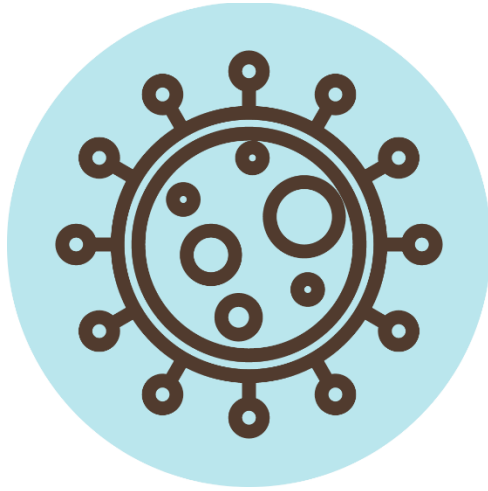


COVID-19: Lessons Learned



A Series by:

Real World Health Care
2021

COVID-19 impacted millions of Americans in 2021 in ways great and small, creating a dark cloud that many people are still living under.

COVID-19: Lessons Learned is a recently published series of articles that spotlights the organizations and efforts dedicated to helping those struggling with the health, financial and mental well-being implications of this world-changing pandemic. Please accept this complimentary copy as our way of thanking you for your commitment to helping patient communities and advocating for healthier futures.



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Just the Facts: Four COVID-19 Resources You Can Trust

Finding information about the COVID-19 pandemic hasn't exactly been difficult over the past 12 months. Just about every organization in the country – from government agencies and media outlets to companies, schools and community groups – has issued at least one COVID-related pronouncement. However, the wealth of information at our fingertips can be confusing. What information can you trust, and what can you do when faced with seemingly contradictory “facts” from different sources?

Here at *Real World Health Care*, we turn to trusted resources when we need information on COVID-19 and other diseases and medical conditions. These resources base their publicly facing information on sound, evidence-based science and continually update their web sites and materials to provide the latest statistics and guidance.

While the following list is not an exhaustive one, these four government agencies are among the most reliable sources of COVID-19 information and should be among your go-to resources when you need information on the pandemic. **For information on when you may expect to be eligible for a COVID-19 vaccine, the best source of information will be your state or county department of health.**

1. Centers for Disease Control and Prevention

CDC is one of the major operating components of the Department of Health and Human Services. It works 24/7 to protect America from health, safety and security threats, whether they start at home or abroad, are chronic or acute, curable or preventable, human error or deliberate attack. CDC conducts critical science, provides health information that protects the nation against expensive and dangerous health threats, and responds when threats arise.

Visit the CDC web site to learn about COVID-19, what CDC is doing to protect and prepare communities, the benefits of getting a COVID-19 vaccine, and information about symptoms, testing, quarantining and mask wearing.

2. Centers for Medicare and Medicaid Services

CMS is also part of the Department of Health and Human Services. With oversight of the federal Medicare and Medicaid programs, CMS has transformed the nation's health care system for more than five decades. It empowers patients to work with their doctors and make health care decisions that are best for them. To help people be active health care consumers, CMS provides meaningful information about

quality and costs and supports innovative approaches to improving health care quality, accessibility and affordability.

The CMS [Coronavirus Disease 2019](#) web site offers information for patients and providers alike, including [vaccine policies and guidance](#) and [tips for staying healthy](#).

3. National Institutes of Health

[NIH](#) is the nation's medical research agency, making important discoveries that improve health and save lives. The NIH seeks to enhance health, lengthen life and reduce illness and disability. It also works to improve the quality and usefulness of information about science and health for the public.

The [NIH's COVID-19 web site](#) focuses on the organization's [strategic response to the pandemic](#), development of [COVID-19 tests](#), information about [treatments and vaccines](#), details on [clinical trials](#), and the latest [news and research initiatives](#).

4. U.S. Department of Health & Human Services

[HHS](#) works to enhance the health and well-being of all Americans by providing effective health and human services and by fostering sound, sustained advances in the sciences underlying medicine, public health and social services.

HHS offers a number of online [COVID-19 resources](#), including [vaccine updates](#), a searchable index of [COVID-19 testing sites](#) and [updated news](#).

A Message from our Sponsor

At the onset of the pandemic, the HealthWell Foundation implemented programs to provide financial assistance to individuals who were directly affected by COVID-19. Since launching their first COVID-19 fund in March 2020, the Foundation has served as a valuable, potentially lifesaving, resource to underinsured Americans by providing grants for reimbursement assistance for delivered food and medication and transportation costs to manage COVID-19, while maintaining social distancing protocols, including drive-thru testing, delivery of test kits and future treatments.

In addition, HealthWell recognized the critical, unmet, needs of individuals who had been laid off or furloughed as a result of the public health crisis and opened a second COVID-19 fund to provide up to \$6,000 in financial assistance for 3 months following grant approval to eligible households which had annual incomes up to 500 percent of the federal poverty level prior to being laid off or furloughed. To qualify for a grant, the policyholder or covered member of the policy must have a diagnosis of cancer or chronic illness and must be in active treatment where disruption of therapy could cause serious, potentially life-threatening, consequences for the patient.

To learn more about the HealthWell Foundation and how you can support their COVID-19 relief funds, visit: www.HealthWellFoundation.org.

Help is Available for Frontline Health Care Workers Struggling to Manage Their Own Anxiety and Depression Resulting from COVID-19 Patient Care

NOTE FROM THE EDITOR: To help meet the mental health needs of frontline health care workers during the COVID-19 pandemic, our sponsor, the HealthWell Foundation, has launched a new fund to provide copayment assistance for behavioral health treatments. Through the [COVID-19 Frontline Health Care Workers Behavioral Health Fund](#), HealthWell will provide up to \$2,000 in financial assistance for a 12-month grant period to eligible health care workers who have annual household incomes up to 500 percent of the federal poverty level.



Jeffrey Peppercorn, MD, MPH

In mid-March, Jeffrey Peppercorn, MD, MPH, found his professional life flipped upside down. As the COVID-19 pandemic quickly filled Massachusetts General Hospital with patients, he became one of the first medical oncologists on staff to serve on the new COVID-19 pandemic unit, managing patients with the novel coronavirus instead of those with cancer. Soon, other health care professionals at the hospital also found themselves in new roles, facing new challenges and struggling to treat patients with a complicated and poorly understood infectious disease.

"Massachusetts General Hospital was one of the busiest in the country during the initial surge in March 2020," said Dr. Peppercorn, Director, Massachusetts General Hospital Cancer Center Supportive Care and Survivorship Program and Associated Professor of Medicine, Harvard Medical School. "By April, we had to turn entire floors of the hospital once devoted to cardiology, oncology or pediatrics to COVID care units. This meant

changes in workload and practice for everyone involved – not only the nurses and physicians but also food service workers, custodial staff, medical and nursing students, respiratory therapists and many others."

Dr. Peppercorn saw the mental health impacts on his colleagues and co-workers almost immediately. The need to isolate patients – while devastating for the

patients and their families – hit the care teams hard as well, he said. Even with personal protective equipment, they worried about getting sick themselves or bringing the virus home to their families. His own anxiety led to trouble sleeping and increased stress.

“I remember conversations with the nurses about the emotional exhaustion of caring for patients in isolation for weeks and months at a time,” he said. “As frontline care providers, the sheer volume of patients with COVID, disruption to our usual practices, and ongoing concerns for ourselves and our families took a mental toll.”

