

Chief Editor's word



Dear colleagues and associates, friends,

In the extremely difficult time of the spread of the new coronavirus infection, when our country, our patients and our colleagues are in an unfamiliar, complicated, and often dangerous situation, we cannot stay away from what is happening.

The special issue of Pallium magazine that you are currently holding in your hands is wholly devoted to various aspects of palliative care during COVID-19 pandemic. Articles, useful links, recommendations on organizing care contain the most relevant material on the topic, which may be of interest to palliative care specialists for adults and children, healthcare organizers, medical specialists, nurses, psychologists and social workers.

Palliative care can play an important role in the COVID-19 pandemic, but our scarce resources may be overloaded. By developing a plan for organizing the medical care system, reformatting rooms, routing patients, attracting certain resources or specialists considering palliative services, we can at large fulfil our duty to patients with the most severe course of the disease, to those whom we may lose in this fight. We should take care of everyone.

Palliative care specialists work daily with severely ill patients. Our competencies are implemented based on an individual approach to solving problems of patients in a rapidly changing reality. Often communication and teamwork skills, support for the relatives of our patients and each other come to the fore. We can work under challenging conditions.

On the pages of this journal issue, we discuss a new approach to the role of palliative care for patients with severe coronavirus infection, as well as at the changing goals of palliative care services.

Every day our services face new challenges. I am sure that we will cope with them with dignity.

We keep you updated on what is happening on our website <https://www.pro-hospice.ru/>.

Take care of yourself and your loved ones.

With respect and appreciation for your work,

Yours faithfully,

Diana Nevzorova

Editor-in-Chief, Pallium: Palliative and Hospice Care,
Director of Scientific and Practical Center for Palliative Care, First Moscow State Medical
University of the Ministry of Health of the Russian Federation,
Chief Specialist on palliative care of the Ministry of Health of the Russian Federation,
Chairman of the Board of the Association of Hospice Care Professionals.

Pallium: palliative and hospice care

Russian Scientific and Practical magazine

*Special issue**

* Dear readers, we use external links to the original documents that we had published in Russian edition in translation. All the visual materials - posters and memos - you can look up in the Russian edition.

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Chief Editor

Nevezorova Diana Vladimirovna - MD (Author ID: 393652), Director of the Federal Scientific and Practical Center for Palliative Medical Care, Associate Professor of the Department of Medical and Social Expertise, Emergency and Outpatient Therapy of First MSMU I. M Sechenov, Ministry of Health of Russia; Chairman of the Board of the Association of Hospice Care Professionals.

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The organisation of palliative medical care in the constituent entities of the Russian Federation during the spread of coronavirus infection

Diana Nevzorova, Anastasia Ustinova

Federal State Autonomous Educational Institution of Higher Education I.M. Sechenov, First Moscow State Medical University of the Ministry of Health of the Russian Federation (Sechenov University)

Nevzorova Diana Vladimirovna - MD (AuthorID: 393652), Director of the Federal Scientific and Practical Center for Palliative Medical Care, Associate Professor of the Department of Medical and Social Expertise, Emergency and Outpatient Therapy of First MSMU I. M Sechenov, Ministry of Health of Russia; Chairman of the Board of the Association of Hospice Care Professionals. 2 Bolshaya Pirogovskaya, 119991, Moscow, Russia. e-mail: gyn_nevzorova@mail.ru.

Ustinova Anastasia Igorevna - Junior Research Fellow of the Federal Scientific and Practical Center for Palliative Care Medical Care of the First Moscow State Medical University I. M. Sechenov. 2 Bolshaya Pirogovskaya, 119991, Moscow, Russia. e-mail: anst.ustinova@gmail.com.

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Abstract

In the situation of the COVID-19 pandemic, when healthcare systems of different countries make urgent organisational decisions due to the shortage of various resources, including personnel, palliative medical care and its patients are in a very vulnerable position, experiencing daily difficulties in fulfilling their needs. Changes in the possibilities of providing and receiving services that occur in ultra-short terms, do not allow to adapt without loss of quality. The World Health Organisation formulated the main postulates of the organisation of the PC and its role in emergencies, epidemics, wars [1].

Keywords: *organization of palliative medical care, crisis response, epidemic, COVID-19*

The relevance of the problem. The first problems associated with coronavirus infection hit the Russian healthcare system in March 2020, when the first infected patients were identified in Moscow. The spread of coronavirus infection in the regions of Russia occurs according to individual exponents, and therefore the organizational decisions differ. Thus, we have the opportunity to evaluate and describe the stages of changes in the conditions and principles of work of the country's primary health care services in real-time.

Care in stationary conditions. The first restrictive measures to prevent the spread of coronavirus infection were taken by the chief sanitary officer and the mayor of Moscow on March 5, 2020 [2]. As a result, the city's palliative care services were forced to restrict visits of patients' relatives and friends to inpatient facilities, hospices and palliative departments, while retaining the ability to access dying patients using protective measures (masks, gowns, disinfectants, thermometry). However, as the epidemic situation in the city worsened, this possibility was limited in some institutions. It should be noted that similar measures in other regions of the country were taken during March. In regions with just a few cases of coronavirus infection, such a regimen was introduced only in April. Currently, such measures, with one or other restrictions, are extended to all inpatient facilities in the country. Despite their apparent simplicity, patients and their relatives experience severe distress, and medical personnel experience increased workload. One of the golden tenets of palliative care is that the patient and his relatives are a single whole, and all decisions about treatment and its planning are made together. Now, this tenet is implemented in tough conditions, and the impossibility to say goodbye to a dying person is often the deepest stress for all team members. Numerous difficult telephone conversations and video connections using Internet technologies greatly complicate the work of physicians in a situation of already increased workload. It should be noted that the American Center for Disease Control and Prevention in the guide for nursing homes in the context of the COVID-19 epidemic, states that: "facilities should immediately restrict all visitation to their facilities except for certain compassionate care reasons, such as end-of-life situations". [3]

The restriction on visiting patients in hospitals generally also applies to other palliative care participants, such as volunteers, philanthropists, representatives of non-profit and religious organizations, which affects the implementation of a multidisciplinary approach and the provision of spiritual and social support for patients and their families. Thus, the services of the palliative care system are becoming completely medical.

In a number of regions (Moscow, Moscow region, Kaluga, Kirov and Nizhny Novgorod regions, Bashkiriya, the republics of Dagestan, Sakha (Yakutia), the Chechen and Kabardino-Balkarian republics), some palliative care departments were repurposed as COVID-hospitals in a short time. Their patients were transferred for outpatient monitoring (home) or to other hospitals, both palliative and specialized, with the transfer of personnel to other palliative institutions, both inpatient and outpatient, or to departments for COVID-infected patients. Thus, another principle of palliative care - an individual approach, which takes into account the patient's choice of location and treatment, was limited. It was also serious stress for the patients and family, as well as a burden on medical personnel at all levels of health care, especially in the context of further uncertainties.

In some regions, the rules for hospitalization and routing of patients have changed, hospitals for more severely ill patients have been allocated, planned hospitalizations have been cancelled (Chuvash Republic, Bashkortostan, Arkhangelsk, Kaluga, Astrakhan regions, Republic of Crimea, Moscow). Chelyabinsk, Yekaterinburg, Tomsk, Tula, Yaroslavskaaya, Bryansk, Smolensk, Ryazan, Ulyanovsk regions, Trans-Baikal Territory, Altai Territory, Altai Republic, Primorsky Territory, Belgorod, Nizhny Novgorod, Kirov, Samara Regions have not changed rules for hospitalization at the moment; in Perm Territory and the Chechen Republic, hospitalizations are suspended

altogether. In regions with isolated cases of coronavirus infection, the work of departments and entire palliative care services practically has not changed, for example, in the Karachay-Cherkess Republic. Thus, one of the reasons for hospitalization - a social respite - turned out to be inapplicable or limited, which could not but affect the quality and accessibility of the care provided to patients, support for patients and families at home and the workload on staff.

In-home care. Changes in patient monitoring at home have occurred in all regions of the country. Moreover, here the restrictive measures concerned mainly social visits in order to conduct hygienic treatment of patients, as well as planned visits to assess the dynamics of the condition, dressing of chronic wounds, educating relatives, as well as patients whose families are in quarantine due to contact with infected people. At the moment, in the vast majority of constituent entities of the Russian Federation, specific restrictive measures have been taken in the work of visiting patronage services and palliative care rooms. Visits are made either only to patients with pain and other painful symptoms or only to terminal patients. A significant part of the work, condition monitoring, correction of the treatment regimen is carried out using remote technologies (telephone and Internet connection). Some subjects solve the issues of the complete cessation of home visits by visiting patronage services or PC rooms (the Chechen Republic, Republic of Crimea, Yekaterinburg, Kemerovo, Astrakhan Oblasts), or even their closure with the reassignment of human resources. Thus, the essential principle of palliative care - supporting families 24/7, is also difficult, especially given the congestion of primary health care services (PHC). The current situation requires restructuring in a short time, taking into account the individual needs of families and their resource capabilities.

Anaesthesia. One of the main tasks of PC is the timely and regular treatment of chronic pain syndrome with the use of opioid analgesics. Administration of treatment, prescribing, monitoring the effectiveness of these drugs for use at home is carried out by the PHC and PC services. In conditions where all the efforts of primary care specialists are directed to the fight against coronavirus infection, and hospitalizations in the primary care units are limited, the availability of anaesthesia can be significantly reduced, both due to the timeliness of administration and prescribing drugs, and due to the difficulty of regular monitoring, monitoring of effectiveness and side effects. In many regions, for example, in Moscow, the general prescription for opioid analgesics for palliative patients was undertaken by the PC service.

In the Russian Federation, at the federal and regional levels, various types of resources have been created for counselling and resolving issues of quality anaesthesia and providing palliative care, including hotlines. Hotlines of the Federal Service for Supervision of Healthcare (Roszdravnadzor) - 8 800 550 99 03, executive authorities in the field of protection in the constituent entities of the Russian Federation, and NGOs (charity and professional), such as the Vera Hospice Assistance Foundation - 8 800 700 84 36 and other funds operating in the regions and carrying out their activities in the field of palliative care, the Association of Hospice Assistance - 8 495 545 58 95.

