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Cancer in the Time of COVID

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The Coronavirus (COVID-19) pandemic has created practical, financial, and legal challenges for most Americans, and perhaps much of the world. However, populations that are simultaneously coping with serious medical issues, like cancer, are especially vulnerable. Delays in screening, diagnosis, treatment, and follow-up care are occurring. Individuals with cancer, and their caregivers, are also coping with losing employment or a reduction in hours, which may lead to the loss of health insurance coverage. This population is then left struggling to pay everyday living expenses in addition to mounting medical bills. The added financial stress surrounding COVID-19 is compounded by the existing financial toxicity, anxiety, and stress that too often accompanies a cancer diagnosis.

Existing Options and Protections

Laws that existed pre-pandemic might provide qualified employees with cancer the opportunity to modify the way they perform their jobs, take time off if needed, and replace lost wages.

Reasonable Accommodations

The manner in which COVID-19 is transmitted adds an additional level of health risk to people with cancer who work in close proximity to other people. Eligible employees may be entitled to reasonable accommodations through the federal Americans with Disabilities Act (ADA) or a state fair employment law.1 The ADA provides eligible individuals with protections in several contexts, including at work.2 Many individuals with cancer meet the ADA’s definition of disability due to side effects of cancer treatment or the cancer itself, and under the ADA or applicable state law are, therefore, eligible for protection from discrimination as well as reasonable accommodations.3 Reasonable accommodations can be any change to the “work environment, or to the manner or circumstances under which the position held or desired is customarily performed, that enable an individual with a disability who is qualified to perform the essential functions of that position.”4

For those with compromised immune systems, telecommuting, working from a location with fewer employees, shifting responsibilities to limit exposure, or modifying schedules are all potential reasonable accommodations. Many states and localities have responded to COVID-19 by requiring new safety protocols, such as social distancing, spacing of workstations, taking employee temperatures, and requiring masks. If one’s locality does not require certain physical protections, access to effective physical protections may also be a reasonable accommodation. Reasonable accommodations can be very flexible and are an excellent option for many individuals coping with cancer to continue working safely during the pandemic.

ADA protections against discrimination can extend to employees who are associated with an individual with a disability (e.g., caregivers).5 The rationale behind the “association with” provision is “to prevent employers from taking adverse actions based on unfounded stereotypes
and assumptions about individuals who associate with people who have disabilities.” For example, an employer cannot deny a promotion to an employee based on the fact that he is a caregiver to his seriously ill spouse.

While the ADA protects caregivers from discrimination at work, it does not afford them access to reasonable accommodations. This poses a practical challenge for caregivers of individuals with cancer, who likely have compromised immune systems. If caregivers are required to work in proximity to others, they risk contracting COVID-19 and infecting their loved ones. Because caregivers are not entitled to reasonable accommodations, they do not have the same legal standing as the individual with cancer to request remote work or other modifications. However, employers often want to keep valuable employees, so in many circumstances it may be in caregivers’ best interest to ask for the modification, even if they are not legally entitled.

**Family Medical Leave Act**

When reasonable accommodations are not possible or effective, employees may need to take time off from work. The Family Medical Leave Act (FMLA) protects qualified employees by preserving their jobs when they need time off for their own serious medical condition, or to act as a caregiver to a seriously ill child, parent, or spouse.

While the FMLA is helpful for some, it does not meet the needs of many families. The FMLA only applies to employees of large employers (with 50 or more employees) or a public agency, so those who work for smaller employers do not have access to this leave. To be eligible for FMLA leave, the employee must have worked for the employer long enough (i.e., a total of 12 months in the last seven years, and at least 1,250 hours during the 12 months prior to the start of leave). The law also has a restrictive definition of family and does not extend to leave taken by an employee to care for other family members that may live with the employee, such as a grandparent or sibling. In addition, the FMLA only provides 12 weeks of leave. The pandemic has already lasted three times that long with no definite end in sight. Furthermore, those coping with cancer may have already exhausted their FMLA leave for the year either while dealing with cancer treatment and its effects or towards the start of the pandemic.

