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CAREGIVING POLICY DIGEST

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As the saying goes, just when you thought things couldn't get any — take your pick — crazier, unpredictable, upending, along came the first two weeks of the new year. Preceding them was a year unlike any other during our lifetimes. And while the swift, seemingly miraculous production of an effective vaccine held the promise of an end to the devastation caused by COVID-19, the light at the end of that tunnel still remained dim on the eve of a presidential inauguration.

The all-encompassing impact of the virus manifested itself in the pages of Caregiving Policy Digest during 2020. Item after item documented the devastating toll on patients, their health providers, and their loved ones — the desolation and isolation wrought by an invisible cluster of microscopic spikes running uncontrollably through vital organs and making basic human interactions an avenue of destruction. The worst of it played out among the most vulnerable, elderly residents in long-term care, dependent on caregiving from overwhelmed and fearful professional caregivers and denied access to the soothing and vital support of loved ones. The pictures of aged parents and their children and grandchildren straining to connect through closed windows will forever represent the terrible impact of the world's experience with coronavirus.

— WRAPPING UP 2020 —

COVID-19 AND CAREGIVING AND LEGISLATIVE, ADMINISTRATIVE, AND REGULATORY DEVELOPMENTS

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Congress deals blow to surprise billing

Surprise! An end to surprise billing, that is, managed to make its way to the legislative goal line as the year-end spending and COVID-19 relief package included the hitherto elusive ban. “It seemed like déjà vu,” [wrote](#) Modern Healthcare’s Rachel Cohrs, “another mid-December bipartisan compromise on banning surprise medical bills negotiated behind closed doors is announced just days before a crucial end-of-year government funding deadline. (But) unlike their 2019 failure, lawmakers this year succeeded in sealing the deal. The surprise billing ban takes effect in 2022. Surprise bills happen, [noted](#) The New York Times’ Sarah Kliff and Margot Sanger-Katz, “when an out-of-network provider is unexpectedly involved in a patient’s care. Patients go to a hospital that accepts their insurance, for example, but get treated there by an emergency room physician who doesn’t. Such doctors often bill those patients for large fees, far higher than what health plans typically pay. Now, instead of charging patients, health providers will have to work with insurers to settle on a fair price. Hospitals and doctors, who tend to benefit from the current system, fought to defeat solutions that would lower their pay. Insurance companies and large employer groups, on the other hand, have wanted a stronger ability to negotiate lower payments according to the types of medical providers who can currently send patients surprise bills. This year, many of the same legislators behind last year’s failed effort tried again, softening several provisions that had been most objectionable to influential doctor and hospital lobbies. The current version will probably not do as much to lower health care spending as the previous version, but will still protect patients. After years of defeats, consumer advocacy groups cheered the new legislation. ‘This was a real victory for American people against moneyed interests,’ said Frederick Isasi, executive director of Families USA. ‘This was about Congress recognizing in a bipartisan way the obscenity of families who were paying insurance still having financial bombs going off.’ The final compromise requires insurers and medical providers who cannot agree on a payment rate to use an outside arbiter to decide. The arbiter would determine a fair amount based, in part, on what other doctors and hospitals are typically paid for similar services. Patients could be charged the kind of cost sharing they would pay for in-network services, but nothing more. Several states have set up their own arbitration systems, and have found that most price disputes are negotiated before an arbiter is involved. ‘If this bill will force them to come to the table and negotiate a solution, it will be a definite win for everybody,’ said Christopher Garmon, an assistant professor of health administration at the University of Missouri, Kansas City.”

Ambulance charges await future action

Slightly tempering the good news about surprise bills was the legislation’s one exception: ground ambulance transportation. Legislators and staffers who have worked on surprise billing, [reported](#) The Times’ Kliff and Sanger-Katz, “say the omission doesn’t reflect the influence of a big ambulance lobby. Local governments provide a majority of emergency ambulance rides, via fire departments or stand-alone rescue squads. Though private corporations provide a growing share of ambulance rides, those entities haven’t been buying television ads or flooding congressional offices with calls, as doctor and hospital groups did on other kinds of surprise medical bills. But lawmakers have been reluctant to regulate surprise billing among ambulances, citing the diversity of providers, complex layers of state and local regulation, and a dearth of information about precisely what it costs to keep an ambulance stocked and running. Amid the bruising surprise-billing debate, many lawmakers saw it as one tricky issue too many. Two new developments may change that hesitancy in the coming years. Medicare, which pays ambulances set rates and bans surprise billing for the patients it covers, is reviewing its payment rates. And the surprise-billing legislation passed this week establishes a commission to study the problem of ground ambulance bills, another way for lawmakers to learn more about how things are currently working.”