Support for Frontline Care Providers

Dr. Peppercorn was quick to praise Mass General for the way the hospital supported its staff. In addition to making sure frontline workers were equipped with the right personal protective equipment, the hospital set up a service to allow staff to stay in hotels when needed, helping to reduce their fears of spreading the virus to their family members at home. Other employee services included group resiliency programs, individual counseling and free access to stress reduction apps.

The hospital also shifted its outpatient services to telehealth, allowing clinicians to see patients by video or telephone. The switch, while appropriate and convenient for patients, was highly disruptive for providers and challenging for some older patients.

“Over the last 11 months, we have learned how to spread the burden among medical and nursing staff,” Dr. Peppercorn said. “We clearly have adequate PPE, readily available COVID testing for staff, and increased confidence in our ability to manage the disease based on evidence and experience. However, just as it has been a long year for everyone in the U.S., as health care workers, we still live with the changes and disruptions every day.”

Dr. Peppercorn, who serves as Scientific and Ethics Advisor for HealthWell, remarked that HealthWell’s new [COVID-19 Frontline Health Care Workers Behavioral Health Fund](#) addresses a critical need during the pandemic and well beyond, helping frontline care providers access and afford behavioral health services to manage anxiety and depression resulting from their pandemic roles.

The unique, HealthWell-sponsored fund is available to assist frontline health care workers in covering their out-of-pocket treatment-related copayments for prescription drugs, counseling services, psychotherapy, and transportation needed to manage COVID-19 related behavioral health issues.

“Oftentimes, people suffering from feelings of anxiety, helplessness, failure and fear do not seek necessary treatment and counseling, which can lead to more serious situations, including PTSD, and even thoughts of suicide,” said Susan Gurley,

Executive Director, Anxiety and Depression Association of America. “We applaud the HealthWell Foundation for recognizing the paramount need for frontline health care workers who are going to heroic measures to save the lives of those impacted by COVID-19 by providing a vital financial resource that will enable them to obtain critical behavioral health services.”

Dr. Peppercorn echoed Gurley’s sentiments: “Health care workers are not always good about seeking care for ourselves,” he said. “There is a tendency to work long hours and be ‘strong,’ which doesn’t always lend itself to knowing when to ask for help.”

Longer-Term Mental Health Impacts

Stress, anxiety and burnout can have serious, long-term effects on mental wellbeing that can linger or emerge well after the pandemic has passed. Dr. Peppercorn expressed concern that there will be some degree of underdiagnosed post-traumatic stress disorder from the acute challenges health care workers have experienced last March and April.

“Personally, I’m feeling better about things now than I did last March,” he said. “Now, the problem is less anxiety and more fatigue. Unlike our friends and family, health care professionals aren’t working remotely. We never stopped going to work and haven’t really been able to take a break from thinking about COVID. Most of us are grateful for the job security during these difficult times, but the pandemic has taken its toll on us, both physically and mentally. Financial help accessing mental health care will make it easier for health care workers to take the first steps in seeking care without having to worry about whether it will bring additional financial stress for them and their families.”

To determine eligibility and apply for financial assistance, visit HealthWell’s [COVID-19 Frontline Health Care Workers Behavioral Health Fund page](#). To learn how you can support this or other HealthWell programs, visit [HealthWellFoundation.org](#).

A Pandemic of Uncertainty: Mental Health Challenges in the Era of COVID

For over a year, the world has lived under the dark cloud of the COVID-19 pandemic, a global, population-wide traumatizing event that has impacted people in a variety of ways – physically, financially and emotionally.



Maddy Reinert

According to Maddy Reinert, Senior Director of Population Health, Mental Health America (MHA), the pandemic has had “disastrous” effects on mental health and has led to a mental health crisis that will extend long after everyone is vaccinated and the virus is no longer a threat.

She pointed to several COVID-related factors contributing to stress, anxiety, depression and other mental health conditions: “Fear of contracting the

disease or a loved one contracting the disease is very real, as are uncertainties around how to keep ourselves and our loved ones safe,” she said. “Add to that the fact that our entire physical and social environment, and the ‘normal’ ways in which we interact with that environment, have changed. Those changes come with grief for what our world once was.”



Dr. Debra Kissen

According to Reinert, people are experiencing anxiety and uncertainty about immediate concerns like losing their jobs, homes, and ability to access food and medical care. They also may feel a sense of shame if they contract the virus, especially if they have been following public health guidance. These issues are compounded when normal avenues for assistance are more difficult to find due to stay-at-home orders and shutdowns.

“Uncertainty has come in waves,” added Debra Kissen, PhD, MHSA, CEO of Light on Anxiety CBT Treatment Centers and co-chair of the Public Education committee of the Anxiety and Depression Association of America. “It started with questions like how long will the pandemic go on? How am I going to work from home? Is my

children's education going to suffer? Then it moved to questions like Should I get tested? Is it ok for me to get a vaccine before someone else who may be more deserving?"

Screening for Mental Health Distress

At MHA, Reinert is responsible for collecting, analyzing and interpreting data from the organization's free, confidential and clinically validated mental health screening tools. She shared results of MHA's screening data for the period of April-December 2020, noting that loneliness was the most-often reported contributing factor to mental distress during that time – even more than the virus itself.

"Humans are social animals who make connections with others," Reinert said. "Now that school, work and other gatherings have gone virtual or have been cancelled, we can no longer be in close proximity with others, which can make us feel like we're lacking those connections."

Just over 70 percent of those who screened at risk for moderate to severe anxiety or depression said they experienced loneliness, a figure that jumped to 78 percent among children ages 11-17. Children 11-17 also screened at higher rates for moderate to severe symptoms of depression and anxiety in general, and more frequent suicidal ideation, than other age groups.

"We typically think of children as being resilient, but they are showing more negative effects than other age groups," she said. "Most teens and children have not experienced this level of consistent trauma and they may not have the perspective and foresight that adults do in terms of knowing that things **will** get better eventually."

Health Care Workers Face Significant Mental Health Burden

According to Reinert, health care workers also are particularly vulnerable to mental health issues arising from the pandemic. "They are exposed to the virus every day, their workloads have drastically increased, and they're not getting a break," she said. "There's a tremendous amount of emotional exhaustion associated with witnessing daily suffering among patients and their families."

MHA used its online mental health screening site to survey more than a thousand health care workers over a four-month period last year and found:

- 93 percent reported experiencing stress.
- 86 percent reported experiencing anxiety.
- 77 percent reported experiencing frustration.

- 76 percent reported experiencing exhaustion and burnout.
- 70 percent reported trouble sleeping.
- 63 percent reported experiencing work-related dread.

“Of particular concern, the survey found that 39 percent of health care workers and 45 percent of nurses felt they weren’t receiving adequate social support,” Reinert said. “We must remember, even when the pandemic goes away, the mental health impacts of what health care workers have experienced will remain for quite a while.”

Validating and Addressing Mental Health Concerns

Reinert stressed the importance of addressing mental health concerns before they rise to the level of crisis or become a chronic condition. Immediate support for a mental health crisis is available from the [National Suicide Prevention Lifeline](#), a 24/7, free and confidential support program, by calling 1-800-273-8255. Immediate support also is available from [Crisis Text Line](#), by texting MHA to 741741 to be connected to a trained Crisis Counselor 24/7.

