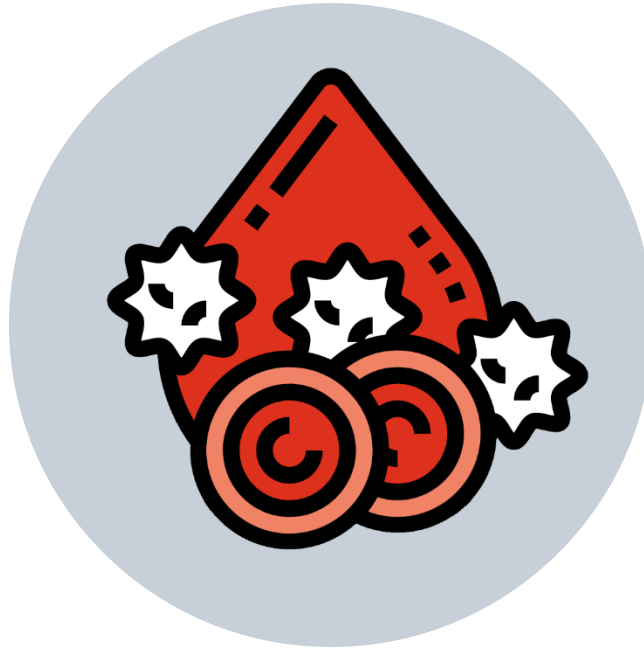


AML & CLL: Navigating Care



A Series by:

Real World Health Care

2021

Acute myeloid leukemia and chronic lymphocytic leukemia are common blood cancers in adults and can lead to infection, anemia or easy bleeding.

AML & CLL: Navigating Care is a recently published series of articles that spotlights the organizations and efforts dedicated to helping patients cope with these cancers and ensure they get the support they need.



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Understanding Acute Myeloid Leukemia

Acute myeloid leukemia (AML) is a cancer that affects the blood and bone marrow and is the most common type of acute leukemia in adults. With AML, the bone marrow (the center of the bone containing many blood vessels) makes abnormal white blood cells, red blood cells or platelets.

Normally, the bone marrow makes blood stem cells (immature cells) that over time, become mature blood cells. These immature myeloid stem cells become one of three types of mature blood cells:

- White blood cells that fight infection and disease,
- Red blood cells that carry oxygen and other substances to all tissues of the body,
- And platelets that form blood clots to stop bleeding.

In AML, the myeloid stem cells usually become a type of immature, abnormal white blood cell called myeloblasts. Sometimes in AML, too many stem cells become abnormal red blood cells or platelets. These abnormal white blood cells, red blood cells or platelets are also called leukemia cells or blasts.

Leukemia cells can build up in the bone marrow and blood so there is less room for healthy white blood cells, red blood cells and platelets. When this happens, infection, anemia or easy bleeding may occur. The leukemia cells can spread outside the blood to other parts of the body, including the central nervous system (brain and spinal cord), skin and gums.

AML Treatment

AML usually gets worse quickly if it is not treated. Chances of recovery and treatment options depend on:

- The age of the patient.
- The subtype of AML.
- Whether the patient received chemotherapy in the past to treat a different cancer.
- Whether there is a history of a blood disorder such as myelodysplastic syndrome.
- Whether the cancer has spread to the central nervous system.
- Whether the cancer has been treated before or has come back.

AML may be treated with chemotherapy, radiation therapy, chemotherapy with stem cell transplant, and in some cases, drug therapies including arsenic trioxide and all-trans retinoic acid (ATRA). Treatment usually has two phases:

- Remission induction therapy is the first phase of treatment. The goal is to kill the leukemia cells in the blood and bone marrow to put the leukemia into remission.
- Post-remission therapy is the second phase and begins after the leukemia is in remission. The goal is to kill any remaining leukemia cells that may not be active but could begin to regrow and cause a relapse.

In addition to standard (currently used) treatments, new types of treatments are being tested in [clinical trials](#), including monoclonal antibody therapy, a targeted therapy that may cause less harm to normal cells than chemotherapy or radiation therapy. According to the National Cancer Institute, patients who take part in clinical trials can help improve the way cancer will be treated in the future. They note that even when clinical trials do not lead to effective new treatments, such trials often answer important questions and help move research forward.