SCOTUS adds Medicaid work requirements to 2021 docket

Add one more major health policy case to the Supreme Court docket for 2021; in early December the court, having already heard arguments on the constitutionality of the

Affordable Care Act, agreed to consider the Trump administration's plan to let states impose work requirements on some who receive health-care benefits under the Medicaid program for the poor. Acting Solicitor General Jeffrey B. Wall, [wrote](#) The Washington Post's Robert Barnes, "said the law allows the HHS secretary to approve programs that might enhance reaching the objectives of the Medicaid program. 'The secretary determined that such requirements may help beneficiaries transition to employer sponsored or federally subsidized commercial coverage and may lead to improved beneficiary health, which in turn may help states conserve resources that can be redirected to providing other coverage.' But judges who have addressed the issue said the purpose of Medicaid was to provide the needy with health benefits, not to shed those eligible for its help. 'Failure to consider whether the project will result in coverage loss is arbitrary and capricious,' the earlier appeals court opinion by Judge David B. Sentelle said. The ruling noted that during the five months that Arkansas Works was in effect before being blocked by a judge, more than 18,000 Medicaid recipients were dropped from the program." Of course both the ACA and Medicaid cases now face one very significant pre-ruling reconsideration, namely the Biden administration's; one case or both may in fact wind up on the moot pile.

CMS greenlights Tennessee Medicaid block grant plan

In perhaps its final major move before turning out the office lights, [reports](#) Kaiser Health News' Phil Galewitz, HHS/CMS announced "a radically different Medicaid financing system in Tennessee that for the first time would give the state broader authority in running the health insurance program for the poor in exchange for capping its annual federal funding. The approval is a 10-year 'experiment.' Instead of the open-ended federal funding that rises with higher enrollment and health costs, Tennessee will instead get an annual block grant. The approach has been pushed for decades by conservatives who say states too often chafe under strict federal guidelines about enrollment and coverage and can find ways to provide care more efficiently. But under the agreement, Tennessee's annual funding cap will increase if enrollment grows. What's different is that unlike other states, federal Medicaid funding in Tennessee won't automatically keep up with rising per-person Medicaid expenses. 'The TennCare III demonstration builds on all the good ideas that have been out there around a new financing model for Medicaid, but addresses many of the most prominent concerns,' said CMS Administrator Seema Verma. 'This groundbreaking waiver puts guardrails in place to ensure appropriate oversight and protections for beneficiaries, while also creating incentives for states to manage costs while holding them accountable for improving access, quality and health outcomes. It's no exaggeration to say that this carefully crafted demonstration could be a national model moving forward.' The approval faces an uncertain future because the incoming Biden administration is likely to oppose such a move. But to unravel it, officials would need to set up a review that includes a public hearing. Meanwhile, the changes in Tennessee will take months to implement because they need final legislative approval, and state officials must negotiate quality-of-care targets with the administration." [Added](#) The New York Times' Margot Sanger-Katz: "Michele Johnson, executive director of the Tennessee Justice Center, a legal aid group that helps poor Tennesseans, said she was trying to encourage legislators to reject the waiver. 'A block grant is a particularly poor match for a public health crisis in which health spending can accelerate in unusual ways.' She also noted a history of challenges the state has faced running its more traditional Medicaid program: 'It's hard to imagine a state that would be a worse fit for a block grant than ours.'"

Medicare telehealth coverage expands

Amid the flurry of "end-of -life" Trump administration moves, one of them reflected a broadly positive consensus and is likely to flourish in the new HHS. "The final Medicare 2021 physician fee schedule," [reported](#) Modern Healthcare's Michael Brady and Maria Castellucci, "permanently allows Medicare providers to use telehealth to carry out home visits for so-called evaluation and management services and some visits for people with cognitive impairments. It also temporarily continues telehealth services for emergency department visits and other services with an eye toward making them permanent. 'Telehealth has long been a priority for the Trump Administration, which is why we started paying for short virtual visits in rural areas long before the pandemic struck. But the pandemic accentuated just how transformative it could be,' CMS Administrator Seema Verma said in a statement. According to CMS, more than 24.5 million of Medicare's 63 million beneficiaries and enrollees received a Medicare telemedicine service during the

public health emergency. The agency expanded the telehealth services rural enrollees can receive at healthcare facilities. During a call with reporters, Verma reiterated that Congress needs to change federal law to permanently allow non-rural beneficiaries to receive telehealth benefits or for Medicare beneficiaries to receive telehealth services at home.” [Commenting](#) on the expansion of insured telehealth services sparked by COVID-19, Health Affairs blogger Sean Cavanaugh offered both praise and a note of caution. “First, we have to understand that the future of telehealth isn’t binary. We can’t go back to a system in which virtually no one could use telehealth. Policymakers and payers should make sure patients can get the kind of care they need, when and how they need it. But the alternative shouldn’t be to create a new piston in the fee-for-service utilization engine either. Medicare is in the midst of a significant movement away from paying for volume toward paying for value. When providers accept responsibility for the total cost of care, many of the rules and regulations created to prevent overutilization are no longer relevant. So, the key is to embed telehealth in a payment system already designed to prevent overutilization. That means a payment system that takes into account the total cost of care for a patient; one that rewards providers for keeping patients healthy and reducing wasteful spending. In that kind of system, telehealth can be used prudently — as a substitute for in-person care — rather than as an addition to in-person care.”