“It is crucial for people and their loved ones to validate feelings of stress, anxiety and depression,” Reinert said. “These are all normal reactions. Let yourself feel what you’re feeling and treat yourself with compassion. Don’t be afraid to ask for help or to talk to the people in your life about what you’re feeling. You may be surprised to learn they share your feelings.”

If a friend or loved one seems to be showing symptoms of mental distress, Dr. Kissen said it is important to be available for them in a non-judgmental manner.

“It’s natural for people to want to solve a loved one’s problem, but that often can have the opposite effect,” she said. “Instead of saying ‘you don’t seem well, and I think you need therapy,’ just listen to and validate what they’re saying, and try to relate in a genuine way.”

Validating feelings of stress or anxiety is especially important for those who had a pre-existing mental health condition, because worsening stress can exacerbate existing symptoms. Moreover, pandemic restrictions and a lack of daily structure can make it difficult for people to maintain coping strategies like exercising, visiting with loved ones and maintaining treatment regimens.

“In some ways, people with existing mental health conditions are doing quite well, because they already understand what it’s like to be afraid and to push themselves forward when they’re struggling,” said Dr. Kissen. “It’s like they’ve been training for this marathon we know as the COVID pandemic and have already learned the lessons and coping skills they need to exhibit.”

According to MHA's Reinert, the increased acceptance and use of tele-mental health services has helped improve access to mental health treatment at a time when in-person therapies were placed on hold – a trend she hopes will continue after the pandemic ends.

"The good news is that more people are striving to get mental health services," said Dr. Kissen. "The not-so-good news is that some mental health services providers have struggled to meet the increased demand. That's one of the reasons our practice has continued to offer in-person appointments, using proper social distancing inside and even moving outside to walk and talk. For some clients, getting out of their home and interacting with another human being is beneficial. The important thing as a therapist is to be as accessible and creative as possible to meet our clients' needs."

Mental Health Resources

MHA and ADAA offer COVID-specific online resources for those seeking mental health information.

ADAA's [Coronavirus Corner](#) includes helpful tips and resources to manage anxiety. A series of free videos covers COVID-related topics as diverse as [managing COVID fatigue](#), [racial inequities](#), and how to cope with worries and [fears about finances](#) during the pandemic. The site also provides links to resources on tele-mental health for both therapists and the general public.

"ADAA has done an outstanding job of presenting free, high-quality resources from top mental health experts as well as professional education and training resources for therapists," said Dr. Kissen. "As clinicians, we tend to get down in the trenches with our clients, so it's nice to have ADAA as a professional home of sorts."

MHA's [COVID-19 site](#) provides information from trusted sources on topics such as [wellness and coping skills](#) and [caregiving and parenting](#), as well as targeted information to help vulnerable populations, including those with [existing mental health concerns](#), [frontline workers](#) and [Black, indigenous, and persons of color \(BIPOC\) and LGBTQ communities](#). It also provides access to a variety of [mental health screening tools](#) that give people a quick snapshot of their mental health, after which they are immediately directed to information, resources and tools to help them understand and improve their mental health.

"These screening tools are useful for early identification and intervention," Reinert said. "We're also using the de-identified data we collect to further our population health initiatives and advocate for more mental health resources on a federal level as well as support and inform services for our national network of 200 local affiliates. It has become the largest data set of mental health help-seeking individuals and the only real-time data set to monitor mental health throughout the U.S. during the pandemic."

Reinert concluded with a message of hope: “The COVID-19 pandemic will not last forever. It’s OK to be in mourning for your old life and the people and things that have been lost. But try to keep looking forward. Don’t give up on new possibilities. Even if life can’t be the **same** again, it can be **good** again.”

A Message from our Sponsor

To help meet the mental health needs of frontline health care workers during the COVID-19 pandemic, the HealthWell Foundation has launched a new fund to provide copayment assistance for behavioral health treatments. Through the [COVID-19 Frontline Health Care Workers Behavioral Health Fund](#), HealthWell will provide up to \$2,000 in financial assistance for a 12-month grant period to eligible health care workers who have annual household incomes up to 500 percent of the federal poverty level.

Peer Support Workers Provide Critical Behavioral Health Services During COVID-19 Pandemic

In the field of behavioral health, peer support workers – people who have faced similar stresses, trauma and mental health challenges to those they serve – have played a crucial role providing non-clinical, “experientially credentialed” support. That role has not abated during the COVID-19 pandemic, according to a recent [editorial](#) in the journal *Translational Behavioral Medicine*.

In fact, the editorial suggests that the role of peer support has increased and become more complicated amid the pressing demands for food, housing, safety and economic assistance that have grown during the pandemic.

Real World Health Care spoke with one of the editorial’s authors, [Suzanne M. Miller, PhD](#), Director of Patient Empowerment and Decision Making Department, [Fox Chase Cancer Center](#). Dr. Miller also serves as editor-in-chief of [Translational Behavioral Medicine](#) and as board member of the [HealthWell Foundation](#), sponsor of *Real World Health Care*. Dr. Miller was instrumental in helping the HealthWell Foundation design and launch a new fund that provides [grants to frontline health care workers](#) to help them afford behavioral health treatments.

We asked Dr. Miller to address how stress and trauma have affected peer support workers over the past year and why peer support is particularly important for frontline health care workers.

Common Themes among Peer Support Groups

Real World Health Care: Your editorial in *TBM* focused specifically on peer support workers in parenting children with special needs, child protective services, and police. What sort of themes emerged among these groups that may also apply to health care workers?

Suzanne Miller: We have been studying peer support workers who were serving parents of children with special needs, child protective services workers, and police. We found three themes of services needed by these groups: (1) stressors directly related to the virus, (2) preexisting stressors that were exacerbated by the virus, and (3) styles of coping used to deal with these stressors.



Suzanne Miller, PhD

First, stressors that police and child protection workers experienced directly related to the virus included known risks (e.g., face-to-face contact, inadequate PPE) and unknown risks (e.g., being “left in the dark” about exposures), changes to work schedules and arrangements, and a heightened complexity of work which peer support workers attributed to the additional financial and emotional stress facing the people they were serving.

Peer support workers and their clients are by no means the only ones dealing with these stressors. Health care workers are at high risk of exposure. Risk is especially high when proper PPE is not

provided. Moreover, many health care systems have experienced an intensity of workload and a demand for staffing that have contributed to stress and burnout at the provider level, as well as the personal impact of being the lifeline to the patient.

Second, not only peer support workers, but also health care workers, need to deal with preexisting stressors among patients. These stressors include demands around childcare and education, housing and food insecurity, and health-related concerns. These demands have been exacerbated by the financial challenges that have been associated with the pandemic, along with the lack of available support services. Ironically, health care workers themselves face these very psychosocial/social determinant challenges, all the while trying to care for clients and patients who themselves are trapped in a downward health care spiral of stress and lack of access to services.

Third, in terms of coping, our research has shown that many people try not to think about health stressors or to “keep their minds busy.” We call these people “blunters” in behavioral science because they psychologically “tune down” incoming messages about health threats. Others, “monitors,” focus on and magnify incoming health threat messages. Peer support workers find that just “being there” and providing “space to talk” provides relief and support to the people they serve.