Treatment Planning: Questions to Ask Your AML Care Team

Cancer Support Community offers [advice to those diagnosed with AML](#), to help them sort through the whirlwind of information, decisions, and life adjustments related to their diagnosis. They suggest having a list of specific questions patients should ask at every stage:

- What subtype do I have?
- Does my cancer test positive for any biomarkers that help make treatment decisions, such as FLT3, TP53, IDH1, IDH2, NPM1, and CEBPA?
- What are my different treatment options?
- Are there any clinical trials that would be right for me? How do I find out more about them?
- Am I healthy enough for high-dose chemotherapy?
- Should I be thinking about a stem cell transplant? If so, when will the transplant team start looking for a donor?
- Can my leukemia be cured? What would a “cure” look like for me?
- What treatment do you recommend for me, and why?
- What are the risks of this treatment? What are the benefits?

- What are the side effects (short- and long-term)? What can I do to prepare for them?
- Do I need to go to an academic medical center for my treatment?
- How long will I be in the hospital?
- Do I need to go get dental work done before beginning treatment?
- How will treatment affect my everyday life? Will I need to miss work/school?
- How much will this treatment cost? Will it be covered by my insurance? Is there a social worker or financial counselor that I could meet with?
- How do I apply for disability?

Cancer Support Community also offers advice on preparing for in-hospital treatment, including:

- Consider travel arrangements if the nearest treatment center is far away, or if you decide to join a clinical trial.
- Anticipate long stays in the hospital, for weeks to months. A hospital social worker or financial counselor can aid you in researching and coordinating insurance, travel, and housing.
- Often patients with AML will not be able to work during treatment. Talk to your hospital social worker and workplace Human Resources right away about how to apply for short- and long-term disability benefits. It can take up to six months for long-term benefits to begin.
- Start thinking about how friends and family can help. You can expect to need six to nine months of help with household tasks, cooking, cleaning, errands, rides, childcare, financial support, etc.

Financial Assistance for AML Treatment

The HealthWell Foundation offers an Acute Myeloid Leukemia (AML) fund to provide medication copayment and insurance premium assistance to eligible AML patients on Medicare. HealthWell will provide up to \$10,000 in financial assistance to individuals who have annual household incomes up to 500 percent of the federal poverty level. Grants through the fund assist AML patients in covering out-of-pocket costs for treatment.

Sources:

PDQ® Adult Treatment Editorial Board. PDQ Adult Acute Myeloid Leukemia Treatment. Bethesda, MD: National Cancer Institute. Updated 3/6/2020. Available at: <https://www.cancer.gov/types/leukemia/patient/adult-aml-treatment-pdq>. Accessed 5/27/2021. [PMID: 26389377]

Cancer Support Community. Frankly Speaking About Cancer: Treatment for Acute Myeloid Leukemia. Accessed 5/27/2021.

Cancer Support Community. Frankly Speaking About Cancer: Acute Myeloid Leukemia. Accessed 5/27/2021.

Treating Chronic Lymphocytic Leukemia

Chronic lymphocytic leukemia (CLL) is a cancer of the blood and bone marrow that usually gets worse slowly. It is one of the most common types of adult leukemia, often occurring during or after middle age. With CLL, the bone marrow makes too many of a type of white blood cell called lymphocytes.

Normally, the bone marrow makes blood stem cells (immature cells) that over time, become mature blood cells. A blood stem cell may become a lymphoid stem cell, which then becomes a lymphoblast stem cell before becoming one of three types of lymphocytes:

- B lymphocytes that make antibodies to help fight infection,
- T lymphocytes that help B lymphocytes make the antibodies that help fight infection,
- And natural killer cells that attack cancer cells and viruses.

In CLL, too many blood stem cells become abnormal lymphocytes, also known as leukemia cells. These leukemia cells are not able to fight infection very well. As the number of leukemia cells increases in the blood and bone marrow, there is less room for healthy white blood cells, red blood cells and platelets. This may lead to infection, anemia and easy bleeding.

CLL Treatment

Certain factors affect treatment options and prognosis for CLL:

- Red blood cell, white blood cell and platelet blood counts.
- Whether the liver, spleen or lymph nodes are larger than normal.
- The age and health of the patient at the time of diagnosis.
- Whether there are signs or symptoms, such as fever, chills or weight loss.
- Response to initial treatment.
- Whether the CLL has recurred (come back).