President-elect hears from patient advocacy groups

One sure sign of the onset of a new presidential administration is the outpouring of lists of recommendations from advocacy groups seeking to influence policy development. President-elect Biden’s ascendancy is no exception. Among the entries from patient advocacy organizations: [Justice in Aging](#) — Health Policy Priorities for the New Administration and Congress; [Kaiser Family Foundation](#) — Five Targeted Actions a Biden Administration Could Use to Expand Medicaid Coverage; [Families USA](#), et.al. — Letter on Family Priorities; [Center for Medicare Advocacy](#) — Transition Memorandum for HHS, and [Community Catalyst](#) — Policy Priorities for the Biden-Harris Administration.

Biden faces immediate health policy challenges

As for the recipient of these and other action blueprints — the President-elect, HHS-Secretary-designate Xavier Becerra, the CMS administrator (yet to be announced), and all their various colleagues — specific policy responses will unfold in due course. As The New York Times Sarah Kliff [observed](#) in mid-December, “Some of the early decisions facing the Biden team are small, practical ones: Should Medicare continue paying the high but temporary reimbursement rates it offered for telemedicine visits this year, a signal that would encourage private plans to do the same? Other decisions are bigger, like whether to provide additional stimulus funding for health providers and how to allocate it. Doctors know patients have been putting off some kinds of care and are bracing for the consequences. The Biden administration’s policies will help determine how providers care for this sicker population while health insurance coverage is declining. To increase sign-ups, the administration could use waivers expanding Medicaid coverage or restore the Affordable Care Act’s advertising budget. Bigger coverage expansions, like a public option that would allow all Americans to sign up for Medicare, would require congressional approval. ‘There’s a big population I’m really worried about that has diabetes, hypertension and heart failure, and deferred all this care,’ said Dr. Ateev Mehrotra, a Harvard health researcher ‘The accumulation of not getting care will result in complications.’”

New administration envisions far-reaching family caregiving support

In a major health policy address last summer President-elect Biden gave some clear indications of his legislative intentions. “Mr. Biden,” [reported](#) the times Paula Span, “does not address elder care separately from child care, or divide plans to support family caregivers from those for paid caregivers. Rather, he takes on Medicaid benefits for older and disabled adults, preschool for toddlers and better jobs for home care workers, all in one ambitious, \$775 billion-over-a-decade package. Despite its integrated approach, the Biden plan does call for certain programs most likely to benefit older people and their caregivers. For example, it proposes a tax credit for as much as \$5,000 to reimburse families for expenses associated with unpaid caregiving. The Biden plan would also give

family members Social Security credits for the time they spend out of the work force caring for loved ones. ‘It approaches the care economy in a holistic way, across the age spectrum,’ said Ai-jen Poo, executive director of the National Domestic Workers Alliance, which has long pushed many of those measures. One of the Biden plan’s most far-reaching components for seniors concerns Medicaid. About 800,000 people linger on state waiting lists for home care, sometimes for years. The shift to home services, which now represents more than half of Medicaid spending on long-term care, has been ‘vastly inadequate,’ Ms. Poo said. ‘It’s still not mandatory for states to offer home and community-based services as an option.’ The Biden plan vows to eliminate the wait list, then enhance federal contributions to allow states to develop more community alternatives, which are generally less expensive than nursing home care. Finally, it tackles the issues that have led to persistent churn in the mostly female work force that provides elder care and child care, including low wages, lack of benefits like health insurance and sick leave, and the need for further training.”

AARP ‘Dashboard’ documents COVID’s SNF death toll

The epicenter of the pandemic’s death toll — the nation’s senior care facilities — continues to generate ongoing causal analysis and prescriptions for averting future catastrophes. According to [AARP’s COVID-19 Dashboard](#), “deaths have risen dramatically in nursing homes in recent months. The resident death rate across the nation increased by two-thirds from the four-week period ending October 18 to the four-week period ending November 15, from 0.47 per 100 residents to 0.78 per 100 residents. New resident cases doubled, from 2.8 to 5.7 per 100 residents, and new staff cases also doubled, from 2.7 to 5.4 per 100 residents. Five states — Montana, North Dakota, South Dakota, Wisconsin, and Wyoming — had at least two resident deaths, 12 resident cases, and 13 staff cases per 100 residents — more than twice the national average and higher than any state in any previous four-week period going back to the beginning of June.

ProPublica launches online ‘Nursing Home Inspect’ tool

Gauging COVID-19 SNF impact has gained an added tool with ProPublica’s launch of [Nursing Home Inspect](#), a comprehensive online database of nursing home deficiencies cited by regulators and corresponding penalties over the past three years, include including coronavirus statistics.

AARP ‘LTSS Choices’ charts path to long-term care renewal

AARP’s Public Policy Institute has initiated [LTSS Choices](#), a series of reports, blogs, videos, podcasts and virtual sessions exploring “innovative models and evidenced-based solutions to achieve systemwide LTSS reform. At the very basic level, people who need LTSS have [four requirements](#). They need a place to live, services and supports, a workforce to provide those services and supports, and community integration, or connection to others in their community. These four basic requirements must be pieced together for each person in a way that works for them, addressing their individual needs and preferences in a person-centered way. Nursing homes provide housing, although a drawback is the form it takes: It is most often offered within a ‘big box’ institutional design with shared rooms. They provide a range of services, typically offered on a set schedule. Paid staff are on site, although the ratio of staff to residents varies considerably. Connection to others comes usually within the nursing home itself, through planned activities with staff and other residents. Some nursing homes do include a focus on bringing in members of the external community, at least for special events like holiday parties. There are ideas to transform nursing homes by addressing each of the four pillars in new ways, especially in combining changes in each of them.