Although peer support workers are aware that they do not have the resources to solve many of the problems their clients face, simply providing space and empathy, especially for monitors, is a valued service which can help clients process the fact that being less productive or involved is the new normal. This message can also motivate individuals to get back to addressing their families’ most important priorities. This sort of psychological “space” (characterized by empathy and support) is directly relevant to health care workers as they increasingly deal with COVID-related challenges in discussions with their colleagues, clients, and supervisors. This approach enables providers to more effectively respond to the needs of patients and staff, and it helps them to maintain their own ability to carry out their essential work.

Psychological Impacts Intensifying

RWHC: Your editorial was published in the early days of the pandemic. Almost a year later, how are stress and trauma continuing to impact peer support workers?

SM: We are a year from the early days of the pandemic and yet the psychological impact has, if anything, become intensified. Psychological science has shown us that, over time, the toll of undergoing sustained psychological stress can and does grow in intensity and negative impact. For example, people become less committed to adhering to behaviors for their own and the social good (like distancing and masking) due to psychological and emotional fatigue. Our social nature as humans often pulls us to come together during times of distress, which is positive but also poses a challenge to protective health behaviors. Even individuals who were most vigilant in the beginning may be slipping into more leniency or complacency, despite new cases being higher now than the initial peak last April. We need to empower patients to connect and derive the therapeutic support of being together, while at the same time practicing the behavioral distancing that will protect them from potentially serious infections.

Among the good news, a new tool has emerged on the scene: the vaccine, which has been touted as the ultimate saving grace. Yet, the vaccine rollout in the U.S. has been disorganized and the stress of being one's own navigator trying to get a vaccine can be exhausting. People are registering on multiple counties' lists trying to get access, even though they're within the eligibility criteria. That's likely because the infrastructure for disseminating vaccines and the health communication about it has, until now, been generally conflicting, confusing, and disorganized. Even when people get past those hurdles and get vaccinated, the news is full of stories about new variants of the virus that the vaccine may or may not protect against. In addition, it is still not clear whether vaccinated individuals can be vectors of spread of infection, though asymptomatic themselves. These are some of the many conflicts that people have been living with and it is unclear whether and how they will change over time.

So the nature of stress and trauma remains significant and people continue to live with a chronic stressor with no clear end in sight. Further, the burden of having to maintain long-term preventive behaviors (like distancing and masking despite the magic vaccine bullet) takes its toll on every aspect of life, including the economy, personal identity, social connectedness, parenting, and the list goes on. "Monitors" are increasingly sensitized to it, are afraid to move about, and are somewhat paralyzed by how to proceed. "Blunters" are increasingly engaged in distraction and denial, often with feelings of invulnerability, and are less and less likely to adhere to public health directives. These diametrically opposed coping strategies can add to the complexity of the situation as each group deals with their own confusion, anger, and other barriers to healthful responses.

Mind-Body Connection

RWHC: How do stress, trauma and fear impact one's physical well-being and ability to resist and/or recover from COVID-19?

SM: When people are depressed and anxious, it has a significant impact on their physical well-being. Decades of robust evidence on the relationship between the mind and the body show that stress is capable of impairing one's immune system, disease vulnerability and recovery, sleep patterns, and other physiologic functions. This physiological pattern can also lead to a lack of energy that can behaviorally paralyze patients from participating in essential protective behaviors, such as exercise, activity, nutrition, social connection, and recommended screening, diagnostic, and treatment regimens. All of these factors combined are vital to maintaining immune function, psychological well-being, and health. This biobehavioral process can set up a perpetuating spiral of increased stress and decreased health behaviors, which can intensify stress and disease vulnerability. These complex biobehavioral factors can leave individuals at increased vulnerability to a myriad of diseases, such as cancer and cardiovascular disease.

RWHC: How do stress, trauma and fear impact one's mental well-being in the longer-term?

SM: Stress, trauma, and fear are toxic for long-term mental well-being because they set the stage for hopelessness, pessimism, and self-destructive behaviors, including drug use, alcohol, and smoking, as a way of self-treating the stress. This means there is an increasing burden on the health care system, not just directly from COVID, but from the psychosocial aftereffects of COVID. Yet, the very people who need behavioral health services (e.g., first responders, frontline health care workers, the underserved) are now less likely to have access to them, as these services are overwhelmed and put on the backburner.

Resources for Health Care Workers

RWHC: How is your institution providing or enabling peer support among its employees?

SM: Fox Chase is often dubbed a "family" institution by its employees which is an indication of the supportive culture, the work-life balance, and the care of patients as if they are family. This provides a rich foundation on which peer support can flourish. Throughout the pandemic, Fox Chase/Temple Health has provided special gifts to staff, addressed frequently asked questions about the vaccine, and offered multiple types of virtual support sessions through Carebridge, the employee assistance program. Notably, Fox Chase Cancer Center/Temple University Health System (FCCC/TUHS) is the first health system in the country to partner with Ginger, a 24/7 therapy and psychiatric service app that is available for all medical

plan participants. Further, Fox Chase has shifted relevant services to the telehealth platform which allows health care workers to communicate with patients by phone, video, and other remote channels, thereby lessening unnecessary exposure.

In addition, FCCC/TUHS has been highly communicative about the protective policies, the procurement and availability of PPE, and the rollout of vaccination (which is now vaccinating patients and, soon, the community), which are critical for COVID management. These protocols build a sense of trust which bolsters the feelings of support and security in what is an otherwise chaotic time.

RWHC: How can other health care workers access peer support services?

SM: For the Frontlines provides free text-based crisis counseling 24/7 to all those on the frontline (text FRONTLINE to 741741 for those in the U.S.). The American Academy of Experts in Traumatic Stress (AAETS) offers online support groups for emergency responders and health care workers. There are other resources, specific to health care workers, like The Emotional PPE Project, the Physician Support Line (1-888-409-0141), and NurseGroups. All of these are free of charge.

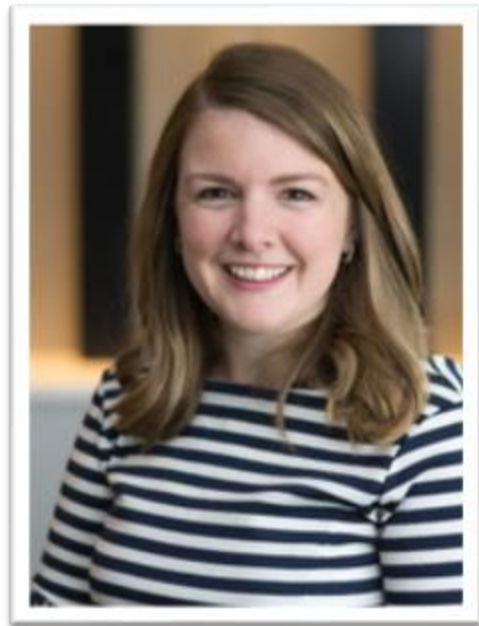
To help meet the mental health needs of frontline health care workers during the COVID-19 pandemic, the HealthWell Foundation has launched a new fund to provide copayment assistance for behavioral health treatments. Through the COVID-19 Frontline Health Care Workers Behavioral Health Fund, HealthWell will provide up to \$2,000 in financial assistance for a 12-month grant period to eligible health care workers who have annual household incomes up to 500 percent of the federal poverty level.