Returning to work from leave may also prove challenging, as employers are permitted to require employees to obtain a return to work certification from a healthcare provider. This creates another circumstance when individuals with cancer may have to expose themselves to COVID-19 and other illnesses in pursuit of medical clearance.

**State Leave Laws**

For people who work for smaller employers, they may have options to take job-protected leave under state laws, but many of the shortcomings noted above are still an issue.

**Replacing Wages**

Employees needing time off due to a disability may learn that FMLA leave, and the leave provided under many state leave laws, is unpaid. Those who have access to disability insurance
may be able to replace a portion of the lost wages. However, many private disability insurance policies are denying these claims during the pandemic. Because the employees are able to work, but cannot do so safely while being in close proximity to others, these employees typically do not meet the policies’ definitions of disability. Disability insurance is also not available to caregivers based on another person’s disability. This leaves individuals who have been diagnosed with cancer and their caregivers with limited options to replace wages if they are able to take time off.13

Should an individual with cancer, or caregiver who wants to protect his/her loved one with a compromised immune system, choose not to go to work and subsequently is terminated, the employee may not have access to unemployment benefits. According to the Department of Labor (DOL), if (1) the employee has not contracted COVID-19, (2) no one in the employee’s household has contracted COVID-19, (3) the employee does not have minor children at home, or (4) the employee has not been advised by a healthcare provider to self-quarantine because of a possible exposure, the terminated employee will typically not qualify for unemployment benefits.14 Additionally, if the employee has had employer-sponsored health insurance coverage the employee will need to determine the best option for coverage moving forward.

Health Insurance Options When Losing Employer-Sponsored Insurance

The pandemic has shone a spotlight on the challenge many Americans have of understanding health insurance options when they lose their jobs and/or employer-sponsored health insurance.15 Depending on their circumstances, they may be eligible to keep their employer-sponsored plan through the Consolidated Omnibus Budget Reconciliation Act (COBRA) or a state COBRA law, purchase a new plan through a state Health Insurance Marketplace during a special enrollment period, move to another group plan (i.e., a spouse’s or parent’s plan), or qualify for coverage through Medicare or Medicaid. These choices are critically important normally, but especially so during a pandemic, as access to adequate health insurance for individuals with cancer has been shown to have a direct correlation to financial health, mental health, and overall health outcomes.16

The Consolidated Omnibus Budget Reconciliation Act

COBRA17 is a federal law that allows eligible employees to keep their existing employer-sponsored health insurance plan after experiencing a qualifying event, such as ending employment or a reduction in hours. Electing COBRA may be beneficial, as it is a continuation of the same plan and any contributions towards deductibles or out-of-pocket maximums are preserved. Additionally, individuals maintain access to the same network of providers and prescription drug benefits. However, a significant barrier is cost, as the employee typically pays all of the monthly premiums plus a two percent administrative fee.18 Pre-pandemic, the choice to use COBRA must occur within 60 days of the qualifying event. In response to COVID-19, the federal government extended the deadline until 60 days after the end of the declared national emergency.19

State Health Insurance Marketplaces
The Marketplaces were created by the Patient Protection and Affordable Care Act (PPACA) to help ensure that consumers could access quality health insurance policies sold by private health insurance companies. Plans sold through the Marketplaces may provide consumers with financial assistance to purchase the plan based on income. The lower a consumer’s income, the more federal assistance is available to contribute to the cost of coverage. Nationally, nearly half of Americans who do not have insurance would qualify for a reduced cost plan on the Marketplace. Marketplace open enrollment occurs annually in the fall; however, a special enrollment period is available to individuals who experience a loss in other creditable coverage.

Important in times of fluctuating employment and income, the financial assistance available in the Marketplaces comes with built-in flexibility. Consumers purchasing health insurance through Marketplaces enter an estimated household income for the year. Those who lost jobs can estimate annual income based on actual earnings to date and add in potential unemployment benefits. As unemployment benefit amounts fluctuate and people hopefully find new jobs, they must report income changes to the Marketplace, triggering an adjustment of assistance. This flexibility is especially helpful when income drops, leading to an increase in Marketplace assistance.