Different types of treatment are available for patients with CLL:

- Observation (closely monitoring the patient's condition without giving any treatment until signs or symptoms appear or change) is often used to treat asymptomatic or progressive CLL.

- Targeted therapy uses drugs or other substances to identify and attack specific cancer cells and usually causes less harm to normal cells than chemotherapy or radiation therapy.
- Chemotherapy (taken by mouth or injected) enters the bloodstream and kills cells or stops them from dividing.
- Chemotherapy may be followed by a bone marrow or peripheral stem cell transplant to help restore the body's blood cells.
- Radiation therapy uses high-energy x-rays or other types of radiation to kill cancer cells or keep them from growing and may be used to reduce pain related to a swollen spleen or lymph nodes.
- Immunotherapy (a type of biologic therapy) uses substances made by the body or in a laboratory to boost, direct or restore the body's natural defenses against cancer.

In addition to standard (currently used) treatments, new types of treatments are being tested in clinical trials, including CAR T-cell therapy, in which the patient's immune cells are taken from their blood and changed in the laboratory so they will attack cancer cells.

Coping with CLL

Cancer Support Community offers advice to those diagnosed with CLL, including questions to ask their care team:

- What stage is the CLL?
- How fast-growing does the CLL appear to be?
- Do I need to start treatment now? If not, how will we know when to start treatment?
- Does the CLL test positive for any biomarkers (such as TP53 or del[17p]) that help make treatment decisions?
- If I need to start treatment now, what are my options?
- Which treatment do you recommend for me and why?
- What is the goal of each of my treatment options? What are the risks?
- How, where and how often will I receive this treatment?
- How long will I need to be on this treatment?
- How will we know if this treatment is working?
- How will this treatment impact my everyday life? Will I need to miss work/school?

- How much will this treatment cost me? Will it be covered under my insurance? Is there a social worker or financial counselor I could meet with?
- Are there any clinical trials that would be right for me? How do I find out more about them?
- Do I need to go to an academic medical center for my treatment?
- What side effects should I expect (short and long term)? What can we do to manage them?
- Which side effects or symptoms do I need to report to my health care team?
- Whom should I call if I have questions or problems during office hours? After hours and weekends?
- How can I find a counselor or mental health services?
- How can I maintain my health and wellness when dealing with CLL?
- Am I up-to-date on flu, pneumococcal, and VZV vaccines? Are there any "live" vaccines I should avoid?

Financial Assistance for CLL Treatment

The HealthWell Foundation offers a Chronic Lymphocytic Leukemia (CLL) fund to provide medication copayment and insurance premium assistance to eligible CLL patients. HealthWell will provide up to \$8,000 in financial assistance to individuals who have household incomes up to 500 percent of the federal poverty level. Grants through the fund assist CLL patients in covering out-of-pocket costs for treatment.

Sources:

PDQ® Adult Treatment Editorial Board. PDQ Chronic Lymphocytic Leukemia Treatment. Bethesda, MD: National Cancer Institute. Updated 11/25/2020. Available at: <https://www.cancer.gov/types/leukemia/patient/ctl-treatment-pdq>. Accessed 6/9/2021. [PMID: 26389485]

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Coping with Acute Myeloid Leukemia

A diagnosis of acute myeloid leukemia (AML) can leave patients and their loved ones feeling uncertain, anxious and overwhelmed. Patients have important treatment decisions to make, emotional concerns to manage, and insurance and financial paperwork to organize, among other practical concerns.

One of the many sources of information and support for people coping with AML is [CancerCare](#), the leading national organization providing free, professional support services and information to help people manage the emotional, practical and financial challenges of cancer.

Real World Health Care recently spoke with CancerCare's Christine Calafiore, MSW, LSW, an oncology social worker who provides counseling to people coping with cancer. She shared advice for those newly diagnosed with AML and highlighted the services CancerCare offers to the AML patient community.

Diagnosing AML Can Be Challenging

Real World Health Care: Why is AML sometimes difficult to diagnose?



Christine Calafiore

Christine Calafiore: Many of our clients go to the doctor complaining about pain, fatigue, abnormal bleeding and bruising. These are symptoms of several different conditions, and it often takes multiple rounds of tests, scans and even misdiagnoses before the final diagnosis of AML is reached. That process may take even longer if the patient is not in the typical age group for AML, or if their primary physician doesn't have much exposure to patients with AML.

