Coronavirus stories

Our recent call for stories, about your experiences during this Corona-time, have resulted in us receiving nice stories from people with lived experience, their family members and professionals.

They are very interesting and very diverse, a summary is difficult. With the consent of the writers we are publishing the stories in the ISPS Newsletter, and on our website. You can read them below.

My Story

Both my wife and I have a susceptibility for psychosis. My last psychotic episode was 5 years ago. The corona situation is, personally speaking, an opportunity to counter my side effects of psychosis, like being afraid to call or pick-up the phone. The crisis forced me to be more communicative and it goes just fine. Moreover, I feel a bit protected against the negative effects of isolation, just because I have known this kind of isolation during the years in which I had my psychoses.

My wife just had an episode of psychosis two weeks ago. It’s difficult to describe why, but a provoking factor was the sense of urge to help other people with psychiatric problems, especially during these corona times. The helper loses herself in helping. Nevertheless I am delighted to see that her resilience has improved over the years. She recovers quickly.”

Miguel van den Bedem, Belgium

“BECAUSE ME, I AM OFF THE MAP”: A short first person narration about the experience of quarantine by a woman with severe psychosis in Greece
“I’ll tell you, being in quarantine (…) I feel anxiety, but I also celebrate it. There is both weakness and anxiety, and the best antidote for them is indifference.

But everything will be fine. The devil is very strong, sickness, the rotten thing, is very strong. This time, however, I say, no, I like it at home, (…) I feel secure, there was a time when I couldn’t stand it, and felt like committing suicide. Now I’m fine, as though a miracle has taken place.

Before the quarantine, I was in very bad shape…. But now some day I thought: Why should I commit suicide since I can be well? On the other side, my anxiety is worse than everybody else’s anxiety. Because me, I’m off the map.

The good God puts these anxieties out here, to test the people and make them stronger. God will punish the sickness one day.”

Anonymous, Greece

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**A Carer’s experience of lockdown during the Coronavirus crisis**

I would like first to give you some background against which I am responding to your email. We celebrated my son’s 40th birthday on Thursday. He had a diagnosis of paranoid schizophrenia at age 21, and has been detained more than once. I became a member of ISPS in the hope that he might be helped by a psychological approach and had years of misgivings and challenges with Psychiatrists about medication. He was prescribed clozapine within a few weeks of first admission, and has now been back on clozapine for several years. As his mother, I am resigned to this being the best compromise for his quality of life. After a flat on his own, he had several years in a MIND rehabilitation centre in the previous city from which we moved in November 2018. I was able to arrange for him to live in a shared house with an organisation providing care for people with serious mental health conditions. As previously, he was spending 3 nights every weekend with us. During the week he had the opportunity to attend a variety of sessions including Music, Art, Creative Writing, and going out into the Community for City Farm, allotment, and swimming. Staff are impressed with his attendance and commitment. Now, both we ourselves and the organisation with which he lives and are in lockdown, with no sessions. Staff arrange for him to Skype me once a week. My husband is 82 and has bronchiectasis and I will be 80 in June. However, one of our daughters (the reason for our move) meets him every Saturday, observing social distancing, although she finds it stressful to have to keep reminding him to “keep away” due to cognitive ‘damage’ he has
suffered. They go to our family allotment and then on to talk over the garden wall with us. On his birthday we celebrated with a meal and cake in the garage, our son seated at the back surrounded by candles and a happy birthday streamer and our daughter with 2 young children near the door, and my husband and I just outside. His other sister and 3 young children in London joined us via Zoom.

Our son appears no different from usual. Can his condition be understood as due to his psychosis, the effects of medication, and how far the result of experimenting with street drugs in his youth, I still wonder. Yes, I always have a sense of a wall and limited communication since the development of his "illness". When he spent weekends with us prior to lockdown, I was aware of his frequently responding to voices sub voce. The present situation does not seem to have facilitated any increase in dialogue. He doesn't seem to have the capacity to say "Now you understand what it is like to live like me" However, he does not seem unhappy and when leaving often indicates he is looking forward to the time when he can return to the routine of spending weekends with us, which he expects to happen "in a few weeks". He seems also to like spending the week where he lives.