Unfortunately, lack of awareness and understanding of the Marketplaces are barriers to people obtaining adequate health insurance and accessing quality healthcare. For the cancer community these barriers generally manifest in more late-stage diagnoses and higher mortality rates, as compared to individuals with adequate health insurance. It could also lead to fewer Americans receiving a COVID-19 vaccine. Addressing the disparities in accessing quality healthcare has become even more imperative in light of the pandemic.

Medicaid and Medicare

There are two main federal health insurance programs: Medicaid and Medicare. Prior to the passage of PPACA, the only way to access Medicaid was to have a low income, a low resource level, and fit into one of several categories. For individuals with cancer, the most common category of eligibility was through the “aged, blind and disabled” program. The strict eligibility requirements were a barrier to childless adults with low incomes. In response, PPACA created a new category of eligibility that is based solely on having an income at or below 138 percent of the federal poverty level. PPACA anticipated this new category of eligibility would exist nationwide, but the United States Supreme Court made it optional for states to expand their Medicaid programs. Only 38 states and the District of Columbia have chosen to expand their Medicaid programs. Individuals who live in the 12 states that did not expand their programs will continue to face challenges accessing healthcare, including cancer screenings and treatment as well as a COVID-19 vaccine.

Individuals over the age of 65 when they stop working, but have declined Medicare coverage because they had other creditable coverage will be eligible for a special enrollment period to elect Medicare coverage without facing penalties.
Understanding health insurance options, and how to make choices between those options, can be stressful at any time, but COVID-19 has exacerbated these challenges. The high potential of job loss, delays in cancer screenings and treatment, concerns about returning to work and being exposed to COVID-19, the availability and access to COVID-19 vaccines, and overall increased levels of anxiety are compounding existing stress levels for individuals coping with cancer and their caregivers. Additionally, even individuals who are not in active cancer treatment, but still have compromised immune systems as a result of past treatment, are concerned about exposure to COVID-19 and returning to their workplace.

New Options

Since the beginning of the pandemic, there have been several actions at the federal level to try and fill gaps in existing legal protections. To address COVID-19, President Trump declared a public health emergency, issued national emergency declarations, and invoked emergency powers via Executive Order. These actions paved the way for federal agencies to implement provisions aimed at helping Americans. For example, the DOL issued an extension to the deadline to elect COBRA and to file an appeal for a health insurance claim denial. President Biden on his first day in office also began issuing a number of COVID-19-related Executive Orders.

In addition, Congress has passed five substantial laws to address the pandemic’s impact on the country. While designed to help Americans cope with COVID-19, many of the benefits included in these laws have been very useful for individuals with cancer and the related financial hardship they experience. For example, the Families First Coronavirus Response Act (FFCRA), amends the FMLA to permit qualified employees to take up to 12 weeks of expanded family and medical leave for specific reasons. Covered private employers could qualify for certain tax credits if they provide paid leave for employees caring for their children when school or childcare is closed. Prior to December 31, 2020, employers were required to provide eligible employees with paid leave. While the paid leave provisions of FFCRA become voluntary for employers as of January 1, 2021, they may still be an avenue to access additional job-protected, paid time off for parents coping with cancer who have children at home.