AARP’s initial LTSS Choices contributions include:

- A detailed [analysis](#) of factors involved in COVID-19 resident cases and deaths based upon national and state studies. Recommendations for quality improvement address emergency response measures, appropriate staffing and payment issues.
- A second [report](#) exploring the potential benefits of small-house nursing homes as exemplified by The Green House® model. The challenges to Green Houses’ expansion are daunting: cost, financing, regulations, and workforce availability. But, the report authors conclude, they are not insurmountable. “Even before the coronavirus pandemic, long-standing problems in traditional nursing homes, such

as infection control violations, low staffing ratios, and safety concerns, led some individuals and their families to seek alternative options, including small-house nursing homes. The Green House model, which generated national interest with its inception in the early 2000s, is the most widely researched small-house nursing home today. Green House homes are small, residential-style living spaces for individuals in need of nursing-home levels of care. The design's overall goal is to achieve a better quality of care and quality of life for residents — and higher satisfaction rates among staff and families — than that experienced in traditional nursing homes. More recently, the COVID-19 pandemic has highlighted the potential value of The Green House model. Green House homes are faring far better than traditional nursing homes in handling COVID-19 — with 2.8 confirmed deaths per thousand residents in Green House homes through July 2020, compared with 38 deaths per thousand residents in all certified skilled nursing homes.”

RAISE Act Council approves caregiver recommendations

The RAISE Act Family Caregiving Advisory Council will [meet](#) virtually on Tuesday, January 19, to finalize its first report to Congress containing recommendations to support family caregivers across the lifespan. At its November session the Council adopted 26 recommendations whose text can be accessed [here](#).

Public webinar on nursing home quality of care on 1/26

NASEM Health and Medicine has initiated a major project to examine the quality of care in nursing homes. The study committee will host its first virtual public webinar on January 26 featuring resident, family, consumer, and practitioner perspectives. Register [here](#).

RESEARCH AND RESOURCES

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FIT fit for colon cancer screening

Colonoscopy is not a word that brings a smile to one's face; Paula Span's unequivocal [endorsement](#) of FIT, the at-home colon cancer screening test, will thus be good news. “A small cardboard mailer contains equipment and instructions for taking a stool sample and returning the test to a lab, to detect microscopic amounts of blood. A week or so later, the results show up on an online patient portal. Five to six percent of patients will have a positive test and need to schedule a follow-up colonoscopy. But the great majority are finished with colon cancer screening for the year — no uncomfortable prep, no need to skip work or find someone to drive them home after anesthesia, no colonoscopy. ‘If your doctor tells you a colonoscopy is better, that’s not accurate,’ said Dr. Alex Krist, chairman of the U.S. Preventive Services Task Force, an independent expert panel that reviews evidence and issues recommendations. ‘The data show the tests are equally effective at saving lives.’ The Task Force is updating its guidelines for colon cancer screening and this year will likely recommend lowering the age at which it should begin, to 45. But the recommendations on the upper end will remain unchanged: Based on strong evidence, adults up to age 75 should be screened regularly. Beyond that age, the disadvantages begin to mount. The Task Force says the benefit of screening 76- to 85-year-olds is small, and that the decision should be an individual one, reached in consultation with a doctor.”

AARP highlights caregiver work-caregiving burden

AARP Public Policy Institute's Lynn Friss Feinberg and Laura Skufca offer [a review](#) of current data concerning the challenges faced by family caregivers juggling paid employment and caregiving efforts. "Managing paid work alongside care for an adult family member or close friend with a serious health condition or disability can be challenging for employed caregivers when their needs are not being met by existing policies and programs. Because most family caregivers now hold paying jobs too, employed caregivers need access to workplace leave benefits and other supports to fulfill both their caregiving and paid work responsibilities. Promoting financial relief to ease some of the financial costs of caregiving, paid sick days and paid family leave, flexible work options, and protecting workers from discrimination on the basis of their caregiving status are important policies for working families. A culture of understanding about elder care needs is especially needed during this unprecedented time to help make the workplace more supportive of workers who are also family caregivers."

AD drug trial offers glimmer of hope; money management woes predict AD onset

Alzheimer's disease treatment: a glimmer of hope? "In a small clinical trial," [reports](#) The New York Times' Gina Kolata, "an experimental Eli Lilly Alzheimer's drug slowed the rate at which patients lost the ability to think and care for themselves, The findings have not been published in any form, and not been widely reviewed by other researchers. 'If accurate, it is the first time a positive result has been found in a so-called Phase 2 study,' said Dr. Lon S. Schneider, professor of psychiatry, neurology and gerontology at the University of Southern California. The drug, donanemab, a monoclonal antibody, binds to a small part of the hard plaques in the brain made of a protein, amyloid, that are hallmarks of Alzheimer's disease. Patients received the drug by infusion every four weeks. Participants who received the drug had a 32 percent deceleration in the rate of decline, compared with those who got a placebo. 'In six to 12 months, plaques were gone and stayed gone,' said Dr. Daniel Skovronsky, Lilly's chief scientific officer. The small study needs to be replicated, noted Dr. Michael Weiner, a leading Alzheimer's researcher at the University of California, San Francisco. Still, 'this is big news,' he said. The trial recruited patients not based on symptoms but on scans showing significant accumulations of amyloid in their brains. The researchers also performed scans for a protein, tau, that forms spaghetti-like tangles in the brain after the disease gets started. 'We needed mild to moderate tangle pathology, but not so many tangles that perhaps the disease is beyond hope,' Dr. Skovronsky said. 'The primary endpoint, or goal of the trial, was a measurement that combined performance on mental tests of reasoning and memory with assessments of how well the participants performed in activities of daily living, like dressing themselves and preparing meals.'"

