groceries. We send kisses to each other then and words of support.

My day starts with exercise and smiles, personal hygiene is next, morning coffee with my parents, chatting and laughing. I like my father's jokes; they make my days better and have me laugh myself to tears. Mom's great too, she cooks tasty meals, we call my sisters and nephews, we like to watch TV series in the evening.

Morning coffee is followed by standing exercises that last an hour. I come to my *magical world*, which is my room, that gives me peace and motivation: it is enough to look at the photos decorating my room, bringing me joy. I read books that speak a lot to me, enrich me and make me more mature, spending time reading really gives me strength. After lunch, I call my sisters or friends, I post a motivational message or photo on social networks. In the



evenings, I watch TV series and films, I work on myself, I try to watch the news as little as possible, because I want to be informed, but I don't want to disturb my peace. I write every day, I am writing my third book, and various other texts. I answer e-mails, I lead group sessions with association members, we provide each other with support. With my personal assistant Jelena, I do different tasks and activities I need support for.

The time in quarantine has made me stronger, I realized being alone wasn't a problem for me, I have proven to myself that my attitude doesn't depend on outside circumstances or other people, but only on me. This global *invisible enemy* has taught me how to live alone and not feel it. I am always thankful, twice as much now, for all that life gives me, be it positive or negative. I draw a lesson from every day and I try to make new habits.

I miss my activities, the public discussions, work at the association, workshops, walks along the Danube. I really miss the *busy Jelena* and I miss my favorite daily exercise, walking on ramps. I used to walk fifty meters before the virus, but my walking is significantly weaker now, which makes me sad, but I know I will go back to my steps, because for me, every step is a great victory.

I don't know when all of this will be in the past, but I know that we need to live and dream of better days. Motivation and smiling are the best medicine for me, I always have these in stock no matter what. The first thing I'm going to do after the quarantine is give a hug to my nephews and thank everyone who was there for me, and then I am going to see the Danube, enjoy the view and walk on ramps.

In Novi Sad, May 1, 2020



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