Individually should be noted about the unique challenges and difficulties arising for non-governmental, non-profit organizations, foundations, associations in the changed working conditions. These organizations present a vital link in the modern Russian palliative care system,

which bears a particular burden of care for patients and their families, often providing both material and social support, as well as spiritual. During the period of the epidemic, quarantine and other restrictive measures, these organizations suffer serious, including financial, losses, and some of them may be on the verge of termination of their activities.

Conclusions: Taking into account the analysis of organizational decisions made in various regions of the Russian Federation, and the international experience in order to maintain the basic principles of providing and improving the quality of palliative care in the context of the epidemic of coronavirus infection and the risk of its spread, in any epidemic situations in the regions any kind of remote technologies should be actively used (telephone, video conferencing) in order to provide:

- discussion of plans for further treatment and care and the severity of the patient's condition;
- emergency (24/7) or planned consultation of patients at home;
- monitoring the patient's condition and the effectiveness of the prescribed treatment;
- training relatives in patient's care;
- enabling patients to communicate with their relatives;
- providing psychological support to patients and relatives.

Training relatives and patients in keeping observation diaries and its further discussion in remote mode makes it possible to adequately monitor the condition of patients and timely detect changes in the situation.

In order to take measures to protect personnel from physical and psychological fatigue and provide them with the conditions to fulfil their duties in high-load circumstances, it is necessary, first of all, to provide the institution's personnel with personal protective equipment and disinfection, as well as consider the possibility of:

- changes in the work schedule and/or job descriptions of employees taking into account their competencies, wishes and needs;
- simplification and unification of medical records;
- recruiting volunteer doctors from among college and university students in both full-time and distance modes;
- changes in the routing of patients, taking into account the complexity of the condition and needs of the patient and the changing capabilities of various inpatient and outpatient facilities;
- expanding the service area by visiting patronage services, increasing or rotating the bed capacity in various institutions with the transfer of employees between institutions and units;
- transferring individual employees of PC services from the risk group (over 65 years old) to remote work, assigning them to remote monitoring of patients with mandatory continuity in the work of the service.

The situation of congestion of the primary care system can lead to difficulties or a change in the timing of prescribing opioid analgesics or psychotropic substances, in connection with which is crucial to provide:

- prescription of these drugs by the palliative care services on a par with the primary care unit, including the use of the norms of a double increase of the prescribed drug per prescription, as well as the norms of electronic prescription specified by law;
- mandatory application of measures to ensure patients who are discharged from hospitals and need to continue treatment with opioid drugs, including potent ones, on an outpatient basis, with prescriptions for these drugs or with the drugs themselves for up to 5 days;
- mandatory use of monitoring of the availability and residues of medicines for patients who are at home with the goal of timely prescription and to avoid interruptions in stock;
- the interaction of outpatient and inpatient services of PC, primary health care and emergency medical care in the form of creating and/or maintaining a single registry (database, list) of all patients who need palliative care and treatment of chronic pain syndrome with the communication of daily information about calls to emergency teams "for pain", discharge or change of the drug or its dosage.

In order to optimize the work of institutions of inpatient and outpatient types of PC, the following should be done:

- to identify the main causes for hospitalization in one or another hospital in the region, limiting planned hospitalizations for the duration of the epidemic, strengthening home monitoring by visiting patronage services, including using remote technologies;
- to determine the principles of patient routing taking into account the patient's residence and the resources of hospitals and outpatient services;
- to consider the possibility of using boarding houses and sanatoriums in the region to accommodate patients who need long-term nursing care, who do not need daily medical supervision with the obligatory solution of the issue of staff training and/or transfer of staff of departments that are subject to repurposing or closing;
- in large cities in the conditions of an advanced epidemic situation, to consider the possibility of allocating separate hospitals for infected or coronavirus-contact patients. Filling of such departments should be carried out after complete release from non-contact patients and providing the necessary personal protective equipment for personnel.

Palliative care staff, as specialists who face daily the end-of-life situations in terminally ill patients, and who are able to treat the symptoms that are observed in patients with coronavirus infection in a terminal situation, such as anxiety, fear, insomnia, shortness of breath, cough may be called on to help treat patients with coronavirus infection. The communicative skills of palliative care services should be used more actively in reporting bad news to relatives or discussing terminal conditions [4].

Thus, palliative care in a pandemic is, on the one hand, a system with rapidly growing needs and difficulties, requiring swift solutions to help chronically ill patients, and on the other hand, a system that can actively participate in helping patients with coronavirus infection in order to ensure the quality of life and alleviate persistent painful symptoms.

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How to organize palliative care in a hospital during the COVID-19 pandemic*

Experience of the Moscow Multidisciplinary Center for Palliative Care

Eugenia Rezvan¹

¹ Source: <http://pro-palliativ.ru/> The material was prepared using a grant from the President of the Russian Federation provided by the Presidential Grants Fund

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* - the article contains visual materials, you can see it in the [Russian edition](#) of the magazine.

Today it is known that coronavirus (COVID - 19) is most dangerous for people over 60 years of age, as well as for those who suffer from chronic diseases. This means that patients in hospices and palliative care are at highest risk. In order to protect patients as much as possible at the Moscow Multidisciplinary Center for Palliative Care, experts developed relevant recommendations, as well as a special checklist (you can download it at the end of the material). It will be useful to managers and employees of hospices and palliative departments and will help to track whether all safety measures have been taken.

Access to information

When people do not know what to do, and no one tells them about it, they experience anxiety. This, in turn, provokes errors, gives rise to speculation and, as a result, panic.

Print and hang in the appropriate places (the entrance to the territory, the front door to the building, wardrobe, information stands, reception, a reception area for UPU documents) memos and instructions. In addition to information, this measure will reassure people and give them the feeling that the situation is under control.

Staff Training

It is important that the hospice or palliative ward staff know exactly what the preventive measures are in times of crisis.

Train all employees on:

- personal protective equipment use,
- hand hygiene rules,

- the rules of work with antiseptic and disinfectant solutions,
- the rules for the disposal of class A, B, C waste,
- surface treatment,
- home visit procedures,
- the procedures for examining patients in a hospital.

Make sure that the staff meeting the visitors are trained in the rules of safe behaviour, know and can tell visitors about safety measures, including restrictions imposed when visiting patients in a hospital.

Do not allow to work:

- employees who have visited countries with an unfavourable epidemiological situation,
- employees living with people on self-isolation,
- employees with signs of ARI or SARS.

Monitor the reasons for the absence of the staff daily

Visits

Unlike regular hospitals, hospices and palliative departments cannot completely prohibit patient visits. This would be inhumane - after all, many of them may simply not have another chance to see relatives. The only thing that can be done is to reduce the number of visitors to one person per day for each patient. And, unfortunately, for the pandemic period, a complete ban on visits of volunteers is introduced.

Organize a temperature measurement for everyone entering the building without exception!

Differentiate zones for temperature control:

- for medical staff
- for non-medical staff
- for visitors

Record the results in an electronic journal. Write down information about people whose temperature has exceeded 37 degrees.

The order of actions for visitors

The following sequence is very important:

1. Take outerwear to the wardrobe
2. Put on shoe covers
3. Wash your hands
4. Treat your hands with an antiseptic
5. Measure the temperature
6. Wear a face mask if necessary
7. Before entering the ward re-treat the hands with an antiseptic

Hygiene and Prevention

Make sure that antiseptic agents are placed in wardrobes and in areas where visitors are most passable. They should also be:

- at the guard post,
- in the lobby,
- in the area in front of the entrance to each ward,
- at a stationary post of a nurse,
- on the backs of patients' beds.

Allocate a room for the organization of an infectious disease ward. It should be available in case of a patient with infectious disease symptoms.

Ensure the ventilation of the rooms at least 4 times a day. And - after each visit.

Daily wet cleaning should be carried out at least 3 times a day.

Surfaces should be regularly treated with disinfectants.

Control the duration of the recirculating irradiators (dezers) – at least 12 hours a day.

Coronavirus Disease: Medical Indications for Provision of Palliative Care

Diana Nevzorova, Anastasia Ustinova

Federal State Autonomous Educational Institution of Higher Education I.M. Sechenov, First Moscow State Medical University of the Ministry of Health of the Russian Federation (Sechenov University)

Nevzorova Diana Vladimirovna - MD (AuthorID: 393652), Director of the Federal Scientific and Practical Center for Palliative Medical Care, Associate Professor of the Department of Medical and Social Expertise, Emergency and Outpatient Therapy of First MSMU I. M Sechenov, Ministry of Health of Russia; Chairman of the Board of the Association of Hospice Care Professionals. 2 Bolshaya Pirogovskaya, 119991, Moscow, Russia. e-mail: gyn_nevzorova@mail.ru.

Ustinova Anastasia Igorevna - Junior Research Fellow of the Federal Scientific and Practical Center for Palliative Care Medical Care of the First Moscow State Medical University I. M. Sechenov. 2 Bolshaya Pirogovskaya, 119991, Moscow, Russia. e-mail: anst.ustinova@gmail.com.

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Abstract

In the circumstances of the epidemic of coronavirus infection, the palliative care specialists can be effectively demanded in resuscitation departments and intensive care units to work with severely ill patients. This need can become especially acute in the case of an increased flow of patients with severe symptoms and a poor prognosis for recovery. Early detection of the patients in need of the specialized palliative care will improve the quality of services provided to the most difficult group of patients.

Keywords: *palliative care, medical indications, epidemic, coronavirus disease, COVID-19*

Introduction

Patients with severe persistent manifestations of coronavirus infection may need palliative care (PC). At present, the main burden of preventing the spread of coronavirus and helping ill citizens lies on the healthcare system at all levels. All types of medical care are involved in the struggle, but PC specialists are engaged in this work insufficiently. According to the WHO recommendations, in emergencies, in cases of pandemics, the PC service shall be involved to provide assistance to affected people and their families [1]. The PC resources can, therefore, be used in planning the medical care organization for patients in the event of an uncontrolled course of the coronavirus pandemic. The experience of countries faced with the massive surge of severe patients to hospitals and the depletion of organizational and other resources shows that in some cases, medical workers are inevitably forced to sort out the patients according to the criterion of the possibility of recovery [2,3]. This fact is one of the most serious moral burdens on staff, especially in the face of a lack of

time and energy, both emotional and physical. Thus, the involvement of the competencies of PC specialists can be carried out in order to provide the greatest possible assistance to the most severe, including dying, patients and their families.

