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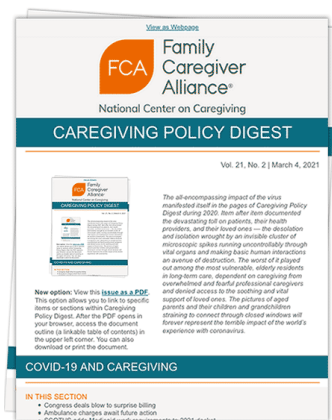
National Center on Caregiving

CAREGIVING POLICY DIGEST

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A NEW LOOK!

Read about FCA's new logo, brand changes, and updated website in the FAMILY CAREGIVER ALLIANCE ANNOUNCEMENTS section below.



New option: If you prefer, you can view and read this issue as a PDF. This option allows you to link to specific items or sections within Caregiving Policy Digest. After the PDF

The day had finally arrived. After nearly a year in lockdown for the residents of Good Shepherd Nursing Home their coronavirus vaccinations were finished and the hallways were slowly beginning to reawaken. West Virginia has emerged as one of the first states to finish giving two doses of vaccines to the thousands of people inside its nursing homes, so Good Shepherd, a 192-bed Catholic home in Wheeling, was among the first facilities in the country to begin tiptoeing back toward normalcy. The first day back was full of ordinary moments: small talk over coffee, bidding wars at an afternoon auction, a game of dice. But after a year of loss, loneliness and disruption, the very ordinariness of it all brought joy and relief. In the lobby of a stained-glass chapel, Frank and Phyllis Ellis savored a quiet reunion. Mr. Ellis, 91, lives at the couple's home in Wheeling, while Ms. Ellis, 87, stays at Good Shepherd. During 69 years of marriage, the Ellises said, they have never spent so much time apart as during the last year. The Ellises' visits are short and sterile: she in a surgical mask, he in a gown, N95 mask and plastic face guard. He does not even think about kissing her, he said, for fear of putting her at risk. When their time together

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ends, she cannot leave with him, as she used to do for Christmas and other special occasions. She longs for the comforts of home, for her children and grandchildren. He longs for her and even their marital spats. "We were always fighting," he said. "I miss that."

— [Sarah Mervosh](#), *The New York Times*

University of Pennsylvania Memory Center's Dr. Jason Karlawish thinks that blanket bans on dementia caregivers are akin to taking away a wheelchair from a person with physical disabilities. "That's a brutal metaphor," he said. "But all of a sudden, the people who would come there and help their minds function were taken away." Jill Harrison, an executive director of the National Institute on Aging's IMPACT Collaboratory, thinks the instinct to lock everything down reflects a broader tendency in dementia care to prioritize physical safety above all else. She told me about a nursing home resident with dementia who liked to dance by his window: "One day he fell. And the response from the nursing home was: 'We're not going to turn on the music anymore.' Shouldn't we be helping him find a way to dance? I always call it surplus safety," Dr. Harrison told me. "It's essentially like, we are going to keep you safe, even if it kills your spirit."

— [Katie Engelhart](#), *The New York Times*

Biden Joins COVID-19 on Center Stage

Slot by slot and piece by piece the contours of the new Biden administration's health policy lineup and agenda are emerging — and the presence of a new sheriff in town is clearly apparent.

The president's choice for HHS Secretary, former Congressman and current California Attorney General, Xavier Becerra, appeared set for confirmation after two days of Senate oversight testimony. Biden's expected choice for the critical post of CMS administrator, Chiquita Brooks-LaSure, will likely pass Senate muster as well. Both individuals bring extensive experience battling for expanded healthcare coverage through the Affordable Care Act and Medicare and Medicaid.

Biden to Supreme Court: Uphold ACA

The administration did not wait until every appointee is in his or her place before weighing in on two of its predecessors' most contentious healthcare stands: asking the Supreme Court, on the one hand, to declare Obamacare unconstitutional and, on the other hand, uphold the legality of CMS-imposed Medicaid work requirements. With respect to the ACA, the Center for Medicare Advocacy [reported](#), "In a letter to the Court, lawyers for the government said that following the change in administration, the Department of Justice has reconsidered, and its position is that the law's individual mandate — which now carries no penalty for failure to carry health insurance — is constitutional. The government also stated that even if the Court finds that that provision of the ACA is unconstitutional, it is 'severable' from the rest of the law, meaning the entire rest of the ACA does not have to fall along with the mandate."