Start a Dialogue with Your Care Team

RWHC: What is your advice for people who are newly diagnosed with AML? What type of questions should they ask their care team?

CC: The mind can go blank when first hearing the diagnosis of leukemia, especially since there are several different types of leukemia with a confusing alphabet's soup of acronyms: CLL, AML, ALL. That's why it's a good idea to schedule a follow up visit where you can ask questions. Write down your questions ahead of time and

bring a notepad to capture the answers so you can refer to the details later. You may also want to bring a friend or a loved one to that session for support and to ask questions you might forget.

During that information-gathering visit, ask about any biomarkers, genetic markers and mutations you can be tested for to help guide your treatment options. Ask what type of treatment options are available and which of the available treatments your care team recommends. Find out how long the treatment will last, what the typical (and atypical) side effects are, including short-term and long-term physical and emotional side effects. Ask how the diagnosis and treatment might impact any other health conditions you have and vice-versa. Younger patients will want to ask how treatments may affect their fertility.

Make sure you know the roles and responsibilities of everyone on your care team and how various care team members can provide support during and after your treatment. Whom can you call on a Saturday if you're having an unexpected side effect?

Confirm that your treatment team is in your insurance network and ask if anyone involved in your care is out-of-network. For example, if you need surgery, your surgeon may be in network, but your anesthesiologist may not, and you may end up getting charged unexpected fees. Speak up about your need for financial counseling or assistance to help cover the cost of treatments, travel to and from treatments, child or dependent care, nutritional supplements and ancillary support. Your treatment center may have in-house resources to help with this, or they may refer you to an outside resource like *CancerCare*.

Be Ready for Potential Lifestyle Changes

RWHC: What sort of restrictions or lifestyle changes should people with AML expect during and after treatment?

CC: Restrictions will likely vary based on the severity of the diagnosis and the type of treatment you're receiving. Before you start treatment, your care team should provide guidance about social distancing in public and with loved ones, how to protect yourself from germs, accommodations you may need at work or school, and recommended nutrition and exercise.

Prepare for your normal routines to be interrupted. Establish a support network among friends and family members – people who can help you with things like grocery shopping, mowing your lawn, ferrying your kids or grandkids to and from school and activities, or walking your dog. Make sure those support people are right for the job. For example, it may not be realistic to ask your 9-to-5 working relative to pick up your kids from school every day at 3pm.

Set up delivery services for food, household goods and pet supplies. Keep foods on hand that are easy to store and prepare. Try to have a variety of foods on-hand so you'll always have something to accommodate changing taste buds.

The oncology social workers at *CancerCare* can help you think through all of these issues and provide guidance on how to navigate the inevitable changes in your life and the lives of your family members.

RWHC: What can the patient's friends and family members do to help them navigate these lifestyle changes?

CC: Friends and family members should be ready for their loved one to experience changes and challenges before, during and after treatment. Their energy may lag. Their mobility may become restricted. As mentioned earlier, they may need assistance with tasks they've done easily before – even the day before – because they need to rest and save their energy for tests, scans and treatments.

Assign a primary caregiver to set up an online Google document, or take advantage of the tools at [My Cancer Circle](#), to organize and coordinate meals and help among the larger friends-and-family support group. These tools also make it easy to share treatment schedules and other information about what's going on with the patient, so the primary caregiver isn't overburdened with providing individual updates.

Accessing AML Support Services

RWHC: How does *CancerCare* support the AML community with services and resources?

CC: *CancerCare* serves the entire cancer community with a number of resources. Our toll-free Hopeline at 800-813-HOPE (4673) is staffed Monday through Thursday from 10 a.m. to 6 p.m. ET and Friday from 10 a.m. to 5 p.m. ET. Through the Hopeline and our [web site](#), our oncology social workers provide individual and group support, practical information and other resources.

We start by gathering information about the patient's diagnosis and location so we can start matching them with services in their area. We provide [case management](#), [educational information](#) and [workshop opportunities](#) for caregivers and other special groups, online and in-person [support groups](#), and for patients in some locations, [individual counseling](#). We also have a [Pet Assistance & Wellness \(PAW\) Program](#) that offers advice on how to care for one's pet during cancer treatment, reduce risk of infection from pets and find local support programs. Plus, we offer special programs that provide socialization and support for seniors, including an online book club and a [pen pal program](#).