In the article published in March 2020, Tao Chen et alia described the clinical symptoms of 113 coronavirus-infected patients (Covid-19) in Tongji Hospital, Wuhan, China [4]. The primary outcomes of the evaluation of clinical characteristics and laboratory data were obtained from electronic medical records of deceased patients. The most frequent symptoms were shortness of breath, chest tightness and disorder of consciousness observed in 62%, 49% and 22% of deceased patients respectively. The authors also identified general complications more frequently observed in deceased patients, including Acute Respiratory Distress Syndrome (113; 100%), type I respiratory failure (18/35; 51%), sepsis (113; 100%), heart failure (41/83; 49%), alkalosis (14/35; 40%), hyperkalemia (42; 37%), acute kidney injury (28; 25%) and hypoxic encephalopathy (23; 20%) [4].

In this regard, it is necessary to emphasize that the competencies of palliative care providers include the correction of full-blown and persistent symptoms that develop due to progression of incurable diseases at the end of life. These symptoms are primarily pain, shortness of breath, coughing, nausea, vomiting, insomnia, anxiety, delirium, cognitive disorders - many of which are observed in severe COVID-19 cases. The specific teamwork skills of palliative care services to implement the basic principles of relief of suffering in poorly controlled and fast-changing situations, as well as excellent communication, psychological support and reflection skills can be used in planning and discussing the most difficult situations and also in communicating with patients and their relatives [5]. Palliative care specialists can be engaged:

- for the remote counselling of difficult patients and making recommendations in medical records;
- for expert review of hard medical cases;
- for providing short lectures on working with terminally ill patients for doctors and nursing staff;
- on a regular basis - for work in intensive care units.

The latter option may be difficult to achieve when palliative care services are overloaded and due to employee scarcity, but it shall be implemented in cases of mass admission of patients with severe symptoms of the disease and a high level of mortality, which means a large number of dying patients. As highlighted in the WHO guidance on the integration of palliative care into emergency medicine [1], the involvement of palliative care specialists helps not only to provide essential comfort to patients with serious medical conditions but also to relieve the emotional and moral strain of health professionals being at the coalface [8].

A critical aspect of this situation is the timely identification of patients in need of palliative care. Medical grounds for palliative care for adults are defined in Annex 1 to Order No. 345n of the Ministry of Health of the Russian Federation and Order No. 372n of the Ministry of Labour and Social Protection of the Russian Federation dated May 31, 2019 "On approval of the regulations on the organization of palliative medical care, including coordination arrangements between healthcare organizations, social service organizations and public associations and other non-profit organizations working in the field of health care" and include general medical indications and

medical indications for the main chronic diseases and conditions [6]. General Medical Indications include:

- worsening general condition, reduced physical and/or cognitive function associated with advanced incurable disease and dismal prognosis despite the optimal provision of expert care;
- reduced functional activity determined using standardized systems of Functional Capacity Evaluation;
- more than 10% body weight loss in the last six months.

When two or more general medical indications are identified in one patient, the therapeutic indications shall be assessed by groups of diseases or conditions. With regard to the latter, the regulatory enactment doesn't provide the conditions that can be classified as complications of coronavirus disease.

CAPC (Center to Advanced PC) experts have attempted to define criteria for palliative care needs in patients with severe coronavirus disease [7]. According to CAPC recommendations, the following patients require specialized palliative care:

- patients who were previously recognized as requiring palliative care;
- patients with severe, poorly controlled, painful symptoms that are not amenable to treatment;
- patients who need respiratory support;
- patients with unmanageable emotional symptoms and having a doubtful prognosis of the disease outcome;
- if they or their families insist on receiving palliative care or medical counselling services.

In addition, experts identified two other groups of patients: patients who were selectively excluded from life-sustaining treatment and young adults, especially with negative anamnesis, who are parents or guardians of small children.

Medical indications for palliative care for adult patients with severe coronavirus disease.

General medical indication for palliative care for adults

- worsening general condition, reduced physical and/or cognitive function associated with advanced incurable disease and dismal prognosis despite the optimal provision of expert care;
- reduced functional activity determined using standardized systems of Functional Capacity Evaluation;

Medical indication for palliative care for patients with severe coronavirus disease.

- the presence of severe, poorly controlled disease manifestations;
- the need for respiratory support;

- the presence of a combined mental and/or somatic symptom disorder that has a significant impact on the quality of life and the possibility of applying the necessary treatments, as well as/or symptoms of the disease;

Categories of patients

- patients who were previously recognized as requiring palliative care;
- patients with unmanageable psychoemotional symptoms and having a doubtful prognosis of the disease outcome;
- patients who insist on receiving palliative care or palliative care counselling services
- patients who were selectively excluded from life-sustaining treatment
- young adults, especially with negative anamnesis, who are parents or guardians of small children.

Conclusion

Despite all the measures taken against the spread of coronavirus infection on the territory of the Russian Federation, we must be prepared, among other things, for a challenging situation in order to provide the most effective and high-quality medical care to the affected citizens. Timely identification of patients in need of palliative care and providing them with all the facilities of this service can play a substantive role in improving the quality of care for the most severe category of patients. As can be seen from the above, palliative care can become an essential component of the coherent overall system of care for patients with severe coronavirus disease in terms of improving the quality of treatment and care provided.

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Analgesics and other prescription drugs at the time of self-isolation mode: how to get it?

By Valeria Mikhailova¹

¹ Source: <http://pro-palliativ.ru/>. The material was prepared using a grant from the President of the Russian Federation provided by the Presidential Grants Fund

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How to get a prescription for an elderly relative living separately in self-isolation? Is it possible to go to the pharmacy if it is in the other part of the city? What to do if an ambulance physician does not have the right medicine?

Self-isolation regime in Russia has been extended for the entire April. But the disease does not recognize any limitations: drug therapy for chronic diseases, pain, and other conditions should not be interrupted. What to do if the drug was not in the nearest pharmacy? How to renew recipes if you sit at home? What should you do if there is no medicine needed at the ambulance that came to relieve acute pain?

What should I do if the prescription for a medicine ends, but it seems impossible to go for a new one — when it is said you can be fined for violating the self-isolation regime?

The declared self-isolation mode cannot be a reason for refusing medical care. A new prescription can be obtained at a health facility or, if the institution's internal regulations require it, you can request a house call by a doctor to write a prescription. For people at risk (chronic disease, age over 65), this is especially of current interest. For this reason, for example, physicians of the Moscow Multidisciplinary Palliative Care Center can make house calls to write out a prescription for medicines. To find out if your clinic or other medical institution issues prescriptions at home, we recommend that you first call the institution and clarify this. Perhaps soon, the regulation will change so that people at risk do not need to appear in public places with a risk to their health.

- It's important! -

In order not to have to issue the prescription twice, pay attention to how it should be drawn up: in addition to the signature and seal of the attending physician, the prescription must have the seal of the medical institution, the seal "For prescriptions" and, if the prescription is being issued for the first time, the signature of the head of the medical organization.

For how long a prescription for drugs is currently valid?

At the end of March, the Russian Ministry of Health recommended that medical institutions issue prescriptions with the maximum possible validity so that people are less likely to go to medical institutions during the period of self-isolation. However, the validity periods themselves have not changed. So, for example, a prescription for narcotic and psychotropic drugs is valid for 15 days from the date of issue. At the same time, for example, for cancer patients, if long-term drug therapy is required in the form of tablets, a prescription can be issued for **180 days**. In essence, this is decided by the attending physician depending on the specific situation.

In Moscow, when prescribing narcotic and psychotropic drugs, the physician will ask the caregiver (patient's medical proxy) to write a receipt saying that he is familiar with the procedures for receiving, storing and returning unused drugs and prescription forms (Decree of the Moscow Department of Health dated 11.12.2015 No. 1077, Appendix 22).

Authorities say you can go outside only to get to the pharmacy closest to my house. But there is no medicine prescribed to me there; I must go to the other part of the city. What to do?

The situation when you or your relative is prescribed a prescription for a medicine, and you need to buy it at a pharmacy refers to getting medical care. In this case, you can go to the right pharmacy, even if it is located far away.

You can find out about the availability and cost of medicines, as well as reserve prescribed drugs in Moscow pharmacies by calling: **8 (495) 874-63-65** (for preferential free of charge drugs) or **8 (495) 974-73-19** (for other drugs). This service is available on weekdays from 8 to 20, on Saturday from 10 to 18.

In any case, the prescriber must inform the patient or his representative about the pharmacy that can provide the prescribed drug.

What to do if the drug is not available in the pharmacy?

You need to ask for a deferred prescription service: this means that a pharmacy working with prescription drugs of this profile must order the medications and provide you with them as soon as possible.

- If prescription contains note "statim" (immediately) - it is serviced within one working day;

- If there is a note “cito” (urgently) - within two business days from the date of contacting the pharmacy;
- A prescription for a drug that is included in the minimum assortment is serviced within five working days from the date of request;
- A prescription for a drug dispensed for free or at a discount and not included in the minimum assortment of medications necessary for the provision of medical care is served within ten working days from the date of contacting the pharmacy.

If you need any pain relief medication and the pharmacy can't provide it during the requested time, please contact the Health Compliance Hotline of the Federal Service for Surveillance in Healthcare (Roszdravnadzor) (8-800-550-599-03). Telephone numbers on pain medication questions in the regions can be found on the Federal Service website.

If elderly spouses or a lonely person over 65 is at home, they are not recommended to go out, can their relative or neighbour get the medicine?

A paper-based prescription can be obtained by both the patient himself and his legal representative or the person to whom a power of attorney was issued (Article 7 of Order No. 4H of the Ministry of Health of Russia dated January 14, 2019).

A power of attorney to obtain the prescription for another person, as well as a power of attorney to receive the prescription medicine for him at the pharmacy, can be printed or written by hand (for the approximate form of a power of attorney, see the end of the article). Notary certification is not required! By such a power of attorney, anyone can receive the medicine, including a nurse. At the pharmacy, an attorney will need to show:

- Power of attorney (original document),
- ID (original document).