Biden to states: Nix Medicaid work requirements

As for Medicaid work requirements, [reported](#) Modern Healthcare's Michael Brady, "CMS has withdrawn a 2018 letter from former CMS Administrator Seema Verma to state Medicaid officials that invited them to apply for the work waivers. The agency also reversed its approval for Georgia's partial Medicaid expansion, which is now 'pending.'" And, according to Politico, "CMS will also send a letter to 10 states that have already received waivers for Medicaid work rules, informing them that the agency will repeal them soon. In a letter to Arkansas, the agency said it had 'preliminarily determined that allowing work and other community engagement requirements to take effect in Arkansas would not promote the objectives of the Medicaid program.' At the same time, eyeing a March 29 scheduled Supreme Court argument on Arkansas and New Hampshire's work requirement waivers, the Biden administration has requested a delay citing 'greatly changed circumstances.'" "The high court," the AP [explains](#), "had in December agreed to review lower-court decisions involving Arkansas and New Hampshire that found that the Trump administration's support for work requirements went beyond what's allowed by law. Arkansas is opposing the Biden administration's request that the cases be dropped, writing in a brief that the 'central question in these cases — what Medicaid's objectives are — will likely return' to the Supreme Court and that the need to decide the cases is 'as pressing today' as when the court agreed to hear them in December."

COVID-19 AND CAREGIVING

IN THIS SECTION

- Nursing homes open arms to COVID-19 vaccines
- SNF family caregivers await vaccine protection
- SNF workforce issues pose ongoing challenge
- SNF ownership maneuvers raise quality concerns
- LTCCC highlights state-by-state SNF staffing data
- CMA: Abolish the SNF three-day hospital stay entry requirement

Nursing homes open arms to COVID-19 vaccines

At last, some good news about nursing homes? “For the first time since the American COVID-19 outbreak began roughly a year ago — at a nursing care center in Kirkland, Wash. — the threat, inside nursing homes,” [reported](#) The New York Times writers in late February, “may have finally reached a turning point. Since the arrival of vaccines, which were prioritized to long-term care facilities starting in late December, new cases and deaths in nursing homes, a large subset of long-term care facilities, have fallen steeply, outpacing national declines. The turnaround is an encouraging sign for vaccine effectiveness and offers an early glimpse at what may be in store for the rest of the country, as more and more people get vaccinated. From late December to early February, new cases among nursing home residents fell by more than 80 percent, nearly double the rate of improvement in the general population. The trendline for deaths was even more striking: Even as fatalities spiked over all this winter, deaths inside the facilities have fallen, decreasing by more than 65 percent. At Valley Senior Living in Grand Forks, N.D., more than 90 percent of residents agreed to be vaccinated. The high rate of uptake, combined with low levels of community transmission, has meant that life is slowly inching back to normal for the 400 or so people who live in the facility’s nursing and assisted living centers. They are singing in choirs, albeit masked and spaced apart. There was even a recent Mardi Gras parade, complete with beads and music. ‘Things are better,’ said Garth Rydland, the chief executive at Valley Senior Living. ‘You kind of knock on wood every time you say something like that, but now, I feel a lot more confident.’”

SNF family caregivers await vaccine protection

Tempering the good news with a [cautionary note](#), Kaiser Health News’ Judith Graham writes that “Tens of thousands of middle-aged sons and daughters caring for older relatives with serious ailments but too young to qualify for a vaccine themselves are similarly terrified of becoming ill and wondering when they can get protected against the coronavirus. Like aides and other workers in nursing homes, these family caregivers routinely administer medications, monitor blood pressure, cook, clean and help relatives wash, get dressed and use the toilet, among many other responsibilities. But they do so in apartments and houses, not in long-term care institutions — and they’re not paid. ‘In all but name, they’re essential health care workers, taking care of patients who are very sick, many of whom are completely reliant upon them, some of whom are dying,’ said Katherine Ornstein, a caregiving expert and associate professor of geriatrics and palliative medicine at Mount Sinai’s medical school in New York City. ‘Yet, we don’t recognize or support them as such, and that’s a tragedy.’ The distinction is critically important because health care workers have been prioritized to get COVID vaccines, along with vulnerable older adults in nursing homes and assisted living facilities. But family members caring for equally vulnerable seniors living in the community are grouped with the general population in most states and may not get vaccines for months. In Tomball, Texas, Robin Davidson’s father was independent before the pandemic, but he began declining as he stopped going out and became more sedentary. For almost a year, Davidson has driven every day to his 11-acre ranch, five miles from where she lives, and spent hours tending to him and the property’s upkeep. ‘Every day, when I would come in, I would wonder, was I careful enough [to avoid the virus]? Could I have picked something up at the store or getting gas? Am I going to be the reason that he dies? My constant proximity to him and my care for him is terrifying.’”

SNF workforce issues pose ongoing challenge

As vaccination rollouts increasingly spread a protective shield over long-term care facilities, assessments seeking long-term solutions to prevent future coronavirus-like destructive swaths are also increasing. For one group of Health Affairs blogger’s, the focus is on “key workforce challenges.”