While the search for dementia and AD treatment unfolds so, too, does the effort to achieve their earlier diagnosis. A new study from Johns Hopkins points a possible finger at the use of payment patterns as a sign of impending cognitive decline. "As early as six years before they were diagnosed with dementia," MedPage's Judy George [reports](#), "people with Alzheimer's disease and related dementias were more likely to miss credit account payments than their peers without dementia. They also were more likely to develop subprime credit scores 2.5 years before their dementia diagnosis. Higher payment delinquency and subprime credit rates persisted for at least 3.5 years after a dementia diagnosis. 'Our study provides the first large-scale evidence of the financial symptoms of Alzheimer's disease and related dementias using administrative financial records,' co-author Lauren Hersch Nicholas, Ph.D., said. 'These results are important because they highlight a new source of data — consumer credit reports — that can help detect early signs of Alzheimer's disease. While doctors have long believed that dementia presents in the checkbook, our study helps show that these financial symptoms are common and span years before and after diagnosis, suggesting unmet need for assistance managing money.' Erratic bill payments, risky financial decisions, and susceptibility to fraud are widely recognized as early signs of dementia. 'The consumer credit industry is, in effect, making money off of Alzheimer's disease and dementia,' observed Jason Karlawish, M.D., of the University of Pennsylvania. 'Credit card companies have statutory protection to charge breathtaking fees and interest rates for late payments and unpaid balances, respectively. There is no reason, however, why artificial intelligence cannot learn from financial transactions and smart devices that their natural user, a human like you and I, is not as

smart as we used to be in managing our money.”

In mid-December the AD crisis gained the attention of the Senate Finance Health subcommittee as four experts discussed therapeutic and diagnostic pipelines, as well as federal policies that might foster treatment breakthroughs. The witnesses' written testimony can be accessed [here](#).

Atypical dementias strikes young victims

“Atypical forms of dementia,” [reports](#) The Washington Post's Jamie Talan, “are being diagnosed more often in people in their 50s and 60s. After 20 years of marriage, after raising two kids, after building a farm in Kentucky and tending horses and dogs, Laura Prewitt knew this much about her husband: He was tenderhearted, fun-loving and never let stress land too long on his shoulders. But in 2014, Ted somehow morphed into a new guy, one who is not so communicative. A guy who lost his social edge and seemed unable to read faces or feelings. Who is tired and withdrawn. ‘He’s just not the same guy,’ she says. ‘I want him back.’ A scan of Ted’s brain helps explain it: Discrete regions of the right temporal lobe that regulate emotion are getting smaller; the tissue is shrinking. Prewitt, who has behavioral variant frontotemporal dementia (bvFTD), is one of a growing number of people in midlife diagnosed with an atypical form of dementia. Unlike Alzheimer’s, which generally occurs in older people, these are rarer dementias — including bvFTD; another frontotemporal variant that leads to language disturbances called primary progressive aphasia; a visual and spatial dementia called posterior cortical atrophy; Lewy body dementia; and early-onset Alzheimer’s in people with no family history. What is clear is that some of the same underlying pathology seen in people with typical Alzheimer’s — amyloid plaque and tau tangles in the brain — is also present in people who have Alzheimer’s with a young age of onset or atypical dementias that affect vision or language or behavior. Some of these atypical dementias are caused by a toxic buildup of other abnormal proteins. ‘There is still limited awareness about early-onset dementias,’ said Liana G. Apostolova, a professor of neurology, radiology, and medical and molecular genetics at Indiana University School of Medicine and the Indiana Alzheimer’s Disease Research Center. ‘When people come in with cognitive complaints in their 40s or 50s, nobody believes them. We are trying to improve our understanding of the risk factors and various disease presentations and raise awareness about it.’ No matter what the presentation, virtually everyone in midlife with visual or spatial problems, language or behavioral symptoms has been through the wringer in trying to get the right diagnosis. It took Ted Prewitt, for instance, two years to get the right diagnosis.”