In practice, although this is not stipulated by law, pharmacies sometimes request a patient's ID, and sometimes they require nothing but a prescription. Again, in practice, at the clinic, a power of attorney may not be necessary. But it's better to have it and take it with you to the clinic and pharmacy.

As for notarization of power of attorney, this is not necessary (see Explanation of the norms of the Order of July 11, 2017 No. 403 n). A power of attorney can be certified by a notary on request of the patient or if the patient is unable to write a power of attorney himself. The validity of a power of attorney, if it was not indicated during the preparation of the document, defaults to one year from the date of signing.

What can older people do if they have no relatives or they live far away?

The mandatory self-isolation regime for people over 65 and for people with chronic diseases was extended until May 1. Still, at the same time, home delivery of medicines (which are prescribed by prescription for free or at discounted prices) and medical devices (prescribed by prescription for free) was organized. To order this service, you need to call the Hotline of the Moscow Health Department (8-495-870-45-09): a social worker should come to you.

In practice, it happens that a social worker does not agree to buy prescribed opioid analgesics. In this case, you need to ask someone from your friends, neighbours to do this by writing a power of attorney on them.

Also, in Moscow and the regions, there is a hotline for the project **#wearetogether**. This is a joint project of the All-Russian National Front (ANF) and volunteer organizations in different cities of Russia ("Medical Volunteers", the Association of Volunteer Centers, etc.), created to help people over 65 years old - with the delivery of food, medicine and other household problems. Hotline number: **8-800-200-34-11**. By calling it, you can leave a request - indicate the address, name, contact phone number, and within three days a volunteer or social worker will contact you, depending on the request (applications for prescription drugs are sent to social workers). You can also download the ANF Help application (for Android and ios) and fill out a form for assistance for your elderly relative electronically

There is no certainty when I can get the drug next time. Can I take my prescribed pain medication less frequently or in a lower dose?

In no case! The scheme of anaesthesia can be adjusted **ONLY** by a doctor. An unauthorized change in the regimen of painkillers may cause the pain to intensify. Pharmaceutical support for citizens in need of palliative care is the state's responsibility: you have the right to receive the necessary medication, regardless of the self-isolation regime. If you have problems receiving opioid analgesics, please contact the Roszdravnadzor Public Health Hotline (**8-800-550-99-03** or the **Helpline for terminally ill people (8 800-700- 84-36)**).

Urgent anaesthesia is needed - what should I do?

Remember that the acute pain syndrome is a life-threatening condition and therefore is a reason to call an ambulance. You will not need a prescription from a doctor for opioid drugs. But the decision about which drug should stop the pain is made by an emergency doctor. We recommend asking the doctor and writing down the name and dosage of the medications used by him. If the used drug does not fit and the pain persists for several hours, you can call the ambulance again. If you are told that there are no narcotic analgesics in the ambulance, refer to the order of the Ministry of Health of Russia No. 36n dated January 22, 2016: according to it, strong analgesics and psychotropic drugs should be included in the ambulance package. After anaesthesia, your GP should adjust the anaesthesia scheme soon. An ambulance doctor writes the fact of the use of narcotic analgesics in the call card, and the substation manager informs the management of the outpatient clinic to which the patient is attached.

In case of problems with anaesthesia, call the **Hotline of Roszdravnadzor** on the rights of citizens in the field of health (**8-800-550-599-03**). You can also contact the **Vera Hospice Assistance Fund Hotline (8-800-700-84-36)**.

Remember the simple rules for taking opioid drugs:

- Take painkillers strictly by the hour (even if there is no pain), according to the schedule prescribed by your physician.
- You cannot arbitrarily change the dosage of pain medication, even to save prescription drugs. If you change the frequency of administration or dosage, as well as when the intensity of pain is changing, consult your physician - he will adjust the scheme of pain relief.
- Drinking alcohol while taking analgesics can cause complications.
- It is also unsafe to take certain drugs at the same time as opioid analgesics: antihistamines, tranquilisers, sleeping pills. Consult your doctor about the combination of these medicines. Abrupt withdrawal of pain medication should not be allowed. The dose can be reduced only gradually, under the supervision of a doctor.

Isolation makes me crazy. What to do?

The regime of self-isolation in an apartment may not have the best effect on the psychological climate in the family, on the state of the mind of a seriously ill person and his relatives. Remember that you can get help - psychological counselling over the phone.

- The Helpline for terminally ill people and their relatives continues to work: 8-800-700-84-36.
- In Moscow, during the period of self-isolation (from March 28 to May 1, 2020), a 24/7 emergency line of psychological assistance operates. The number is 051 (from a landline) or +7 (495) 51 (from a mobile). You can also write to the chat of the Moscow service of psychological assistance at <https://msph.ru/>.
- Hotlines numbers and links to useful resources for seriously ill people (including hotlines on the situation around the coronavirus pandemic) are at <https://propalliativ.ru/blog/poleznye-ssylki-i-nomera-goryachih-lini/>.
- A selection of all texts and guidelines regarding the COVID-19 can be found at <http://propalliativ.ru/specials/covid-19/>

COVID-19 in children: known, unknown and real

E.V. Polevichenko

Pirogov Russian National Research Medical University of the Ministry of Health of Russia

Polevichenko Elena Vladimirovna – MD, PhD, Professor of the Department of Oncology, Hematology and Radiation Therapy, Pirogov Russian National Research Medical University of the Ministry of Health of Russia, 117997 Moscow, ul. Ostrovityanova, house 1. 8–905–543–48–62, e-mail: polevich@mail.ru

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Abstract

The article provides a brief overview of foreign publications on the problem of the new coronavirus infection (COVID-19) in children. The issues of organizing palliative medical care and psychological support for children in a pandemic are considered. The recommendations for pharmacotherapy of coronavirus infection in children are given in detail.

Keywords: *Pediatric palliative care, new coronavirus infection, children, COVID-19, pandemic.*

COVID-19 is a dangerous, rapidly developing situation. The time has come for a selfless struggle for the lives of compatriots: right now there is nothing more crucial than this. After the end of an unprecedented pandemic, we will be able to evaluate the primary medical victories and defeats retrospectively. Today, when we read in foreign publications about triage of patients in new epidemic conditions, it is essential for us to strengthen the idea of palliative care as a bioethical obligation of the health system.

Over the past three months, international experience in the fight against a new coronavirus infection has shown apparent differences in the incidence, severity, and most importantly, in the mortality from COVID-19 between the adult and children's populations. Indeed, children get sick less often and less severe than adults. However, children are an important link in the overall epidemic chain. This is due to the frequency of them being asymptomatic carriers of the COVID-19 virus, the incomplete formation of personal hygiene skills and the mass affiliation of children to organized groups (including closed ones). Daily pandemic statistics only occasionally report deaths of patients under 18 years of age. However, this is not a reason to underestimate the infectious prognosis for the most vulnerable childhood cohort - patients receiving palliative care. In our country in 2019, there were over 15.5 thousands of such children. What needs to be done for them today?

Palliative care for children in a pandemic: key challenges

Decision making in today's epidemic situation is impossible without an analysis of the primary and secondary risks. Assessment of key risks in the complex of regional medical and social problems

associated with COVID-19 will allow PC services to choose priority goals in a pandemic [1; 2]. Here are the main challenges of the current situation:

Organizational and epidemic:

- the urgent reorganization and reprofiling of medical organizations providing pediatric palliative care (PPC) (including, in some cases, for provision of medical care to adults in a pandemic);
- the overload of the healthcare system as a whole and its management in particular;
- the difficulty of providing medical personnel with personal protective equipment and disinfectants;
- the aggravation of the staff shortage of healthcare workers associated with their infection with COVID-19, treatment and professional burnout;
- the necessity to develop professional competencies in fighting a pandemic among medical personnel of PPC services in a limited time;
- the cessation of visits of relatives, patients' friends and volunteers to inpatient medical organizations providing primary care to children, which leads to an additional burden on staff;
- a reduction or termination of home visits to children by visiting patronage palliative care teams for children;
- a significant limitation of the financial capabilities of socially-oriented NPOs and charitable foundations involved in providing PC to the children's population;
- high demand for online kind of interaction "employee-employee", "employee-family", "family-volunteer".

Diagnostic and treatment:

- a complication of the logistics of drug provision for patients, including narcotic and psychotropic drugs;
- high interest of the healthcare system in resources for providing mechanical ventilation for patients with a new coronavirus infection (including resources from the primary care system);
- increased demand in the market of medical devices and supplies for mechanical ventilation;
- severe limitation of the possibilities of diagnostic studies for children receiving palliative care in an outpatient setting;
- the increased epidemic risk for children in need of PC and permanently living in closed children's groups (specialized orphanages, orphanages).

Psychosocial:

- stress factors for PC service staff and patients' parents during the quarantine period: fear of infection of themselves and others, isolation, inadequate support of basic needs (including personal protective equipment), inadequate and/or insufficiently clear information and recommendations of health authorities, risk of job dismissal [3];
- stress factors for the staff of PC services and parents of patients after quarantine: financial difficulties, stigmatization of people who have had an infection (avoiding contact with them, attitude with fear and suspicion, critical comments) [3];

Resources for addressing PC issues for children in the pandemic

1. Planning perspective aid in a more thorough way than has been required so far. This applies not only to the internal work of the medical organization but also to joint planning with the parents for family care for a child in need of palliative care. It is necessary to explain to parents how, together with the physician, to ensure the stability of providing the child with medicines and supplies in the current epidemiological situation. Unique infectious risks of children in need of PC and permanently living in closed children's groups should be accompanied by more careful monitoring of their needs and assessment of their health status. Increased attention should be given to single-parent families in which only one parent provides education and care for a child in need of palliative care. It is essential to plan in advance the complex of medical and social activities in the family with a probable COVID-19 infection of the only legal representative of the child who is caring for him. These are just some examples of how vital is the work "ahead of schedule", timely assessment of prospects and planning.
2. Use of external resources. Restrictions dictated by quarantine measures have dramatically increased the need for online communication. Moreover, some employees and parents of children do not have sufficient user skills. It is possible to find opportunities for their accelerated training with the involvement of not only full-time IT specialists but also IT volunteers, whose help is now merely invaluable. No less important may be the support of employees of medical universities and colleges who rearranged for distant learning and in this regard prepared numerous training materials in electronic form. Some of them may be useful for the development of the necessary competencies of staff of PC services in a pandemic situation. Remote forms of information support from NPOs and foundations may be valuable: the creation of libraries of relevant resources, infographics, and video materials on various practical issues of coronavirus infection.
3. Saving material, human and emotional resources of palliative services. Expert forecasting of the trajectory of the pandemic in the world and our country suggests that some resources of the health system may be prematurely exhausted. Careful attitude to the real potential of the PC infrastructure will help to increase its resistance to ever new challenges.