In addition, as FCCC/Temple Health has done, employers can provide support sessions that validate the challenges and stressors facing employees. Providing the psychosocial “space” to express and discuss is a benefit on its own, as we have seen with peer support workers. Further, demonstrating acts of gratitude can go a long way with employees, especially ones who have been on the frontline. Other resources, such as employee assistance programs or counseling services that are tied into medical plan offerings, can be critical sources of support. Social media has also been shown to help mitigate the psychosocial effects of COVID for frontline workers, health care providers, and patients.

If a health care worker wants to start their own peer support group, a good place to start is by bringing one’s stress and uncertainty to a supervisor so that potential institutional or departmental support can be activated. There may well be counseling professionals within the organization whose duties could be arranged to cover support sessions and other outreach activities. Standing departmental or team meetings could also be an opportunity for this sort of programming. In addition, self-organized virtual or socially distanced meetings, like an outdoor/masked walking group, could build camaraderie.

COVID-Driven Isolation Can Be Dangerous for Older Adults

Stay-at-home and social distancing mandates during the COVID-19 pandemic have forced nearly everyone to become more socially isolated than ever before. However, the effects of social isolation among older adults may be more pronounced and have more dire consequences than among people of other ages.



Kathleen Zuke

"Placing the COVID pandemic aside for a moment, societal trends have led us to the point where older adults are more likely to be isolated or lonely," said Kathleen Zuke, MPH, senior program manager, [Center for Healthy Aging, National Council on Aging \(NCOA\)](#). "They are no longer in the workforce, are more likely to live alone, and have fewer social connections over time. In addition, their extended families may be more geographically dispersed than in past generations, making it difficult to maintain in-person familial contact."

The pandemic, said Zuke, has exacerbated social isolation and loneliness, as well as other issues that older adults commonly face, including economic insecurity, difficulty accessing health care services, and racial inequities.

Zuke cautioned that the effects of social isolation vary from individual to individual and noted that social isolation doesn't always lead to loneliness. She said some older individuals without many social or community connections feel content, while others with many connections and lots of family support may feel a profound sense of loneliness.

Effects on Physical and Mental Health

While social relationships are widely considered crucial to emotional well-being, Zuke said social isolation and loneliness can also have a negative impact on physical health. She pointed to a 2018 study on [potential health risk factors of social isolation and loneliness](#), in which the author concluded that being socially connected significantly reduces risk for premature mortality, while being socially unconnected significantly increases risk. Moreover, these social isolation factors

have a larger impact on mortality than factors that currently receive substantial public health attention such as obesity, physical inactivity and air pollution.

The study presented evidence that social isolation increases risk for depression, cognitive decline, and dementia, and directly influences medication/treatment adherence, blood pressure, immune functioning and inflammation, as well as the ability to conduct activities of daily living (ADL).

The effects of COVID isolation may be particularly acute among older adults in long-term care (LTC) facilities, as outlined in an [AARP report](#) that suggests feelings of loneliness, abandonment, despair and fear among residents – and their toll on physical and neurological health – are pushing the pandemic's death toll higher.

"Before the pandemic, individuals in LTC facilities could benefit from the social connections and mental stimulation provided by visiting friends and family," Zuke said. "Now, while staff members can try to provide interactions, they also have other tasks they need to focus on, making it impossible for them to be the sole source of interaction. Fortunately, restrictions are easing up somewhat."

Zuke urged older adults and their families to stay connected as much as possible while waiting for restrictions to be lifted. She suggested setting a regular time on a weekly basis – make it a new habit – to connect with loved ones via phone, email or video chat.

Community Organizations Struggled to Meet Needs

Before the pandemic, many older adults turned to community organizations and senior centers for social connections, meals, transportation and other services. Once the pandemic struck, those organizations had to pivot from in-person to online services. Some of them have struggled, according to Zuke, who added that the NCOA has worked hard throughout the pandemic to support community organizations and share best practices among them.

The NCOA [surveyed](#) senior-focused community organizations three times throughout 2020 (April, July and October) to understand the pandemic's impact. The most recent survey (October) found that several months in, the pandemic was continuing to impact organizations' resources, with just under half losing funding and having to reduce staff. About a third of organizations were making plans to reopen following local health guidelines, while many continued to expand their virtual, phone and home delivery services including meals, caregiver support and benefits counseling.

"One of the biggest takeaways was the switch from providing in-person meals to home-delivered meals," said Zuke. "That switch created volume and process problems, especially in the beginning, as organizations scrambled for logistical support and faced staffing issues among their largely older volunteer base."

Technology access and skills also have impacted community organizations supporting older adults, from the perspectives of both organization staff/volunteers and clients. The NCOA's July survey found that only 38 percent of older adults feel comfortable using the internet and just under half have broadband access.

"Community organizations are being placed in new roles as technology educators," Zuke said. "They've also had to get themselves acquainted with running their organizations and providing services via Zoom. Some are more tech-savvy than others, which gives them a leg up on adopting new services and getting their clients onboard."

Resources for Older Adults

Regardless of their struggles, community organizations remain one of the best sources of help for older adults, according to Zuke. In many cases, they are bolstering the resources of health care providers by providing health education and helping older adults self-manage chronic health conditions.

NCOA offers a wide range of [online COVID-19 resources](#) for older adults and caregivers, including information [en Español](#). A special web page outlines what older adults need to know about [COVID-19 vaccines](#), including important tips from the federal government about vaccine-related scams.

NCOA also will offer a free, full-day [Older Adult Mental Health Awareness Day Symposium](#) on May 6. The event, which will include discussion of the impacts of social isolation and loneliness during the pandemic, is geared to public health practitioners, professionals in the aging network, mental health providers, health care professionals and anyone interested in the mental health of older adults.

"NCOA's mission is to ensure that older adults live with dignity, purpose and security," Zuke concluded. "Those goals are more challenging now, but we are re-doubling our focus on those who are struggling and supporting them in their local communities to make sure their needs are being met."

Stress on Family Caregivers Soars During COVID-19 Pandemic

Serving as a family caregiver for a loved one can be stressful under the best of circumstances. However, throughout the COVID-19 pandemic, the nation's estimated 53 million family caregivers have faced additional challenges and taken on new responsibilities that may be pushing some to the brink.

An October 2020 report issued by the Rosalynn Carter Institute for Caregiving (RCI) found that 83 percent of caregivers they surveyed said they are under increased stress related to caregiving since the start of the pandemic. Moreover, many of these caregivers haven't been receiving the support they were accustomed to before the pandemic; 42 percent said the number of other caregivers available to help them has declined during the pandemic.

RCI stated, "with increased health and safety COVID restrictions being imposed on an already overburdened medical and home care workforce, unpaid home and family caregivers are being increasingly relied upon to provide complex care in the home – often without any training, respite or ongoing support."

Effects of COVID-19 on Family Caregivers

A community survey from the University of Pittsburgh looked at specific effects of the pandemic on families and family caregivers. Among their findings:

- 43 percent of caregivers reported their mental health was worse than before the pandemic.
- 27 percent of caregivers said their physical health was worse than before the pandemic, compared to 18 percent of non-caregivers.
- 43 percent of caregivers said their finances are now worse than before the pandemic.
- 29 percent of caregivers said that since the pandemic started, they are now more worried about having enough food and being able to pay for food.
- 31 percent of caregivers said their ability to access health care was worse than before the pandemic.