Family visitation restrictions cause greater acute brain dysfunction

Chalk up a higher burden of acute brain dysfunction for COVID-19 ICU patients to, in part, the curbs on family visitation wrought by the pandemic. So say researchers from Vanderbilt University Medical Center (VUMC) and Spain. Their study, [reports](#) VUMC, “tracks the incidence of delirium and coma in 2,088 COVID-19 patients admitted before April 28, 2020, to 69 adult intensive care units across 14 countries. Some 82% of patients in this observational study were comatose for a median of 10 days, and 55% were delirious for a median of three days. Acute brain dysfunction (coma or delirium) lasted for a median of 12 days. The study appears to show a reversion to outmoded critical care practices, including deep sedation, widespread use of benzodiazepine infusions, immobilization, and isolation from families. Patients receiving benzodiazepine sedative infusions were at 59% higher risk of developing delirium. Patients who received family visitation (in-person or virtual) were at 30% lower risk of delirium. ‘There’s no reason to think that, since the close of our study, the situation for these patients has changed,’ said one of the study’s senior authors, Pratik Pandharipande, M.D., MSCI, professor of Anesthesiology. ‘These prolonged periods of acute brain dysfunction are largely avoidable. Our study sounds an alarm: as we enter the second and third waves of COVID-19, ICU teams need above all to return to lighter levels of sedation for these patients, frequent awakening and breathing trials, mobilization and safe in-person or virtual visitation.’”

Evidence grows of COVID ‘long hauler’ symptoms

[Writing](#) in the Lancet, Chinese COVID-19 researchers further document the reality of patients’ lingering symptoms six months after first falling ill. “We found that at six months

after symptom onset, most patients experienced at least one symptom, particularly fatigue or muscle weakness, sleep difficulties, and anxiety or depression. More severely ill patients had increased risk of pulmonary diffusion abnormality, fatigue or muscle weakness, and anxiety or depression.” Fred Pelzman, who practices internal medicine in New York and was not involved in the study, told STAT [reporter](#) Elizabeth Cooney that the experiences of patients in China square with what has been happening in the United States. “It certainly is compelling evidence that there are a lot of people with a lot of persistent symptoms. We’re seeing in our post-COVID recovery clinics that people are coming in with cardiomyopathy and neuropathies and cognitive changes and balance changes. This is just a virus our body hasn’t seen before that has an enormous inflammatory response, so it’s not surprising that every organ system is upset.” Pelzman himself was infected with COVID-19 in March. “It definitely has lingered,” he said. “I can get a little winded on Zoom calls. I walk home from work and I get a little out of breath, and a couple foods taste funny still. But you know, I’m alive and so I’m OK.”

Vitamin D stirs anti-COVID researchers

Could popping a vitamin pill — specifically vitamin D—help in the fight against COVID 19? Belgian researchers think it might, given their correlation of the vitamin’s deficiency to the incidence or severity of COVID-19 pneumonia. “Deficiency on admission to hospital,” [reports](#) MedScape’s Becky McCall, “was associated with a 3.7-fold increase in the odds of dying from COVID-19, according to an observational study looking back at data from the first wave of the pandemic. Nearly 60% of patients with COVID-19 were vitamin D deficient upon hospitalization, with men in the advanced stages of COVID-19 pneumonia showing the greatest deficit. With regard to the potential role in prevention, ‘Numerous observational studies have shown that low vitamin D levels are a major predictor for poor COVID outcomes,’ notes Jacob Teitelbaum, M.D., an internist who specializes in treating chronic fatigue syndrome and fibromyalgia. ‘This study shows how severe a problem this is. A 3.7-fold increase in death rate if someone’s vitamin D level was below 20 [ng/mL] is staggering. It is arguably one of the most important risk factors to consider.’ Asked to comment, Andrea Giustina, M.D., president of the European Society of Endocrinology, stated: ‘This is likely due to the loss in the protective action of vitamin D on the immune system and against the SARS-CoV-2-induced cytokine storm.’ He said it is particularly interesting that the authors of the new study had reported more prevalent vitamin D deficiency among men than women, most likely because women are more often treated with vitamin D for osteoporosis. ‘The new study should prompt all clinicians and health authorities to seriously consider vitamin D supplementation as an additional tool in the fight against COVID-19, particularly for the prevention of infection in those at high risk of both COVID-19 and hypovitaminosis D, such as the elderly.’”

New guide to caregiving

A comprehensive [guide](#) — How to Be a Caregiver — has been prepared by The New York Times’ Tara Parker-Pope. The materials cover caregiving preparation and organization, finding help, self-care and caring and care during the pandemic. FCA is pleased to be mentioned and to have Client Services Director Christina Irving, LCSW, quoted.

Upcoming webcast on elder abuse

The National Center on Law and Elder Rights (NCLER) will webcast a program on elder abuse January 21, focusing on prevention, intervention and remediation. Registration information is available [here](#).

MEDIA WATCH

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- The elderly’s ‘crisis competence’ yields resilience

Caregiver contribution awes patient's oncologist

For Johns Hopkins cancer specialist Arjun Gupta, his experience with patient Ron and Ron's wife Lara opened his eyes to the critical contribution caregiving makes in the patient's journey and the doctor-patient relationship. "I realize," he **wrote** in The New England Journal of Medicine, "that as exciting as the science is, at its core, oncology remains fundamentally about relationships — not just between patients and oncologists, but also with caregivers. It's easy to overlook caregivers. Only when I read chronologically through all 500-plus of our emails do I fully appreciate Lara's burden. The day she misplaced the needles, she drove from the clinic to the pharmacy, picked up their daughter from school, brought her family home, walked the dogs, bought groceries, prepared dinner, and then spent hours catching up with a full-time professional job. I was fortunate to be able to rely on Lara, a superwoman, as a caregiver to Ron. Though better prepared than most caregivers, even Lara had occasional breakdowns, once weeping on an airplane. Other caregivers may not have a fraction of her capacity — they may need our care even more than the patient does. And their suffering, unfortunately, continues after their loved one dies. But so does their strength: a week after Ron enrolled in hospice, my phone pinged: 'Arjun, can I drop off the leftover osimertinib? (Ron's medication),' Lara asks. 'I don't want another patient to have to wait for insurance.'"