Foreign experience in the treatment of children with a new coronavirus infection COVID-19

The most extensive analysis of the publications on a new coronavirus infection in children (ICD-X code - B 34.2) could be found in the March 2020 review of Ludvigsson J.F. [4]. In general, this review of 45 articles showed that children accounted for 1-5% of diagnosed cases of COVID-19, they had a milder course of the disease than adults, and deaths were extremely rare. However, in different countries the clinical and epidemiological data on coronavirus infection in children vary. Moreover, there is practically no information about the course of new coronavirus infection in children who previously received palliative care.

In the publication of an extensive data analysis of the National Health Commission of the People's Republic China, as of February 11, 2020, among 44,672 patients with a positive diagnostic test for COVID-19, only about 2% were children from 0 to 19 years old [5].

An Italian study published on March 18, 2020, reported that only 1.2% of patients out of 22,512 confirmed cases of COVID-19 were children [6], with no deaths.

Of the 4,226 cases of COVID-19 infection diagnosed in the United States before March 16, 2020, 5% were children. Children accounted for less than 1% of all hospitalizations for coronavirus infection in the United States [7].

The authors from Madrid (Spain) report that in the first two weeks of the epidemic 41 children under the age of 18 were identified with a positive diagnostic test for COVID-19 infection, which made up only 0.8% of 4,695 cases confirmed by this time [8]. Among children with a confirmed diagnosis of COVID-19, 25 children out of 41 (60%) were hospitalized, 4 (9.7%) children were admitted to the ICU, and 4 more patients (9.7%) needed respiratory support. None of the children died.

The incubation period in children is short: usually about two days (2-10 days) [9]. The clinical symptoms of coronavirus infection in children were analyzed in 171 children with a confirmed diagnosis [10].

The most common symptoms of COVID-19 infection in children were: cough (48.5%), hyperemia of the pharyngeal mucosa (46.2%) and fever above 37.5 degrees (41.5%). Diarrhea (8.8%), weakness (7.6%), runny nose (7.6%), and vomiting (6.4%) were less common.

Another Chinese study [11] noted that more than 90% of 2,143 children with a laboratory-confirmed diagnosis of a new coronavirus infection COVID-19 had an asymptomatic, mild, or moderate course of the disease. According to the severity classification used in China, the criteria for severe coronavirus infection were dyspnea, central cyanosis, and an oxygen saturation level of less than 92%.

It should be emphasized that in the 45 publications included in the review of Ludvigsson J. F. [4], only two registered cases of death of children from coronavirus infection are reported. Given the rarity of descriptions of severe cases of new coronavirus infection in children, Table 1 gives detailed clinical and laboratory data of two infants who, at the time of publication, continued to receive treatment [12].

Table 1. Clinical and laboratory parameters of 2 children from Hubei province with a critical course of a new coronavirus infection COVID-19 * [12].

Characteristic	Patient 1	Patient 2
Age	8 months	12 months
Sex	boy	boy

Underlying disease	Congenital heart disease, malnutrition, suspected hereditary metabolic diseases	Congenital heart disease
Epidemiological history	Visit to Wuhan city	Residence in Wuhan city
Clinical symptoms	Cough, dyspnea, fever	Fever, diarrhea, dyspnea
Laboratory data		
White blood cells (10 ⁹ /L)	4.43	11.96
Lymphocytes (10 ⁹ /L)	1.46	2.47
Haemoglobin (g/L)	153	100
Platelet count (10 ⁹ /L)	202	184
Alanine aminotransferase (U/L)	12	20
Albumin (g/L)	30	30.1
Creatine kinase isoenzyme (U/L)	98.8	62
Prothrombin time (s)	14	14.3
Lactate dehydrogenase (U/L)	609	361
Creatinine (μ mol/L)	45	224.5
Potassium (mmol/L)	3.5	4.45
Sodium (mmol/L)	136	126
C-reaction protein (mg/L)	0.5	24.6
Pathogens	SARS-CoV-2	SARS-CoV-2, Enterobacter aerogenes
Treatment		
Antiviral therapy	Interferon, oseltamivir	Interferon, oseltamivir
Antibiotics	Cefoperazone/sulbactam	Meropenem, linezolid
Immunoglobulin	2 g/kg	2 g/kg
Corticosteroid	2 mg/kg	2 mg/kg
Respiratory support	Invasive mechanical ventilation	Invasive mechanical ventilation
Blood purification	No	CVVHDF, PE
Outcome	Partially alleviated	Significantly alleviated

** Normal reference values: white blood cells, $(3.5-9.5) \times 10^9 / l$; lymphocytes, $(2.1-5.7) \times 10^9 / l$ (<3 years); haemoglobin 130-175 g / l; platelet count $(125-350) \times 10^9 / l$; alanine aminotransferase 9-50 U / L; albumin 35-55 g / l; creatine kinase isoenzyme <25 U / L; prothrombin time 9.4-12.5 s; lactate dehydrogenase 125-243 U / l; creatinine 44-133 $\mu\text{mol} / l$; potassium 3.5-5.5 mmol / l; sodium, 136-145 mmol / l; C-reactive protein, <10 mg / ml.*

Pharmacotherapy options for new coronavirus infection (COVID-19) in children

There are no specific antiviral drugs for this infection yet. The etiotropic treatment of the new coronavirus infection COVID-19 is experimental; the doses and treatment regimens are selected empirically by physicians. Despite the limited evidence base on the effectiveness of the antiviral treatment of COVID-19 in children, the National Scientific Society of Infectious Diseases in Russia prepared Clinical Recommendations "New Coronavirus Infection (COVID-19) in Adults and Children" in April 2020. Until the approval of these clinical recommendations in practical work, one should be guided by the Temporary Clinical Recommendations approved by the Ministry of Health of Russia "Prevention, Diagnosis and Treatment of New Coronavirus Infection (COVID-19)" (version 5 of April 2, 2020) [13].

All over the world today COVID-19 is treated with drugs that are used for HIV infection, viral hepatitis C, malaria and other infectious diseases. The results of using these drugs are contradictory. This is due to the short period of struggle with the pandemic and the difficulties of organizing clinical trials considering a dramatically increased load on the healthcare system.

In previous years, with the development of COVID-19 precursor infections such as severe acute respiratory syndrome (SARS) and Middle Eastern respiratory syndrome (MERS), lopinavir + ritonavir and ribavirin were used. These drugs are quite toxic, so their use in children is likely to be limited. Umifenovir ("Arbidol") was previously widely used for influenza and SARS. However, when using umifenovir in China during a pandemic, no convincing data were demonstrated in its favour, as well as in favour of the drug Lopinavir + Ritonavir ("Kaletra").

The antimalarial drugs chloroquine ("Delagil") and hydroxychloroquine ("Plaquenil") were previously used for SARS and MERS. There are a number of publications about their effectiveness in the treatment of COVID-19, but there are also opposite data.

A summary of the drugs recommended for the treatment of new coronavirus infection in children is presented in Table 2. Temporary guidelines [13] emphasize that influenza medications (oseltamivir and others) can only be used in patients infected with the influenza virus. Antibacterial therapy is recommended if there is evidence of bacterial infection present along with the COVID-19. However, azithromycin can be prescribed for coronavirus infection in combination with chloroquine and hydroxychloroquine.

Table 2. Medications for the pharmacotherapy of a new coronavirus infection (COVID-19) in children, according to the Temporary Guidelines of the Ministry of Health of the Russian Federation (version 5 of April 2, 2020)

INN	Pharmacotherapeutic group	Route of Administration	Release forms	Age restrictions
Lopinavir + Ritonavir	Antiviral (HIV) agent	Enteral	Tablets; oral solution	From 6 months
Ribavirin	Antiviral, synthetic nucleoside analogue	Enteral	Tablets, capsules	From 3 years
Umifenovir	Antiviral	Enteral	Tablets, capsules	From 3 years
Interferon-alpha	Antiviral and immunostimulant	Enteral Intranasally IV SC Per rectum	Capsules, Dosage nasal spray, nasal drops IV and subcutaneous administration solution Rectal suppositories	From 3 years From 0 years From 0 years
Human immunoglobulin, Normal	Medical immunobiological preparation - globulin	IV	Infusion solution	From 0 years
Chloroquine	Antimalarial drug	Enteral	Tablets	With body weight > 50 kg
Hydroxychloroquine	Antimalarial drug	Enteral	Tablets	With body weight > 50 kg
Azithromycin	Antibiotic-azalide	Enteral IV	Tablets, capsules, powder for preparation, lyophilisate for IV administration	From 6 months

For mild and moderate forms of coronavirus infection in children, interferon-alpha preparations are recommended. In severe cases of the disease intravenous immunoglobulins, HIV-1 and HIV-2 protease inhibitors (Lopinavir + ritonavir), as well as ribavirin are recommended.

Most children who need palliative care receive long-term syndrome therapy as planned. Therefore, in the treatment of coronavirus infection, it is important to consider inter-drug interactions. Table 3 presents data on the compatibility of opioids and psychotropic drugs with some drugs for the treatment of COVID-19 infection. A complete list of drug interactions in the treatment of coronavirus infection can be found on the website of the University of Liverpool (UK) [14].