"Decades of research on family caregiving has shown that long-term and complex caregiving tasks often result in chronic stress for family caregivers, which can lead to negative health outcomes for both the caregiver and care recipient," stated the University of Pittsburgh researchers. "The COVID-19 pandemic has the potential to add to the complexity of caregiving given stay-at-home requirements, reduced

access to health care services, and the vulnerability of individuals at higher risk for severe side effects.”

Looking at the issue of caregiver finances in more detail, a [September 2020 study](#) conducted by Embracing Carers found that 54 percent of caregivers are experiencing worsened financial health as a result of the pandemic, with 37 percent indicating that more of their money is going toward supplies and resources they need to provide care.

Caregivers Need a Strong Foundation

C. Grace Whiting, J.D., is president and CEO of the [National Alliance for Caregiving](#), a non-profit dedicated to improving the quality of life for family caregivers and those in their care through research, innovation and advocacy. She offered guidance for caregivers who are new to the role.



C. Grace Whiting

“The first challenge is a foundational one – getting yourself grounded and identifying what you need to do,” Whiting said. “Learn about the disease or condition and what you may be called upon to do to help your friend or family member. What sort of assistance will they need with activities of daily living like dressing, bathing and feeding? Will they have mobility issues? Will they need help managing their finances or shopping? What sort of medical nursing tasks might you be required to handle?”

She encouraged caregivers to talk with their care recipients to understand their caregiving goals and wishes and to work together to map out a plan for what the

caregiver can handle themselves and where they need outside help.

Adapting to COVID Challenges

The COVID-19 pandemic has caused some existing caregiving issues to erupt. Whiting pointed to telehealth and technology in general as one of the COVID-19 pressure points facing caregivers.

“Stay at home and social distancing mandates have shifted the navigation and delivery of health care from in-person to online,” she said. “Caregivers need to make sure they have the internet access and tech savviness needed to access

online patient portals as well as the authorization to log in and act on someone's behalf."

Another pressure point exists when a care recipient is in the hospital or a long-term care facility, said Whiting: "Under COVID restrictions, caregivers typically aren't permitted to visit someone, making it difficult to participate in decision-making as part of the care team and get in-person guidance on managing care after discharge," she said.

Caregivers also must pay special attention to COVID-related hygiene, especially if they frequently go in and out of their care recipient's home or if their care recipient is immunocompromised. That means following CDC guidance on mask wearing, hand hygiene and social distancing at all times, as well as being cognizant of how vaccines work.

"Access to vaccines varies from state to state and county to county, and there's a good chance the caregiver may not be eligible until long after their care recipient has been vaccinated," said Whiting. "Even if both parties have received the vaccine, they shouldn't use it as an excuse to go out and about until we reach a critical mass of vaccinated people."

Additional COVID-related challenges adding to caregiver stress include closure of childcare supports; potential job loss, long-term career and income security damage; and restricted access to medicine, equipment and care providers.

Support for Caregivers

The Embracing Carers study found that caregivers are spending over 7 hours a week more on caregiving activities during the COVID pandemic than they were before the pandemic started. Whiting encouraged caregivers to seek support when they are overwhelmed, but admitted that in many cases, support infrastructure may be lacking due to COVID-imposed restrictions.

"Start by asking your care recipient's medical care team if they provide training, respite or support services for caregivers," she said. "Then, seek out community-based services through senior centers, area agencies on aging, and faith communities. If you are working while caregiving, you may be able to receive help with elder care through your employee assistance programs as well as self-care and wellness programs through your health insurance provider."

To help support caregivers, NAC has been working with health care researchers, innovators and grassroots advocates in community and global town hall sessions designed to gather insights on issues impacting various segments of the caregiving population, particularly people of color.

“Some of the themes we have uncovered are not just specific to the United States,” said Whiting. “Health disparities facing communities of color, women bearing a disproportionate amount of care responsibilities and the overwhelming need for respite were common globally.”

NAC also is working with the [Adira Foundation](#) to launch an online community called Take Care Community, which will give people an opportunity to reflect on the challenges they’re facing and find resources matched to those challenges. The program is scheduled to launch soon.

In addition, NAC offers a range of online, [caregiving-specific COVID-19 resources](#) for families.

“Caregiving can be incredibly difficult, but also incredibly rewarding,” Whiting concluded. “I encourage everyone to play a role in helping to support caregivers. People may think of caregivers as a shoulder to cry on when often, they too need a shoulder to cry on.”

Lessons Learned: Cancer Care during COVID

Last March, as the COVID-19 pandemic started its relentless progression across the United States, hospitals and clinics nationwide closed their doors to all but the most gravely ill patients. While certain elective procedures and well visits were paused temporarily, patients with cancer didn't have the luxury of waiting for things to return to normal. They needed unfettered access to regular scans, testing, and treatment resources at a time when a visit to a provider's office was fraught with uncertainty.



Randall Oyer, MD

"Patients were understandably concerned," said Randall A. Oyer, MD, Medical Director, Oncology Program, Penn Medicine Lancaster General Health and immediate past president of the Association of Community Cancer Centers (ACCC). "Would they be allowed into the cancer clinic? Would the clinic be fully functional? Would their doctor be there or out sick? Patients expect that the logistics of their care will run smoothly and consistently – from where to park to who greets them when they walk in the door. Early on, many of those support functions we take for granted were upended."

According to Dr. Oyer, patients weren't the only ones with concerns. Doctors, nurses and other provider staff also faced a great deal of uncertainty as processes and procedures changed – sometimes several times a week as new information became available. While COVID-related directives around social distancing, masking, and hygiene and sanitation may seem like second nature now, in the first few weeks of the pandemic, he said many staff were unsure what they needed to do.

For example, staff members were surprised to show up for work on a Monday morning in mid-March to find a tent had been erected outside the cancer center to screen patients for COVID.

"We had to quickly adopt new protocols, and then adapt those protocols to constantly changing conditions, including the weather," he said. "We prioritized teamwork and shared a mindset that focused intently on patient and staff safety."

Thanks to a good dose of humanity and humility, we remained agile and learned from both our successes and failures.”

Some Cancer Patients at Greater Risk for COVID Complications

People with cancer are three times more likely to get sick and die from COVID than the general population, according to Dr. Oyer, who added that some cancer patients – including those with hematologic malignancies and lung cancer – are even more likely to get COVID.



Upal Basu Roy, PhD, MPH

“People with lung cancer need periodic imaging scans to check if the cancer is responding to treatment,” said Upal Basu Roy, PhD, MPH, Executive Director, LUNGEvity Research. “They need laboratory tests to check general health, and access to infusions for chemotherapy or immunotherapy. These visits can increase risk for exposure and can be especially stressful for patients during a global pandemic, when health care facilities may feel unsafe.”

In addition, concerns about getting sick from infections are higher when a patient is on chemotherapy, said Dr. Basu Roy, who also pointed to issues around travel to other cities or states to receive treatments or participate in a clinical trial. These concerns were complicated by oft-changing travel and quarantine restrictions.

Equally worrisome, according to Dr. Basu Roy, was the effect on lung cancer screening. “Screening is considered elective, but it is vital for early detection,” he said. “Many individuals at high risk for lung cancer were delaying or postponing their lung cancer screenings.”