Granddaughter laments loved one's COVID treatment

"We spent much of my grandfather's last year on earth," **writes** his granddaughter Sarah Jones, "navigating an elder care system that was not designed to ensure his survival. My grandfather needed repeat visits to local emergency rooms for a persistent infection, and a pattern emerged. A hospital would admit him, conclude correctly that he needed rehabilitation, and transfer him to a skilled nursing facility for short-term care. That's when the clock would start. He had 20 days to get better, and if he didn't, he was on his own. Each hospital visit introduced a new risk of infection. So did each stay in rehab. He acquired a roommate with a cough. After he finished a course of antibiotics for his latest infection, he spent a brief interval at home before he had to be rushed back to the hospital. This time, he had COVID-19. A family's love can't regulate health care facilities. And no insurance plan can make up for injustices so large they can swallow a person whole. With more than 230,000 Americans dead from a virus that could have been contained, multitudes have plunged into mourning. Black seniors my grandfather's age have been killed at twice the rate of elderly whites. Some 13 million people have swelled the ranks of the unemployed, and one in three families with children now face food shortages. My grandfather's life was important, and not just to me. He was a human being who deserved the same level of dignity and peace that more fortunate men can purchase. He didn't have to die the way he did, in a small, cold room, separated from everyone he loved. All his hard work, all his responsibility, meant a pittance in the end. There is no justice but a fairer future."

Social isolation hastens COVID deaths

As 2020 came to its welcome end The New York Times took note in an **editorial** of one of the pandemic's cruelest byproducts. "Chronic loneliness increases the odds of an early death by about 20 percent. The stress hormones that come from feeling socially isolated can have as serious an impact on the human body as smoking or obesity, presenting such a public health crisis that the British government appointed a minister for loneliness in 2017. For elderly people who struggle to hear and see on phone and video calls, the loneliness of nursing homes could feel overwhelming even before the pandemic set in. Social isolation because of the coronavirus in nursing homes has increased depression, weight loss and other forms of physical deterioration, especially for Alzheimer's patients, who often need more help than understaffed centers can provide. 'We've lost part of the long-term care work force by restricting families,' said Dr. Sheryl Zimmerman, co-director of the Program on Aging, Disability and Long-Term Care at the University of North Carolina. 'Sure, the risk of spreading COVID-19 (or any other infectious disease) is less when visitors are restricted, but the consequence of social detachment may be greater, and this is a serious risk: we've known for more than 40 years that isolation increases death.'"

COVID 'hugging walls' foster life-affirming human touch

As nursing home residents, along with the rest of the population, await vaccination rescue from COVID-19, coping mechanisms have appeared in the form of clever interactive solutions. “Gary Witzenburg,” [writes](#) The Washington Post’s Petula Dvorak, “was stunned by what happened, wiping away tears with the back of his rough, 52-year-old hands as he sidestepped away afterward. Same with his mother, Gay Dixon, a 76-year-old, hair-done, born and raised Southerner who dressed up in an unstructured blazer for the occasion and was so shocked by the way it went, she unleashed a streak of salty words. What happened? The mother and son hugged. ‘I did not expect that,’ Witzenburg said, after embracing his mom for the first time since March, through a plastic ‘hugging wall’ that the folks at Dixon’s senior community created. They clung to each other for hug after hug, both of them sobbing, Dixon cursing, the plastic shower curtain crackling. Human touch has serious power, and while every touch between humans has the potential to transmit the coronavirus, the absence of touch is a slow, dull pain of its own. Applying pressure to a body sets off chemical and electrical internal workings that zing and ping through our nervous systems. Our heart rate slows, our blood pressure slows, the brain waves turn to theta. The production of stress hormones — namely cortisol — also slows. Cortisol targets natural killer cells — the cells that help enhance immunity. So without it, our natural immunity has a fighting chance, which is exactly what you want in a pandemic. ‘For less than \$100, our maintenance guys came up with this,’ the community’s chief executive Ben Unkle said. It’s a square of PVC piping hung from the portico of one of the entrances, with clear shower curtains hung all the way around and taped together to form a tight barrier. On a windy day last week, Dudley Haynie, 86, another resident, ducked into the clear stall to hug a carbon copy of himself, his 56-year-old son, Mark Haynie. ‘You don’t understand the power of touch until you’ve lost it,’ the son said.”