Table 3. Inter-drug interactions of analgesics and psychotropic drugs with some drugs for the treatment of new coronavirus infection (COVID-19) according to www.covid-19-druginteractions.org (University of Liverpool, UK)

PC medications	Lopinavir + Ritonavir	Ribavirin	Chloroquine	Hydroxychloroquine
Tramadol	↑♥ Dosage adjustment or meticulous monitoring is possible	↔	♥↔ Dosage adjustment or meticulous monitoring is possible	♥↔ Dosage adjustment or meticulous monitoring is possible
Morphine	↓	↔	↔	↔

Fentanyl	Dosage adjustment or meticulous monitoring is possible			
	↑ Dosage adjustment or meticulous monitoring is possible	↔	↔	↔
Carbamazepine	↑↓ Dosage adjustment or meticulous monitoring is possible	↔	↓ Should not be used together	↓ Should not be used together
	↓ Dosage adjustment or meticulous monitoring is possible	↔	↓ Should not be used together	↓ Should not be used together
Phenobarbital	↓ Dosage adjustment or meticulous monitoring is possible	↔	↓ Should not be used together	↓ Should not be used together
	↓ Dosage adjustment or meticulous monitoring is possible	↔	↓ Should not be used together	↓ Should not be used together
Amitriptyline	↑ Dosage adjustment or meticulous monitoring is possible	↔	↑ Dosage adjustment or meticulous monitoring is possible	↑ Dosage adjustment or meticulous monitoring is possible
	↑ Dosage adjustment or meticulous monitoring is possible	↔	↔	↔
Diazepam	↑ Dosage adjustment or meticulous monitoring is possible	↔	↔	↔
	↑ Dosage adjustment or meticulous monitoring is possible	↔	↔	↔
Clobazam	↑ Dosage adjustment or meticulous monitoring is possible	↔	↔	↔
	↑ Dosage adjustment or meticulous monitoring is possible	↔	↔	↔

Notation conventions:

↑ - may enhance the effect of the drug used in conjunction with the drug for the treatment of COVID-19

↓ - may decrease the effect of the drug used in conjunction with the drug for the treatment of COVID-19

↕ - a decrease in the effect of the drug used to treat COVID-19 is possible

♥ - prolongation of the QT interval and associated cardiac arrhythmias are possible

↔ - lack of expected significant interactions

How to talk with children about coronavirus

Informing children about quarantine rules, protection measures, epidemic forecasts and risks will require confident communication skills from adults. Children who need palliative care often lag behind in neuropsychological development (usually on an organic basis), and therefore psychologists recommend alternative methods of communication to interact with them. For non-verbal children with learning difficulties, many prohibitions and changes in the daily routine associated with self-isolation of family members may remain incomprehensible. We have yet to evaluate how much information about quarantine is needed for children with special needs. Regarding talking about coronavirus infection to cognitively intact children who are being observed by the palliative service, as well as their healthy brothers and sisters, some knowledge of developmental psychology will help healthcare professionals and parents.

The main tasks of such a conversation with a child are to help to cope with fear and anxiety that arise from misunderstanding or misinformation.

Preschoolers

Even if it seems that the child is not following the news about coronavirus, nevertheless he feels the nervousness of adults and understands that this is a kind of threat to the family. Why is kindergarten closed? Why is dad now at home all the time? Why can you not play on the

playground? Children 4-6 years old may well ask specific children's questions about illnesses, doctors, and death. They may worry if their parents, relatives and friends get sick. It is important to reassure such kids by saying that we are doing everything possible at home so as not to get sick and skillfully take care of each other. Do not stress that you can die from coronavirus. It is better to say that children get ill rarely and not severe. Remind the children to wash their hands and show them how to do it several times. Tell them about the rules of so-called respiratory etiquette. Show how the mask is arranged, let them play with it in a way that is interesting for the child. In quarantine, it is essential to maintain the daily routine as close to normal as possible and to control the young child's access to troubling news.

Junior school children

The level of their anxiety for parents, friends and themselves may be higher than that of preschool children. By the age of 7-9 years, the child has mastered many different ways to independently collect information and draw conclusions from it, which are not always objective. The main ideas of talking with a child of this age are to create a sense of control over the situation and emphasize the parents' willingness to do everything in their power to ensure that nothing bad happens to anyone, including those who were seriously ill before the quarantine. Tell them in an available manner about preventive measures and help the child master them, as far as his or her level of development and condition allows. Remind them that you are always ready to talk on the coronavirus topic and answer questions.

Middle school students

Children 10-14 years old are likely to be aware of everything that is happening. They actively use the Internet, social networks and have the opportunity to discuss the news with friends. Many of them excitedly write their blogs. At this age, it is worth discussing with the child which sources of information should be trusted and which should not. To do this, it is necessary not occasionally, but purposefully and delicately assess the level of anxiety, allowing the child to share his concerns. It is important not to overload the child with your fears and to show new possibilities of life, altered by pandemic and quarantine. Pay special attention to monitoring compliance with personal protective measures: at this age, the child is especially difficult to tolerate hyper protection. But he or she will definitely appreciate your ironic, creative, inventive approach to the coronavirus theme, including video, flash mobs and social media features. Starting from middle school age, healthy siblings of a child receiving palliative care can become real companions for their parents in home care and self-isolation. Encourage brothers and sisters in this regard by emphasizing their role and do remember to praise them.

High school students

A discussion between equals is the universal key to talking with 15-18-year-olds. Sometimes they may pretend that they are not at all interested in quarantine and personal protection issues. But this can only be a way to hide their fear. Teenagers can either underestimate (more often) or overestimate (less often) the importance of respiratory etiquette, hand hygiene, and respect for social distance. They are very dependent on the opinions of their peers. Do not be surprised if during a pandemic a child at this age will be interested in apocalyptic scenarios, disaster films and considerations of a global crisis. In any case, it is worth trying to start a confidential conversation

with them, the content of which largely depends on individual characteristics. Humour helps some teens cope with the situation. Try to find for teenage siblings of a seriously ill child something to do besides their many hours of online activity, so that the whole family can go through self-isolation without psychological losses. Tell them what particular help you need today. Give them the opportunity to share their "epidemiological findings".

Gradually, more and more children's books, cartoons, comics and posters about the coronavirus pandemic appear. One way or another, but talking with a child (ill or healthy) on today's leading topic about coronavirus should be open and not boring.

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To live in a changed world

How the parents of children/teenagers with oncologic/hematologic diseases can support their children and themselves in the pandemic situation

N. Klipinina^{1,2}, A. Khain^{1,2}, T. Riabova¹, N. Nikolskaya¹

¹ Dmitry Rogachev National Research Center of Pediatric Hematology, Oncology and Immunology, 1 Samory Mashela street, 117997, Moscow, Russia.

² Charity foundation "Podari Zhizn", 13 Dovatorov street, 119048, Moscow, Russia.

Klipinina Natalya Valerievna - medical psychologist, researcher at the Department of Clinical Psychology, Dmitry Rogachev National Research Center of Pediatric Hematology, Oncology and Immunology of the Ministry of Health of Russian Federation, psychologist of the "Give Life" charity foundation. ORCID: 0000-0003-2975-0406. 117198, 1, Samory Mashela, Moscow, Russia. 8-495-287-65-81, e-mail: nklip@mail.ru

Khain Alina Evgenievna - medical psychologist, head of the department of clinical psychology, Dmitry Rogachev National Research Center of Pediatric Hematology, Oncology and Immunology of the Ministry of Health of Russian Federation, psychologist of the "Give Life" charity foundation. Russia, 117198 Moscow, st. Samory Mashela, d. 1. 8-495-287-65-81, e-mail: khain.alina@gmail.com

Ryabova Tatyana Vladimirovna - PhD, senior researcher at the Department of Clinical Psychology, Dmitry Rogachev National Research Center of Pediatric Hematology, Oncology and Immunology of the Ministry of Health of Russian Federation. Russia, 117198 Moscow, st. Samo-ri Mashela, d. 1. 8-495-287-65-81, e-mail: riabova07@mail.ru

Natalya Nikolskaya, - PhD, Senior Researcher, Department of Clinical Psychology, Dmitry Rogachev National Research Center of Pediatric Hematology, Oncology and Immunology of the Ministry of Health of Russian Federation. Russia, 117198 Moscow, st. Sa-Mory Mashela, 1. 8-495-287-65-81, e-mail: nsnikolskaya@mail.ru

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The new reality

Just recently the pandemic of coronavirus disease burst into our not so tranquil, but relatively stable (with its own problems, difficulties, diseases) life, and Russia took up this baton as well.

Within 2-3 weeks- we literally found ourselves in a different world, in another physical and mental reality. In this time different reactions to the current events in our consciousness were constantly changing: from denial, rejection, emotional shock (a lot of us thought that was a nightmare or a scary movie), bargain (trust in a myth that this virus is dangerous only for Asian older people), depression (with regrets about our aggressive attitude toward nature and others) to the reality acknowledgement and recognition of its seriousness. Many of us were faced with anxiety, paralyzing fear, panic and adaption difficulties, pulling the rug under our feet. The difficulty to get distracted from messengers and gadgets, an endless search of news on this topic could be followed by the intention to avoid any contact with the unbearable flow of injuring news. Many of us could have experienced some peculiar state of „dissociation “: by reading the latest news you feel the sense of threat, and by observing walking people – you get a strange feeling of unreality and fictional threat. We need time to adapt to changes and this new reality. Moreover, adaptation features differ from person to person. The adapting process to the changing world itself looks like

specific waves: sometimes it is easier for us to understand what and how to do, and sometimes the anxiety can overflow us again, and then again the supporting wave of ideas and possibilities follows.

Nowadays, there is hardly anyone denying the gravity of the situation; we all began to take actions in protecting ourselves and others, and physicians began to fight the virus and cure victims. Our lives have faced different changes, the self-isolation and other limitations were introduced, the work process, as well as forms of interaction and communication, were changed. Many of us register that self-isolation regime violators cause a strong negative sense and condemnation by other citizens. A lot of people have already adapted to the „contactless“ and virtual lifestyle mode in the context of numerous distractions, learning how to solve some issues, the existence of which we could not even imagine.

In such a situation, we will have to live sometime and coexist. It is expected that the situation can sometimes grow progressively worse, making our concerns deeper, restrictions can be prolonged, and new ones can be introduced. The experience of other countries, which faced the pandemic earlier, shows that the situation develops actively in the course of several months. It is fortunate that after the pandemic peak there is a decline of diseased and the number of recovering people starts to increase. The fulfilment of given recommendations and medical work contribute to the recovery and protection of most people. New different tests are used for diagnostics of diseased and recovered, vaccines and sera are being developed; the analysis of mechanisms of the virus effect is being continued, which can be influenced for treatment and saving lives. The world admires the hard work of the healthcare personnel under such circumstances. Funds open new money raisings to equip the medical staff with necessary protective gear. After the end of the pandemic, we will spend some time to recover and to adapt to new economic and social conditions, and maybe we will also have to study the further virus „behaviour“, to follow new rules and form new behaviour habits.