Particularly important for individuals coping with cancer and high out-of-pocket costs, the Coronavirus Aid, Relief, and Economic Security (CARES) Act requires insurers to cover (without cost sharing) COVID-19 testing and urgent care, emergency room, and telehealth visits related to COVID-19 testing. The CARES Act also makes helpful changes to Medicare, such as eliminating some requirements for face-to-face encounters, increasing payments for COVID-19 treatments, and permitting a 90-day supply of some prescription drugs during the COVID-19 emergency. The CARES Act additionally ensures that more individuals will have access to a vaccine without a cost-share. PPACA requires that most health insurance companies provide certain preventative services for free; however, insurers have a “minimum interval” of at least one year before they are required to implement new coverage recommendations from the U.S. Preventative Services Task Force (USPSTF). An interim final rule to implement the CARES Act indicates that non-grandfathered group health plans and health insurance issuers offering non-grandfathered group or individual health insurance coverage have 15 days to begin covering the Advisory Committee on Immunization Practices (APIC) recommended COVID–19
immunizations.\textsuperscript{47} Having access to a COVID-19 vaccine for free could be a significant benefit for people in treatment for cancer who are often forced to take cost saving measures such as avoiding doctors’ appointments, skipping meals, cutting pills in half, or not filling prescriptions at all.\textsuperscript{48}

Two other consumer benefits included in these COVID-19 relief bills that are particularly helpful for the cancer community relate to telehealth and surprise billing. Individuals must have a serious health condition to be eligible for FMLA job-protected leave. The DOL has issued guidance in the past that to meet the standard of serious health condition one must be in “continuing treatment by a health care provider” and that “treatment requires a visit to the health care provider to qualify under FMLA.”\textsuperscript{49} COVID-19 made it unsafe, or at least feel unsafe, for many individuals undergoing cancer treatment who have compromised immune systems to attend in-person medical visits, creating a barrier to accessing FMLA protections.\textsuperscript{50} The DOL has now issued guidance that a telemedicine visit is considered an in-person visit for purposes of FMLA leave.\textsuperscript{51} This expanded access to telemedicine will be extremely useful for those in cancer treatment and their caregivers even outside of a pandemic. Many of the costs that contribute to financial toxicity include transportation, parking, meals away from home, and time away from work for caregivers. Telemedicine can alleviate those costs without hindering access to legal protections.

Surprise billing is another contributing factor to financial toxicity for individuals with cancer. A common example of surprise billing is when a patient does the due diligence to ensure that the hospital and providers are in-network. Then after a procedure the patient finds out that the anesthesiologist was out-of-network and receives a large bill that is not covered by the patient’s health insurance. These situations can leave patients with huge medical bills that they are unable to pay, and can even lead to bankruptcy.

Starting in 2022, insurance companies and hospitals must agree on a payment compromise instead of billing the patient for the balance in three circumstances: out-of-network emergency care services, out-of-network air ambulance services, and out-of-network providers of ancillary services (e.g., anesthesia, pathology, radiology, and neonatology) when provided at in-network facilities.\textsuperscript{52} According to the Senate Committee on Health Education & Labor, this law “creates a framework that takes patients out of the middle, and allows health care providers and insurers to resolve payment disputes without involving the patient,” a welcomed change for the cancer community.\textsuperscript{53}

Individuals coping with cancer and their caregivers routinely navigate a maze of existing laws. This already complicated and stressful system has been compounded by a global pandemic, new federal, state, and local laws, and thrown-together regulations implementing those laws. Congress, states, and localities have addressed some of the practical issues individuals are facing, such as providing new special enrollment periods to enroll in health insurance,\textsuperscript{54} eviction moratoriums,\textsuperscript{55} and economic impact payments,\textsuperscript{56} but the patchwork of protections and benefits can be confusing and have created disparities among Americans. There are few places to find comprehensive, accurate information about one’s rights and benefits. Moreover, many employers are not entirely clear about their current and shifting responsibilities under the law.
Consequently, they are often unable to provide accurate guidance to their employees, even if they wanted to. Despite these challenges and gaps, the new consumer benefits that have been established will likely be very helpful to the cancer community moving forward.

**Unknowns**

In addition to all of the known challenges, there are some unknowns. For example, it is hard for an employer to assess whether remote work is reasonable for an employee requesting an accommodation given the fact that it is unclear how long the pandemic will last, when a vaccine will be readily available to the general public, and when it will be safe for people with compromised immune systems to return to work in-person.