When *CancerCare* can't directly meet the patient's needs, we will provide referrals to other organizations that can help. Our goal is to make sure that people living with AML and other cancers feel prepared for their treatments and have the right support systems in place.

A Message from Our Sponsor

The HealthWell Foundation offers an AML Fund that provides up to \$10,000 in annual grants to help cover the costs of treatment copays or insurance premiums.

By Patricia Koffman, Co-Founder & Communications Director, CLL Society | Sep 15, 2021

Are You Receiving the Best Possible Care for Your CLL?

By Patricia Koffman, Co-Founder and Communications Director, CLL Society



Patricia Koffman

Chronic lymphocytic leukemia (CLL) is the most common adult blood cancer in the United States. There are approximately 178,000 patients currently living with CLL, and about 20,000 new cases are diagnosed annually. The CLL Society understands that a diagnosis of CLL can be overwhelming, but the right care can make all the difference.

The CLL Society Inc. is a 501(c)(3) patient-centric, physician-curated nonprofit organization focused on patient education, support, and research, dedicated to addressing the unmet needs of the CLL and related blood cancer communities. Through our website, we offer a multitude of educational opportunities and services to help patients learn to advocate for the best possible care for their CLL. We explain the rapidly changing therapeutic landscape and the importance of clinical trials. We build patient

support networks and engage in patient research to bring awareness to CLL patients' preferences and needs. Our motto is **Smart Patients Get Smart Care™**.

Expert Care is Crucial

Today, CLL patients are living longer than ever. CLL treatments are better than ever. However, you may find yourself wondering whether *you* are receiving the best possible care for your CLL and reaping the benefits of the extraordinary recent advances that have been made in the understanding and treatment of CLL. Patients often identify the need for a second opinion when it becomes time to select an initial treatment option, or when the question of changing their current treatment regimen has been raised. An expert second opinion can be particularly desired if they have received conflicting advice as to how to proceed.

Data support that having access to a CLL expert provides proven survival and outcomes advantages. In other words, those with a CLL expert as part of their team, live longer than those without this advantage.

Free Second Opinion Consult

For many, although an expert second opinion may be desirable, it may be out of reach. Patients may live far from a cancer center of excellence, have inadequate insurance coverage, or face other barriers. The CLL Society addresses this challenge by offering no-cost 30-minute online HIPPA-compliant second opinion consults with a CLL expert through its Expert Access™ Program. Nearly 400 CLL patients have benefitted from this program.



 Awake worrying?
Stop it!
Receive an Online 2nd
Opinion Consult
with a CLL Expert
**CLL Society's Expert
Access™ Program**
It's free.
You deserve some
sleep!

APPLY NOW!

A CLL EXPERT PHYSICIAN CAN GIVE YOU A
2nd OPINION ONLINE AT NO COST TO YOU!

- Easy to qualify
- Easy to apply online
- No need to leave your house



CLL SOCIETY

Smart Patients Get Smart Care™

In order to qualify for this service, you must have a diagnosis of CLL, live in the United States, and not be in the care of a CLL expert. These are the only qualifying criteria. No financial questions are asked. No demonstration of financial need is required.

Upon acceptance into the program, patients complete a brief pre-consultation survey and authorize release of their CLL medical records to be summarized for the consulting physician to be ready to discuss during the 30-minute consult. In preparation, the patient will receive help formulating their

most important concerns to discuss with the CLL expert. At completion, patients are asked to fill out a brief post consultation survey. You will also receive a summary of the consultation written by the CLL Expert, which can be shared with your treating physician and to keep for your own records.

In our recent survey of Expert Access™ participants, 99 percent of respondents indicated that they would recommend the service to other patients, and 74 percent were planning to implement at least one change following completion of the program.

In a testimonial sent to CLL Society, an exuberant participant stated, "I went from fatalistic to hopeful in 30 minutes!" If you are in need of a no-cost second opinion on your CLL journey, please apply to CLL Society's Expert Access™ Program today at <https://cllsociety.org/dl-society-expert-access/>

Stay strong.

We are all in this together!

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."



Samantha Bordeau

"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.

"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."