Emotional Impacts Take Their Toll

Drs. Oyer and Basu Roy said providers needed to be aware of the mental and emotional impacts of COVID among the cancer community.

“LUNGEvity is well attuned to the educational and psychosocial needs of our community,” said Dr. Basu Roy. “We partnered with thought leaders in the

community to bring the latest information to members who are dealing with stress, anxiety and isolation.”

To help address patients’ mental health and separate coronavirus fact from fiction, LUNGevery created a series of webinars and virtual meet-ups to connect patients with psychologists, art therapists, nutritionists and wellness experts. These efforts were designed to help patients relieve stress and find ways to be active and engaged from the safety of their homes.

As someone on the caregiving frontlines, Dr. Oyer has seen first-hand the emotional tolls of COVID on both patients and providers.

“One of the most difficult conversations our providers and staff have had with patients over the last year is why their loved ones are not allowed to visit them in the hospital or be with them during hours-long infusion sessions,” he said. “Patients benefit from the emotional and physical support of having a loved one nearby. And our staff is in a better position to care for patients when their loved ones provide input and share in decision making. It can be dispiriting to tell a patient that her husband of 50 years needs to wait in the car.”

In addition to the emotional toll of difficult conversations like that, he said cancer clinic staff have also been under tremendous stress managing the new workflow processes and procedures he referenced earlier.

“Cancer care is incredibly complex,” said Dr. Oyer. “On top of their traditional care duties, a good portion of our staff were forced to quickly pivot to COVID screening, standing all day in a tent outdoors, managing waiting lines, and directing patients and their loved ones where they could and couldn’t go. Everything required extra discussions and explanations – and all the while, messages are coming in, prescriptions are piling up, doctors need help, and patients need care.”

To help meet the mental health needs of frontline health care workers during the COVID-19 pandemic, Real World Health Care’s sponsor, the [HealthWell Foundation](#), launched a fund to provide copayment assistance for behavioral health treatments. Through the [COVID-19 Frontline Health Care Workers Behavioral Health Fund](#), HealthWell will provide up to \$2,000 in financial assistance for a 12-month grant period to eligible health care workers who have annual household incomes up to 500 percent of the federal poverty level.

Supporting the Cancer Community

Over the past year-plus, the cancer community has come together to support each other and learn from others’ experiences. For example, the ACCC quickly scheduled teleconferences in which providers from Seattle and New York – two cities hit early and hard by the quickly escalating pandemic – shared their experiences to help other clinics know what to expect.

ACCC also created an ongoing webinar series with insightful discussions about topics such as new social distancing policies, office procedures, personal protective equipment requirements, and the pros and cons of caring for patients remotely through telehealth.

“In the early days of the pandemic, everyone was operating in a data-free zone,” said Dr. Oyer. “Our best course of action was collaborative information sharing and reading the latest literature together. I have never seen the oncology community come together so quickly before.”

LUNGeVity also sprang into action in the early days of the pandemic, publishing “COVID-19 and Lung Cancer” on its website (in English and Spanish) to provide accurate, up-to-date information on the COVID-19 pandemic and how it affects people with lung cancer. As lockdowns became more common across the country, LUNGeVity started focusing on self-care for patients and caregivers, with tips and videos on nutrition, exercise and mental health. They also launched a COVID-19 Vaccine FAQ site to answer the most important questions.

“We also worked with other patient advocacy groups to urge the CDC Advisory Committee on Immunization Practices to prioritize people with lung cancer during the vaccine roll-out,” said Dr. Basu Roy. “That effort led states to include people with cancer as high-risk groups to be vaccinated.”

Later this month (June 25-26), LUNGeVity sponsors its annual COPE Summit, a virtual conference that addresses the special needs of family caregivers. The event is designed to give caregivers the tools they need to better manage and navigate their loved one’s care while learning about self-care and the caregiving community. The Summit is free to attend, but advance registration is required.

“We’ve reimaged all our in-person events as virtual over the past year,” Dr. Basu Roy concluded. “The entire lung cancer community as a whole has learned to be flexible and adaptative in everything, from how we reach the people we need to how care is provided.”

Did People Delay COVID Care Because of Cost?

Lockdown orders during the early phases of the COVID-19 pandemic led to a massive increase in unemployment, leaving millions of workers without employer-sponsored health insurance, according to a [report](#) published earlier this year by the Commonwealth Fund. Those early days of the pandemic also saw about one-third of adults falling behind in paying bills or having problems affording household expenses like food or health insurance coverage, according to the [Kaiser Family Foundation](#).

However, even those who did not lose their insurance may have faced – and continue to face – problems accessing treatments for COVID and other chronic diseases. That’s because out-of-pocket treatment costs are often so high that they essentially create a barrier to appropriate care.

According to one [health insurance expert](#), “inpatient care [for COVID-19 treatments] is expensive, and so is outpatient care.” The expert says this is where patients’ cost-sharing comes into play, noting that for most patients who need COVID treatment in 2021, out-of-pocket costs won’t exceed \$8,500, but that’s “still a huge amount of money and most people don’t have it sitting around.”

When Costs Create a Barrier to Care

“Recent data suggests that four in ten Americans would struggle to come up with \$400 to cover an emergency,” said Krista Zodet, president and CEO, [HealthWell Foundation](#). “When hit with the costs of a chronic or life-altering disease, they may be forced to choose between needed medical treatments and paying their rent, mortgage, or utility bills; buying food; or saving for the future. Some even declare bankruptcy.”

These out-of-pocket costs can have a chilling effect on the public’s willingness to seek care. In a [Gallup poll](#) conducted early in the pandemic (April 2020), 14 percent of U.S. adults reported they would avoid seeking health care for the two most common symptoms of COVID-19 (fever and a dry cough) due to concerns about their ability to pay for it. An [earlier Gallup poll](#) found that just over 13 percent of American adults (about 34 million people) report knowing of at least one friend or family member in the past five years who died after not receiving needed medical treatment because they were unable to pay for it.



Krista Zodet

People of color are especially affected by inconsistent health care due to underinsurance, according to Sherita Golden, MD, MHS, a specialist in endocrinology, diabetes and metabolism, and chief diversity officer at Johns Hopkins Medicine. She notes that being able to afford doctors' visits, medications and equipment to manage chronic disease is essential to lowering the risk of death from COVID-19 and other conditions, adding that people of color have a higher burden of chronic health conditions associated with a poor outcome of COVID-19, including diabetes, heart disease and lung disease.

Affording treatments for chronic illness can also be an ordeal for Medicare patients, who have a median annual income of \$26,000. That's because, unlike private health

insurance, Part D drug plans have no cap on patients' five percent coinsurance costs once they hit \$6,550 in drug spending this year (except for very low-income beneficiaries).

According to the Commonwealth Fund, "the economic recession caused by the pandemic has put current and future Medicare beneficiaries at financial risk. Many still in the workforce have lost jobs and will likely experience difficulty regaining employment."

Extended Availability for Health Plans

For those under 65 who no longer have employer-sponsored health insurance, the federal Health Insurance Marketplace® offers a special enrollment period for the COVID-19 public health emergency, allowing people to enroll in or change Marketplace health insurance plans through August 15, 2021. After that date, those who lost health coverage through their employer or the employer of a family member in the past 60 days or those who expect to lose coverage in the next 60 days, also may qualify for a special enrollment period.