The elderly’s ‘crisis competence’ yields resilience

Finally, the power of innate human resilience: “A surprise of the pandemic,” [wrote](#) The New York Times’ John Leland on the first day of the new year, “has been how well many older adults have adapted to the restrictions. ‘There’s crisis competence,’ said Mark Brennan-Ing, a senior research scientist at Hunter College’s Brookdale Center for Healthy Aging. ‘As we get older, we get the sense that we’re going to be able to handle it, because we’ve been able to handle challenges in the past. You know you get past it.’ Catherine Thurston, chief program officer at Service Program for Older People, which provides mental health services, said her staff had seen this kind of resilience in many older clients this year. ‘They’ve been a real lesson for us,’ she said. ‘I often tell the story of my own parents, who were Holocaust survivors. And after 9/11 it was so good to talk to them, because they said, “Look, horrible stuff happens, and people rebound from it.” A motto to take into the new year: Horrible stuff happens, and people rebound from it.’”

FAMILY CAREGIVER ALLIANCE ANNOUNCEMENTS

FCA’s Christina Irving featured on KQED Forum

Earlier this month, FCA Client Services Director Christina Irving, LCSW, was a guest on San Francisco public radio station KQED’s [Forum](#). The day’s program, ***Caregivers Shoulder Increased Burdens During Pandemic***, also included guests Donna Benton, Research Associate Professor of Gerontology and director of the [Family Caregiver Support Center](#), USC Leonard Davis School of Gerontology, and [Jessica Zitter](#), palliative and critical care physician and co-director of the documentary short, *Caregiver: A Love Story*.

[Listen to the program here.](#)



Expect the Best: *How to Get the Most Out of Your Hospice Care*

Choosing hospice for yourself or a loved one can be a challenging task. Guests Helen Bauer and Jerry Fenter, from [The Heart of Hospice](#), will share ways to choose an agency that's a good fit and what to expect from your care team. The presentation will also debunk myths about hospice care and educate you about how to navigate the end-of-life experience. Participants will learn about: hospice myths and misinformation; how to choose a hospice agency; rights of the patient and caregiver; and learn about the hospice interdisciplinary team.



When: Wednesday, January 27, from 11 a.m. to 12 noon (PT)

Where: ONLINE

Cost: No Charge

Contact: Calvin Hu, chu@caregiver.org

Registration: [Click here](#)

Online classes from the California Caregiver Resource Centers

Family Caregiver Alliance (FCA) hosts a calendar of online classes, workshops, and events — compiled from the 11 California Caregiver Resource Centers (CRCs) — and open to family caregivers across the country. To view the list of CRC offerings in January, or download a PDF of the flyer, please [click here](#). The [California Caregiver Resource Centers \(CRC\)](#) serve families and caregivers of adults affected by chronic and debilitating health conditions (FCA is the San Francisco [Bay Area CRC](#)).



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Send your feedback or questions to akkaplan@verizon.net or info@caregiver.org.

FCA TWEETS [@CaregiverAlly](#)



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2020 was tough. If you have patients or clients whose family caregivers have been struggling, let them know we have 14 free, expert-led webinars on self-care for caregivers. #caregiving #caregiving caregiver.org/fca-webinars



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FCA/NCC RESEARCH REGISTRY

LIST YOUR STUDY

Professional Studies

- [The Impact of Emotions on Social Distancing among spousal caregivers for Alzheimer's disease or related dementias during the COVID-19 Pandemic](#)
- [Social Connection During COVID-19](#)
- [Do you provide care for a spouse or partner recently diagnosed with a memory problem?](#)
- [The Pain Identification and Communication Toolkit \(PICT\) for Family Caregivers of Persons with Dementia](#)
- [Seeking Family Caregivers of Adults with Disorders of Consciousness Following a Brain Injury: a Survey Study](#)
- [Development of the Caregiver Assisted Transfer Technique \(CATT\) Instrument](#)
- [Experiences of Family Caregivers during the COVID-19 Pandemic](#)
- [Family Caregivers of persons in Long-term Care Facilities](#)
- [Life Enhancing Activities for Family Caregivers \(LEAF\) \(SP0044459; NCT03610698\)](#)
- [Residents, family members and professionals needed for assisted living research interviews](#)

Graduate Studies

- [Pilot study of an education and skills training program for caregivers post-stroke](#)
 - [Exploring the impact of compassion fatigue and burnout among family caregivers: Consider taking the PROQOL](#)
 - [Complete a 30-minute survey at home!](#)
 - [Caring for Family with Dementia: The Impact of Paid Family Leave](#)
 - [Exploring the Use of Weighted Blankets as a Non-Pharmacologic Intervention for Home Dwelling Older Adults with Dementia](#)
 - [Dementia Family Caregiver Needs Assessment Project](#)
 - [Seeking Family Caregivers of Adults with Disorders of Consciousness Following a Brain Injury: a study evaluating the development of a Recovery Ruler](#)
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If you shop on Amazon please consider supporting FCA through AmazonSmile. Amazon will donate to FCA based on your purchase. All you need to do is use the following link when you shop: smile.amazon.com/ch/94-2687079.

Are You Receiving Connections?

FCA's Connections e-newsletter focuses on issues and information important to family caregivers. The newsletter regularly covers tips, articles, and helpful advice that can assist families with the numerous daily care tasks that caregiving for loved ones presents—including the often overlooked “caring for yourself.” While much of the content can prove helpful to caregivers nationwide, the events included are local to the six-county region of FCA’s Bay Area Caregiver Resource Center.



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