Moreover, many of the health insurance protections and benefits discussed above are rooted in PPACA, the constitutionality of which is currently being challenged. If the Supreme Court were to rule that even portions of PPACA were unconstitutional, it could potentially have catastrophic consequences for the cancer community. In pre-pandemic numbers, an estimated 20 million people would lose health insurance (those with Marketplace plans or coverage through expanded Medicaid). This estimate is likely extremely low, as the COVID-19 pandemic caused close to 14 million people to lose employer-sponsored insurance, and many of those people have picked up coverage through the Marketplace or expanded Medicaid. Furthermore, it is estimated that more than 135 million Americans have a pre-existing condition, all of whom could face barriers in accessing quality cancer care, or even a COVID-19 vaccine, should PPACA be struck down.57

People with pre-existing conditions are not the only ones who would be impacted by losing PPACA. PPACA has been the law for over a decade, and the entire healthcare system has been impacted, in one way or another. Employer plans could also begin to deny health insurance coverage for any pre-existing conditions (for up to one year).58 Programs that assist consumers could also disappear or lose funding. PPACA currently requires most health insurance policies to provide 100 percent coverage for preventive services. Eliminating this provision would not only reinstitute a known barrier to accessing early cancer detection screenings, it would also create a barrier to accessing a COVID-19 vaccine, as it is through PPACA and the CARES Act that individual and employer plans would be required to provide the vaccine for free.59

There are other, less direct impacts voiding PPACA would have on the cancer community that would be concerning at any time, but certainly more so during a pandemic. For example, PPACA provides grants for rural hospitals and for doctors willing to work in rural areas. Nearly one-fifth of the nation’s population resides in rural areas, yet even with financial incentives provided by PPACA, only three percent of medical oncologists practice in rural areas. These grants are critical to address the disparities in access to cancer care for people living in rural areas, and losing existing funding would only exacerbate the barriers to care and disproportionately high mortality rates for individuals in rural areas.

Some states have begun to act in anticipation of a potential Supreme Court ruling striking down PPACA and have passed legislation to provide people with similar protections.60 While
helpful, should PPACA be voided the lack of federal law would result in a patchwork of protections, leading to greater disparities in health outcomes.

Other Concerns

Of course, work and health insurance are not the only challenges facing individuals coping with cancer and their caregivers. Practical issues have also arisen around access to emotional support, feelings of isolation, barriers to clinical trial participation, and challenges to creating or modifying estate plans. To address the latter, states have established some protections around remote witnessing and electronics signing.61

Legal Aid to Individuals Coping with Cancer and Their Caregivers

Healthcare providers have responded to the COVID-19 pandemic with clever new ways of providing services (e.g., utilizing wearable patient monitoring devices, paperless transactions, telehealth, curbside care).62 Lawyers have, too. Many state bar associations and local public interest law groups have expanded pro bono and low-cost legal services, established hotlines, and created additional volunteer opportunities for attorneys.63 These expanded legal services may be another avenue for individuals with cancer and their caregivers to obtain assistance during the pandemic.

Conclusion

Addressing the legal and practical issues that arise after a cancer diagnosis is often as difficult as dealing with the disease itself, and COVID-19 has only added to the challenge. By all accounts this pandemic has been tragic. However, there may be a few silver linings to emerge for the cancer community. Congress has passed over 3,000 pages of legislation to address various aspects of COVID-19 that have the potential to have long-lasting benefits for the cancer community. With that legislation will likely come with federal and state regulations and guidance, additional Executive Orders and legislative action, possible changes to employer policies, and differing health insurance options. In this quickly changing landscape attorneys should stay abreast of new developments and share relevant information and resources with those that may be impacted.