During the whole long-time period, we will have to get through the giant internal and external discomfort and to learn how to support ourselves and others.

Patients with oncologic/ hematologic diseases.

For the patients with oncologic diseases and their families, this situation is a time of multiple stress, trauma and loss. Every life-threatening situation adds on top of another, or the newly acquired calm is disturbed, revealing lack of psychophysical resources and provoking a wave of negative memories from the past.

However, we cannot forget that oncological patients and their families have in some way a specific advantage. Among the most efficient measures to fight the new pandemic are quarantine regulations and caution. People receiving oncological treatment (or who had such experience in the past) as well as their relatives and friends are familiar with such regulations when the therapy was

accompanied by different infectious complications. It was vital to adhere to all restrictions (contacts, diet, hygiene, etc.), to wait patiently, to cope with anxiety, to trust physicians and hope for the best. We can assure you, that most people with such experience are remarkable for caution, discipline and conscious attitude toward the potentially dangerous situation. At the same time, the current situation has its specific and can easily throw off balance even the “experienced” ones.

How to maintain emotional balance during this period. Psychologists' recommendations.

- The loss of sense of security, sense of discomfort, poor physical or emotional condition in such situations is **a natural and normal reaction**. You need time to find the ground under your feet; you need to rely upon specialists' opinion, a search of inner resources and actions within your own competence. It is important to remember: this is a crisis, but not a total fall of any hope.
- One of the essential steps in this situation is organizing and maintaining **a sense of security (your own and others)**. Reduction of the most maximum of the contamination risks, personal responsibility are the most basic conditions for adaptation and solving this situation.
- **Continue the necessary treatment of the oncological/haematological disease of a child/teenager**. Most children oncological/haematological hospitals operate in the usual mode; ambulatory medical care is now complemented with remote medical consulting. Oncologists and epidemiologists continue to provide thorough care for their patients, even in these new conditions. Discuss with specialists all necessary recommendations and action plans in such a situation.
- The experience of other countries in fighting the pandemic shows that we need not only to fence and hide ourselves for a few weeks, but we have to accurately **rebuild and adjust our lives for some time** according to the requirements of this constantly changing situation. Thus we have to preserve the quality of life as much as possible. Consider what can help you not only to “survive” but also to maintain a sense of energy and abundant life, give positive emotions, bring pleasure.
- **Trust only to the verifiable sources of information**. Studying information and self-educating the topic, give priority to documents, booklets, regulations, expert comments, but not to the personal stories of familiar and unfamiliar people. Trust only to the verifiable sources of information.
- **Abstain from negative emotions and information overflow**. Try to limit the time that you spend reading news and messengers on that issue. For example, half an hour in the morning and the evening are enough to get access to all the important news. If you use the social network and are frightened to miss something important, you can use a function of

prioritized demonstration of 2-3 resources chosen by yourself as a way not to scroll the whole news feed. Do not read the news in the early morning, directly before bedtime and during mealtime.

- The situation of threat and suspense makes us **reevaluate** our activity and actions. Try to estimate plans, goals, aims, their importance and significance from the point of the current situation and short-term prospects. It is wonderful if we succeed in the reorientation of the life plan from long-term planning to life-critical signals, needs and „right here, right now“ opportunities, doing what has to be done right now and what is relevant and meaningful by all the perspectives.
- **Overcome the limits (in a safe manner)**. For example, being on quarantine and having lack of communication, make a list of online meetings with friends, phone calls, chats etc., to make up for the feeling of loneliness and communication restrictions during this period.
- *Take good care of yourself and others. Don`t waste your energy on an accusation, sorting out difficult situations and on conflicts. “Ceasefire! Temporary ceasefire!!” – so the heroes of the «Mowgli» said, when they were forced to drink from one spring during the drought.*
- Refill your **psychological and physical resources**. Support your daily well-being: try to nourish yourself good, keep hydrated, observe your chronic diseases and your state of health. Don`t forget about physical exercise. Doing some easy exercise (stretching, pull-ups or relaxation) helps not only to become stronger but also to keep fit. Many apps can help you to exercise regularly. Physical exercise helps you to shift your attention from troubling thoughts to body sensations and actions. Write a diary, putting into all the things that gave you joy: favourite food, music, films. Try not to estimate the gravity of these things; now it is time to return the value to everything.
- Find a **balance between planning everything and preserving the sense of freedom**, spontaneity in life organization. Both parts are essential, but the recipe of comfortable proportions is individual for everyone. Mark some more stable points in your daily life –personal and collective (working or studying hours, joint lunch, or movie hours). Take care of freedom zones, respect the private space of everybody! In the situation of restrictions, deprivation and prohibitions, strengthening of outer isolation and at the same time during the higher interdependency in the family, the freedom, that previously you haven't paid attention to, has become more important.
- **Try to use the positive** potential of that period of the forced quarantine, do necessary chores, that you have postponed for some reasons. By the way, this situation gives us an exclusive opportunity to improve relations with relatives, to try new formats. However, remember this period is not very good for new beginnings, sophisticated education, extremely energy-consuming things. Be indulgent to your results and results of your child/teenager during this period.

- **Be sure to handle the anxiety, fear, panic.** Prolonged negative emotions become the source of additional stress and body exhaustion. To take back control over life, to get rid of anxiety, fear, panic, obsessions, you can choose from a lot of free apps and games. Various body, breathing techniques, relaxation practices and meditations can be useful for stress reduction. Most of them are not connected with any religious beliefs. The apps for beginners give short and clear instructions that are often followed with ambient music and visualizations
- **Ask for psychological help not only in cases** when the self-help resources are already exhausted. Prolonged crisis urges to spare the mental and emotional resource, to search for creative ways to solve difficult situations, to maintain positive thinking, to help to form emotional stability and posttraumatic personal growth. These processes become easier during the crisis counselling or psychotherapeutic treatment.

How parents can support their children.

- Try to carefully but honestly explain to the child **everything that is going on and the changes** that are happening in an accessible way, according to his/her peculiarities and issues, explaining strange terms and words (like pandemic). Explain to the child/teenager the sense of following all necessary recommendations.
- Keep as much as possible **the usual daily routine and rules** (meals, bedtime etc.) In the situation of growing uncertainty and anxiety of grown-ups, that children also feel in some way, the islands of stability are essential for them.
- Make a schedule for a day together **with a child or teenager**, where all the necessary things and time for favourite and pleasant occupations are written down – movies, tabletop games, reading. Do not forget that children also need some private space like grown-ups.
- Let your children **freely express their emotions** and accept them. Meanwhile, offer them some different peaceful ways to express them in actions/behaviour. For example, you can use a pillow for punching, crumple or tear the paper and plasticine to express irritation, resentment or anger.
- Encourage all the types of **creative activities**, be it painting, needlework, the building of different worlds out of construction sets. Sensorimotor games, massage, games with water or kinetic sand, modelling, activities with paper/ cardboard or with different textures, free painting with hands, fingers etc. can be very helpful to lift the emotional and physical tension for kids.

- Note, save, **collect together pleasant developments and experiences of the day**, exchange them before bedtime. You can have a special box/jar, where letters with these occasions will be kept.
- Think about **how you can support the child's activity and maybe diversify it**. Use different online-sources – educational, cognitive, entertaining.
- **Encourage your child** for his/her success in the fulfilment of plans. For little children, you can draw a timetable and mark with stickers things done and little progress.
- Remember a funny quote from famous Russian clown Yuri Nikulin **about the benefit of humour**: „Even after the slightest smile some little germ dies in your body“. We are convinced at least in the psychological benefit of this recommendation for 100%.

It is not necessary to follow all the recommendations at once. Choose the most important points for you and your child that is the most suitable for you right now. Maybe tomorrow you pick other ideas or even suggest some of your own.

Stay safe, be healthy and happy.

A word from clinical psychologists to health care professionals in times of the epidemic

N. V. Klipinina, A. R. Kudryavitskiy, A. E. Khain

Klipinina Natalya Valerievna - medical psychologist, researcher at the Department of Clinical Psychology, Dmitry Rogachev National Research Center of Pediatric Hematology, Oncology and Immunology of the Ministry of Health of Russian Federation, psychologist of the "Give Life" charity foundation. ORCID: 0000-0003-2975-0406. Russia, 117198 Moscow, st. Samory Mashela, d. 1. 8-495-287-65-81, e-mail: nklip@mail.ru

Kudryavitsky Alexander Rafailovich - clinical psychologist, psychotherapist. Russia, 115280 Moscow, st. Vostochnaya, d. 15/6, apt. 44. 8-968-658-14-21, e-mail: yakudryavitskiy@gmail.com

Khain Alina Evgenievna - medical psychologist, head of the department of clinical psychology, Dmitry Rogachev National Research Center of Pediatric Hematology, Oncology and Immunology of the Ministry of Health of Russian Federation, psychologist of the "Give Life" charity foundation. Russia, 117198 Moscow, st. Samory Mashela, d. 1. 8-495-287-65-81, e-mail: khain.alina@gmail.com

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The coronavirus pandemic has made the difficult medical job worldwide even more complex, bringing the operation mode closer to the wartime one. Some doctors and nurses are forced to urgently retrain, to change a job profile, and stop providing high-technological assistance to regular patient categories. Others have faced the necessity to leave their workplaces, the third ones continue to attend the high-risk patients in very hazardous conditions. Yet today, many healthcare facilities have suffered the lack of healthcare workforce, difficulties with equipment and deficiency of protection equipment. The current situation demands the health personnel to make lightning-fast difficult decisions because there is no possibility to study this wholly new and still unclear situation successively. It also requires to study new medical skills very quickly and comprehend logistics and crisis management; moreover, it has to be done without leaving patients unattended.