All Marketplace plans cover treatment for pre-existing medical conditions and can't terminate coverage due to a change in health status, including diagnosis or treatment of COVID-19. All Marketplace health plans also cover COVID-19 diagnostic tests, even for those who don't have symptoms or don't know if they've been exposed to COVID-19. In addition, the federal government has declared that COVID-19 vaccines be provided free of charge to all people living in the United States, regardless of their immigration or health insurance status.

The Health Insurance Marketplace offers advice to those who can't pay their premiums because of a hardship due to COVID19:

- Check with your insurance company about extending your premium payment deadline or ask if they will delay terminating your coverage because you can't pay your premiums.
- Most of the time, if you aren't receiving financial assistance with your premiums, you have a grace period determined by state law (often one month). If you're getting financial assistance, you have a three-month grace period during which your coverage can't be terminated for not paying your premiums.
- If your household income changed, update your application immediately. You could qualify for more savings than you're getting now.

Patient Assistance Foundations Offer Relief

People struggling to pay treatment costs for chronic illnesses can also turn to charitable patient assistance programs (CPAPs) for financial assistance. One such CPAP is the HealthWell Foundation, sponsor of *Real World Health Care*.

In 2020, even as the COVID pandemic impacted the nation's economy, HealthWell's generous donors allowed the Foundation to award over \$650 million in medication copayment and insurance premium assistance grants to nearly 170,000 underinsured Americans. In addition to its standard disease funds, HealthWell used its own financial resources – before being joined by other corporate and individual donors – to create two COVID-19 specific funds last year.

The first, launched on March 17, 2020, provided up to \$250 in assistance to 8,330 qualifying households to help them afford food and medication delivery in support of social distancing requirements. The second, opened on April 28, 2020, provided up to \$6,000 in financial assistance to 644 qualifying households, where the policyholder lost their employee-related private insurance during the economic downturn. This fund allowed the covered patient with either a serious, chronic or oncologic disease to continue their usual treatment programs.

In February of 2021, the Foundation opened its third, HealthWell-sponsored, COVID-19 fund to provide up to \$2,000 in financial assistance for behavioral health services for COVID-19 frontline health care workers. Through the [COVID-19 Frontline Health Care Workers Behavioral Health Fund](#), HealthWell assists frontline health care workers in covering their out-of-pocket treatment-related copayments for prescription drugs, counseling services, psychotherapy, and transportation needed to manage COVID-19 related behavioral health issues.

"It is during times like these that we realize just how fortunate we are to be able to continue making a difference in the lives of those so negatively impacted by the pandemic," Zodet concluded.

Social Workers Helped Leukemia Patients Navigate Care during COVID Pandemic

Social workers play an important role in a leukemia patient's care. As an integral part of a patient's total care team, they look beyond a patient's pathology and focus on the whole person to ensure they are cared for holistically and their psychosocial needs are met.



Paula Brumbak

"Here at Advent Health, oncology social workers examine the mind, body and spirit," said Paula Brumbak, MSW, LCSW, head of the Association of Oncology Social Workers Blood Cancer and Bone Marrow Transplant Special Interest Group, and Licensed Clinical Social Worker at Advent Health. "In addition to making sure that patients receive the proper clinical care, we can help them cope with their leukemia diagnosis and treatment and connect them with resources they and their loved ones need."

"Social workers are a rich resource of education and connections to services in the health care system," added Samantha Bordeau, Licensed Clinical Social Worker, Advent Health and also a member of AOSW. "We can help patients access home health care, employer and government assistance, disability and FMLA benefits, and more. Often, we open patients' eyes to opportunities they may not be familiar with."

Caring for Emotional Health

Bordeau noted that oncology social workers also help leukemia patients access psychosocial and emotional support, through individual counseling, community and online support groups and sometimes through a referral to a psychiatrist.

Shortly after diagnosis a social worker meets with each patient and explains the role of social work role. The social worker also administers a distress screening tool to measure a patient's emotional health and then offers emotional and educational services throughout the patient's continuum of care.



Samantha Bordeau

"The leukemia treatment process can be incredibly intensive from an emotional perspective on both patients and their family caregivers, especially because both the patient and their primary caregiver must take time off from work and activities, which can throw their sense of self off balance," Brumback said.

Caring for Financial Health

Oncology social workers also can help patients access financial assistance resources to help cover expensive treatments as well as travel and lodging costs associated with treatments.

Financial assistance was particularly important during the early days of the COVID pandemic, when patients and family caregivers alike faced furloughs and layoffs and stimulus checks had yet to be issued.

The [HealthWell Foundation](#), sponsor of *Real World Health Care* provides financial assistance through its program. HealthWell offers two funds to help leukemia patients afford the costs of treatments. Their [Acute Myeloid Leukemia](#) fund provides up to \$10,000 a year to help patients afford the prescription drugs and biologics used in treatment as well as provide assistance with insurance premiums. Their [Chronic Lymphocytic Leukemia](#) fund provides up to \$8,000 a year for the same type of copay and premium assistance.

Caring during COVID

Brumback and her colleagues faced special challenges helping their leukemia patients navigate care – and life in general – during the height of the COVID-19 pandemic. One challenge was the longer isolation periods patients were forced into.

"Typically, once a patient's blood counts recover after treatment, they are given the green light to go out and about – see family, go shopping and do many of the things they used to do," she said. "But with the risks associated with COVID, instead of a 100-day waiting period, they had an indefinite waiting period. In response, we established weekly online support groups to help patients and their loved ones cope with the related stress and depression of long-term isolation."



Geena Festa

Brumback's and Bordeau's colleague, Geena Festa, Licensed Clinical Social Worker and AOSW member said she and her team at Advent Health also needed to pivot during the early days of the pandemic to help people find pre- and post-transplant lodging and transportation at a time when medical transport systems and local hotels were shut down. She found options in ride-sharing and home-sharing resources and worked with patients' insurance providers and charitable assistance programs to get those services covered.

"By our nature and our training, social workers adapt quickly to current events," she said. "We know how events and trends affect the care of our patients, and we're incredibly creative when it comes to investigating any and all options to advocate on behalf of our patients and get them what they need."

Caring Virtually

While in-person leukemia treatments couldn't be paused during the height of the COVID pandemic, some support services, like those provided by social workers, had to be conducted virtually. Festa said that before the pandemic, telehealth had started to become a general health care trend, but not among social workers.

"When COVID first hit, many social workers were sent home and had to quickly learn to set up virtual care and support through the phone or Zoom," she said. "It was initially difficult to provide care when we couldn't meet with our patients face-to-face. But now, I think telehealth is here to stay for the social worker profession."

As one of the leading organizations of oncology social workers, AOSW supported its members as they transitioned to providing virtual care by communicating with federal agencies in support of initiatives such as reimbursement for services delivered via telehealth.

"Our members experienced disruptions in how their work was performed, where their work was performed and the type of work they performed," said Michael L. Grignon, LMSW, CCM, MBA, Secretary-Treasurer of AOSW. "We anticipate that these changes will persist, and to a greater degree post-COVID than before. How such changes affect both oncology social workers and patients will need to continue to be explored and supported. We believe we are emerging stronger and even better positioned to support our members and the greater cancer community as a whole."