Monica Bryant is a cancer rights attorney and chief operating officer at Triage Cancer, a national, nonprofit organization that provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers. Throughout her career, Ms. Bryant has provided hundreds of educational seminars, written articles and blogs, and appeared on television and radio shows discussing healthcare-related legal issues. She teaches a class on Cancer Rights as an Adjunct Law Professor at John Marshall School of Law in Chicago. In 2018, she co-authored a book, Cancer Rights Law: An Interdisciplinary Approach, published by the American Bar Association. She may be reached at mb@triagecancer.org.
Steven Knox is a staff attorney for Triage Cancer. He has an informed passion for providing empowerment through education to people in crisis. Mr. Knox earned a Juris Doctor from Wayne State University Law School in Detroit and a Bachelor of Social Work from Oakland University. He is a member of both the Michigan and Arizona bars. He may be reached at sk@triagecancer.org.

Authors’ Note:

Attorneys interested in getting more involved in cancer advocacy efforts can join the ABA’s Cancer Legal Advocacy Interest Group (Note: you do not need to be a member of the Health Law Section to join). In addition, Triage Cancer has a national Legal Advisory Council and is seeking new members. More information can be found at https://triagecancer.org/legal-advisory-council. As cancer-related legal issues are vast, attorneys from all practice areas are welcome and can make an impact with minimal time commitment. Together the legal community has an opportunity to improve the quality of life and survivorship outcomes of individuals diagnosed with cancer, even during a pandemic.

1 Americans with Disabilities Act, 42 U.S.C. § 12101 (1194). In addition, each state has a fair employment law.
2 42 U.S. Code § 12112.
3 42 U.S. Code § 12111(9).
7 Id. at Question 4.
10 29 C.F.R. § 825.110.
11 Under the FMLA employers are entitled to choose the year period for FMLA leave, so even though we are at the beginning of a new calendar year, an employee may still be in his/her prior FMLA year period. 29 C.F.R. § 825.200(b).
12 Learn more about state law options at https://triagecancer.org/employment-state-laws#tto.
13 Taking leave and replacing lost wages, while separate issues, are intertwined. FMLA leave may combine with ADA protections for job-protected time off, and paid time off and disability insurance can be utilized to replace lost wages. See examples of the FMLA combining with other laws and benefits at https://triagecancer.org/QuickGuide-FMLA-OtherBenefits.
20 42 U.S. Code § 18031.
22 Note: states that run their own Marketplaces may have a different open enrollment period. See https://triagecancer.org/health-insurance-state-laws.
24 HealthCare.gov offers instructions, tips, and a calculator to estimate household income at https://www.healthcare.gov/lower-costs/.
28 42 C.F.R. § 430.0
30 42 C.F.R. § 435.218.
33 42 C.F.R. § 406.24.
37 42 U.S.C. § 247d.
40 https://www.whitehouse.gov/briefing-room/presidential-actions/.
42 PL 116-127 (2020).
43 PL 116–260 (2020). Under this new provision, employers can choose to grant paid leave to their employees and receive tax credits through March 31, 2021.
45 Id. at § 3203.
47 29 C.F.R. Part 2590.
48 National Cancer Opinion Survey, Harris Poll on behalf of the American Society of Clinical Society, 2017. It is unclear how this provision might be impacted should PPACA be ruled unconstitutional.
56 PL 116-136 § 2201.
58 PL 104-191. Note: If PPACA is voided, the lesser protections under the Health Insurance Portability and Accountability Act of 1996 (HIPAA) remain in effect. HIPAA’s creditable coverage provision provides an individual day-for-day credit for previous health coverage against the application of a preexisting condition exclusion period when moving from one group health plan to another, from a group health plan to individual coverage under certain circumstances, or from an individual policy to a group health plan. 
59 H.R. 748 § 3203.
60 A number of states have codified consumer protections related to health insurance or established state-level individual mandates requiring individuals to maintain health coverage. See https://www.ncsl.org/research/health/state-laws-and-actions-challenging-ppaca.aspx. 
61 The American College of Trust and Estate Counsel compiles a list of states allowing remote witnessing or notarization at https://www.actec.org/resources/emergency-remote-notarization-and-witnessing-orders/.
63 For example, the Public Interest Law Initiative has created the COVID-19 Illinois Free Legal Answers Task Force and is actively recruiting attorneys from all practice areas to help answer legal questions. See https://pili.org/covid-19-task-force/