I took the liberty of forwarding your invitation to the organisation with which he lives and this is the Manager's response:

"Thank you for sending this article through, it is a very interesting insight and perspective. I will pass this on to the team as I think it's a useful topic for us to consider during this time."

Anonymous, United Kingdom

What Experts by Experience have to teach us: A Mom and son perspective by Pat Wright and Gabe

As I pondered this question that was recently sent in my email I decided to have a talk with my son, an “expert by experience” in the world of “extreme states and unusual beliefs”. I was grateful our timing was good, a lucky break for me as our communication is not always easy.

He talked to me about the following ideas:

Having a caring person to talk to was the first priority, meaning an available person able to listen to whatever is going on even though it may be difficult. I confess to numerous times where I felt unavailable to listen to what my son was saying, I was reacting to my own feelings of either “how did I cause this” or “how can I fix this?”
Being able to do some problem-solving for example in order to get his state rent rebate $, which I told him I would help him with, he needed to get a few other papers first.

Doing something fun can be a great escape, in my son’s case coming over to grill a steak with asparagus, one of his favorite meals. (He put the gas grill together a few years ago even though he’d never even grilled) He continually amazes me with his unfolding talents.

Being reminded of hope, “this too shall pass” is a good slogan.

My son has felt my home a “safe” place which I want to preserve so he has a place to visit in a time of crisis rather than having to leave it if he lives here because he’s no longer feeling safe. We still have tension on this issue at times which I think is a major theme with families of transitioning young adults.

There are no easy answers on this topic and each family decides what’s best for them.

Being reminded of hope, “this too shall pass” is a good slogan for all of us.

When I feel insecure I appreciate being affirmed and hearing about my positive attributes which I tend to forget when I’m stressed—my son agrees this helps him.

When powerless and despairing there are some special points to remember:

Having flexible boundaries as we communicate can be invaluable, practicing the art of forgiveness is crucial with all the damage that can be done in particular when being pitted against each other in some systems and at times being ignored in others.

Honesty, even though someone’s feelings might get hurt in the process is key. Even though my intention is not to take something personally at times it’s difficult to do.

Respect for where each of us is at can lead to empathy especially given that we’ve each had more than our share of health issues along the way.

We’re only in the beginning months of this global tragedy and yet we all have so much to learn and grow from if we take the opportunity. Let’s listen to those around us who have been practicing these skills to survive for a very long time and appreciate the gifts they have to offer us.

Pat Wright, USA

"Virus and Psychosis"
I work as a psychologist at a psychiatric community in Urgnano in the province of Bergamo (the European epicenter of contagion). I want to share a reflection after a long discussion with hospitalized patients (schizophrenics and serious personality disorders).

There is a widespread belief among guests at the facility that Covid-19 was created by a "bad scientist" in a Wuhan laboratory. The predominant primary defensive mechanisms are evident: the projection (the bad part is "outside me") and the denial (reality cannot be so unpredictably terrifying).

The interesting fact is that a SWG survey of April 24 on a sample of 800 Italians says that 47% think the same way as patients. It can therefore be said that when external reality becomes extremely threatening, the use of primary defensive processes spreads indistinctly throughout the population and the boundary between normality and pathology thins.

Mario Apicella, Italy

An example of filial pietas

R., up to 30 years of age, led a rewarding life, made up of work, friendships, passion for motorbikes, beach holidays. He also had fond memories of the military service, carried out at 20 years in Salerno, an experience that a person of his frailty would have had to go through painfully and that instead represented a pleasant experience for R.

R. decompensated 20 years ago, due to repeated harassment at work. He never fully recovered, developing a marked persecutory symptomatology. I met him about 3 years ago, in a new critical phase and I started seeing him weekly, with progressive good results.

R. A month ago he lost his mother, who died of a recurring tumor. R. visited his mother in the hospital twice a day, until the last minute. Not even the fear of Covid-19 has slowed him down.

I thank him for the example.

Oberti Marco, Italy