The psychological pressure faced by physicians and nurses has grown enormously. They have to cope with the flow of their emotions, following each other constantly and often connected with shock, uncertainty, vagueness, sense of danger, vulnerability, sometimes even sense of disempowerment, physical and emotional tension. The harsh emotional reaction and experience of patients and their relatives also affect the emotions of the specialists, connected with the adaptation to the new working conditions.

At the same time, medical workers have found themselves in the focus of worldwide attention, with high expectations for life-saving. Heroism and self-sacrifice of people in scrubs are seen as a guarantee for saving humankind. Meanwhile, the level of responsibility and consciousness of average citizens often is not high enough, and their actions can provoke disappointment, misunderstanding, resentment and deprive physicians and nurses of a sense of support by society and partnership in the struggle against a common calamity. The actions of healthcare officials and national leaders are not always timely, consecutive or provide necessary assurance.

Analyzing personal clinical experience and modern conceptions of stress control allowed the article authors to formulate several psychological recommendations for medical workers. We hope that these pieces of advice will help to improve the professional adaptation at the start of the pandemic, during the rise in the incidence (and respectively growth of public concern), during the pandemic recession, and then in the consecutive time of return to the previous lifestyle.

- **Safety comes first.** Personal safety and health of medical personnel guarantee effective help for the largest possible number of patients and their families. Life and health of every physician or nurse have gained incredible value and meaning. Act to minimize any risk!
- **Take care of yourself!** You should not treat self-care (not only your own but also your colleagues) exceptionally as a manifestation of selfishness. Remember the metaphor saying that first you should put an oxygen mask on an adult and only then on a child. The medical work in the circumstances of the pandemic is associated with severe overload and can lead to exhaustion. Use every opportunity to rest and recover physical and psychological resources.
- **It is essential to estimate your physical and emotional power correctly.** The experience of other countries and dynamics of pandemic there show, using metaphors again, that this is a long-distance run. We have to not only switch over to the different work regime and new tasks, not only prepare ourselves and go fearless through the physical and psychological stress peak of the pandemic but also, we have to estimate our resources for the time of pandemic recovery, further elimination of its different consequences and return to normal „peaceful” life. Make up your mind for the marathon: no athlete is able to run a short distance many times with only good results.
- **The pandemic has the beginning and the end.** From time to time, you will face a feeling of weakness and despair. In such moments it is important to remind yourself, that the pandemic even if not soon but will come to an end. It gives strength and maintains hope, though the repetition of this phrase may seem strange and unusual now. After some time, this pandemic will be a past experience for us. You will get an opportunity to relax and understand that you have done something almost impossible and you will be astonished when you see the amount of power, courage, wisdom you and your colleagues possess!
- **Have compassion for yourself, be your own support.** It is the best time you show all your skills and experience in compassion, not only to patients and their relatives but also to yourself. It is essential not to be too critical and demanding to yourself; it is important to understand yourself, to stay loyal to failures and imperfections. You have to confess to yourself to your own feelings and emotions and accept them even if there are feelings you haven't had before (sense of guilt, betrayal, etc.). You should encourage and console yourself. The efficiency of your work during the pandemic cannot be the same. The success of the fight with the common disaster can be evaluated only sometime after the pandemic end and only as a part of integrated assessment of measures and actions, made by the

government and different specialists within the framework of their competences and civil responsibility.

- **Maintain self-efficacy.** During the work, it is highly important to record your achievements, positive and useful experience, any observations and considerations (even philosophic) which seem to be relevant and interesting. Every effort is valuable and useful. Experience of losses and failures (including unexpected) during the pandemic is unfortunately inevitable. But in the extreme conditions, it has specific value and meaning with respect to learning. Share your ideas, unconventional solutions with colleagues and concerned persons, organize periodic remote discussions and mutual analysis, give feedback and transmit your suggestions to health care managers or to the people who are responsible for the solution of some aspects of the problem. The experience of even a small success, a little victory, of every impactful action is priceless and valuable always, not only now.
- **Maintain the balance between excessive compassion and excessive distancing towards patients.** In the time of the pandemic every medical professional faces emotion of patients and their relatives, natural in such conditions – anxiety, fear, aggression, he will face strong emotional reactions, like grief, death possibility. It is important to sustain such reactions, to understand that they are inevitable and normal. You should not depreciate them, but acknowledge, giving patients the possibility to express them even partially. However, if there are no psychologists and psychiatrists to be involved in facilitating the condition of patients and their families, the burn-out risk of medical personnel can rise exponentially. If there are no such specialists in your teams, use hotlines for psychological aid.
- **Neutralize strong emotional reactions of patients and their families.** Many reactions of our patients are connected with misunderstanding and lack of holistic vision of the current events. Briefings for patients, timely informing about condition, chemical analysis results, simple kindness often neutralize even strongly expressed panic, anxious and aggressive reactions. You can face not only gratitude and appreciation expressed by patients but also accusations, indignation towards you, dissatisfaction with your actions, patient protests and their non-compliance (reluctance to follow received recommendations). Try to be neutral to all the possible reactions. Many of them are just a response to the current situation, and moreover are connected with past encounters of patients with medicine, personal characteristics and adaptation specifics to the situation of stress. It is crucial not to intensify emotions, not to contribute to their escalation to confrontation and conflict.
- **Avoid too much responsibility.** Much medical personnel can face situations where they are forced to take very high responsibility. Remember, it is extremely dangerous to identify oneself with exaggerated, excessive or unrealistic society expectations. Try to keep to realistic tasks and act within the boundaries of your medical competences.
- **Handle moral dilemmas.** The pandemic situation often creates situations of stark choice for health-care personnel, as well as various ethical dilemmas. Be prepared that you and your colleagues will be forced to make difficult decisions and allocate your resources. Share the decision making with your colleagues and management, discuss situations with subordinates, with scientists. If there is an opportunity, try organizing the exchange of views

and discussion on double-edged topics in advance. The best way to solve such situations is the ability to rely on the joint protocols and procedures for crises approved in proper time.

- **Rely on collective interaction.** In the current struggle, you can play different roles. You can serve in a combat zone or on the home front; you can further focus on your patient group (for example on oncological, palliative, surgical), you can also become commander in chief. Anyway, you should remember that you are making an important contribution to the fight against the pandemic, whether hours-long work, data and literature analysis, strategy planning or something else. The results of the struggle will be determined by the coherence of teamwork and by collective interaction. Be supportive of each other, encourage each other, compliment and admire each other, even if distantly, even in little things. Try to involve specialists of varied employment, non-profit-making organizations, volunteers, psychologists to take part in facilitation and support as well as in work process organization.

The article writers express support and gratitude to all medical professionals!

Helping the Helpers in Pandemic Situation

By Margarita Nikushina

«Light in the Hands» Charity Foundation (<https://lightinhands.ru/>)

Margarita Nikushina - clinical psychologist, head of the Department for Interaction with Government Institutions, «Light in the Hands» Charity Foundation. Address: 13, Leningradskoe sh., bldg. 1, office 255, Moscow, Russia, 125171. E-mail: help@lightinhands.ru

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Today we withstand a unique experience. We suddenly faced severe changes in the whole way of life and hard challenges. However, healthcare professionals are those who suffer from the most difficult, sometimes exhausting conditions. Working overtime, a constant flow of information and demands, health threats, general anxiety – all this aggravates the stress for medical workers and forces them to act literally on the verge of human capabilities.

Working in a Person-to-Person system always implies close human contact. For a specialist, this is often energy-consuming, strenuous work that requires high communication skills and self-regulation. Sometimes this very contact is the key to success.

For a physician working with special, "difficult" kinds of patients, the ability to establish this contact and to maintain it is especially important. It becomes possible only if the specialist himself has enough resources - strength, energy, confidence, self-control. In a state of inner balance and peace, it is easier to create effective communication, resolve conflicts, to find solutions beneficial for everyone.

The specialists' ecology may include the daily routine, the schedule of work and rest, the organization of work, as well as the possibility of emotional discharge. Such discharge, "ventilation", is obligatory for helping practitioners in many countries. The specialist needs relief from negative emotions, anxieties and experiences that inevitably arise in constant and close communication with people.

It is important not to keep tension, transferring it daily, passing it on to colleagues or exposing your dear persons to emotional breakdowns. Emotional tension can be relieved correctly, ecologically in a safe environment, with a psychologist or in a support group. Such groups, called "Balint" emerged and became popular with physicians in Europe in the mid-20th century and have become a usual practice in the professional life of many physicians. Researches prove the validity and efficacy of these practices.

Also, helping practitioners need to refill the resource. It is like refuelling a fire truck – with no fuel, it will not move, and the help will not be provided. A healthy diet, positive emotions, sufficient sleep, support from colleagues, a favourite hobby – these are just some of the easiest ways to fill yourself with a precious resource.

A doctor who meets daily the patients' troubles, grieves, pain, anxiety, sufferings, should monitor her or his condition. That means to follow the rules of labour ecology, to fill themselves with resources timely and to relieve stress. Thus it will be easier for them to stay stable even in the most challenging situations. A specialist in this state is ready to resolve conflicts, to establish friendly communication and stable contacts with people at work and in everyday life, and to calm patients in their worries.

In an unusually tense recent situation, when the medicine is working on the edge of its capabilities, the Charity Fund "Light in the Hands" is enhancing its activity of support for medical specialists (physicians, practitioners, nurses). The Foundation's clinical psychologists conduct regular support groups and individual consultations online for all medical professionals. The number of requests from a specialist is not limited.

“I know my life will not be saved in this pandemic”

BBC Article

Lucy Watts MBE is 26 years old and preparing to die if she contracts coronavirus.

Curriculum Vitae:

Lucy Watts is a young woman, who was diagnosed with Ehlers-Danlos syndrome at 14 years old. She lives in Essex, UK, with her mother, her sister, and Molly - assistant dog and needs 24-hour care. Her mom took care of Lucy until the age of 17, but after developing a brain tumour and a stroke, the staff at The J's Hospice helped her with the care. Lucy is widely known in the community for her campaign to improve the transfer of young people from children to adult palliative care, a tireless advocate for children with palliative needs, a participant in many local and national commissions, she has authority in such sensitive issues as young people with life-limiting diseases and sexuality. In 2017, Lucy has founded an international network of palliative care patients and caregivers - Palliative Care Voices.

The original article is available at <https://www.bbc.com/news/disability-52149219>