“The tragedy experienced within the LTC system,” they [write](#), “has been attributed to workforce challenges and wide variation in quality of care. The impact of COVID-19 across LTC facilities has not been uniform. Those nursing homes serving populations significantly composed of African Americans and Latinx patients have been twice as likely to face a COVID-19 outbreak compared to facilities with a majority white patient population. The trends driving these disparities precede COVID-19. Nursing homes that rely on Medicaid payment rates — which are lower than Medicare and private payers’ rates — have long struggled with the interlocking challenge of financial insecurity that, in turn, undermines professional staff recruitment and capacity. Across the United States, nursing homes with lower staff-to-resident ratios are more likely to serve Black patients. Furthermore, more severe quality problems were experienced by nursing homes that disproportionately served Black residents. State and federal officials have responded to these deficiencies with punitive measures. Nursing homes that disproportionately serve Black patients were at greater odds of having their Medicaid and Medicare programs terminated due to poor quality, including insufficient staffing levels. This approach creates a circular depreciation of quality, further harming patients of color and patients with untreated chronic diseases, historically underserved by the health care system.” Possible solutions: a federal minimum wage for nursing home workers, federal minimum staffing levels, and an end to federally mandated lockout periods that unfortunately prevent penalized SNFs from training CNA’s for two years. “Correcting the inequitable state of quality of care provided within long-term care facilities, specifically nursing homes, requires policy makers to intervene in workforce infrastructure. This requires multiple policy interventions operating together. For newly enforced federal staffing mandates and federal minimum wage requirements to be feasible, the federal government needs to provide supplementary funding to assist with additional hiring, compensating, and training of staff. Pursuing all three policy options would represent a step toward prioritizing equity and centering the improvement of care for patients of color disproportionately impacted by the disfunction of the existing long-term care system.”

SNF ownership maneuvers raise quality concerns

While issues involving frontline staff have dominated SNF-related discourse, nursing home ownership, management and financial elements have also come under much scrutiny. “The federal government,” [writes](#) a second group of Health Affairs bloggers, “doesn’t have specific quality and financial standards for approving changes in ownership or management such as meeting minimum staffing standards; meeting quality, life safety, and emergency regulations; preventing abuse and neglect of any residents; complying with financial and ownership reporting requirements; having liability and other insurance coverage; and having adequate financial reserves. In some cases, states have not made any decisions about changes in nursing-home ownership and management for years and have de facto allowed ownership and management changes that do not meet a reasonable standard to ensure resident safety and quality of care. By not establishing and enforcing ownership and management screening requirements, CMS also allows unsuitable persons or companies to acquire and operate facilities.” Among the authors’ recommendations: new federal regulations specifying minimum criteria for the purchase (or change of ownership) or management of any nursing home; a prior approval process for changes in ownership or management; and new cost report requirements calling for each nursing home to provide an annual consolidated financial report. “The reports should provide flow charts of all related party entities including home offices, management organizations, staffing, therapy, supply, pharmaceutical, consulting, insurance, banking, investment entities, parent companies, holding companies, and sister organizations.”

LTCCC highlights state-by-state SNF staffing data

Long-term care residents and family members have a [new tool](#) with which to assess SNF care capability: the Long Term Care Community Coalition’s publication of its latest user-friendly data on staffing for every U.S. nursing home. “The latest federal data indicate that U.S. facilities remained understaffed during the 3rd quarter of 2020. The nationwide averages fall short of the amount of time needed to ensure that residents receive clinical care. Meanwhile, nursing homes have experienced a drastic decline (12.2%) in resident population nationwide since the start of the pandemic. Despite receiving billions of dollars in COVID relief aid, too many facilities are failing to invest in the staffing required to meet their residents’ needs. LTCCC’s Q3 2020 staffing report provides easy-to-use files for every state that include: 1) the levels of care staff; 2) staffing levels for important non-nursing staff, including administrators and activities staff; and 3) the extent to which the facility relies on contract workers to provide resident care.”

CMA: Abolish the SNF three-day hospital stay entry requirement

The Center for Medicare Advocacy (CMA) has [reemphasized](#) its support for a major legislative change in the three-day hospital stay prerequisite for SNF care. While currently, due to the coronavirus emergency, the fee-for-service Medicare program's requirement is on hold, CMA argues, "because of changes in medical care over the half century since enactment of the original Medicare legislation, it may now be medically appropriate for some patients to receive skilled nursing care and/or rehabilitation services provided by SNFs without a prior inpatient hospitalization, or with an inpatient hospital length of stay of less than three days. Repealing the three-day inpatient hospital requirement reflects the realities of modern medicine. In addition, over the last 20 years, acute care hospitals have increasingly described patients as receiving care in observation stays. Observation is an outpatient status, which does not qualify patients for Part A SNF coverage, even though the care and services that observation patients receive may be indistinguishable from the care and services received by inpatients and even when observation patients have been hospitalized for three days or more. The HHS Office of Inspector General has called for ensuring that all Medicare beneficiaries have the same access to post-hospital care in a SNF, regardless of how their hospital stays are classified. While Congress addressed 'surprise' private insurance medical bills in the Consolidated Appropriations Act, Congressman Joseph Courtney (D-CT) has described observation status for Medicare beneficiaries as 'surprise medical bills on steroids.'"

CMA is offering a series of webinars dealing with current Medicare and Medicaid issues, including COVID-19 legislative updates, CMS waiver policies, home care access and telehealth coverage. The first program was aired in early February and may be viewed [here](#). A webinar focusing on home health will occur March 24; register [here](#).

RESEARCH AND RESOURCES

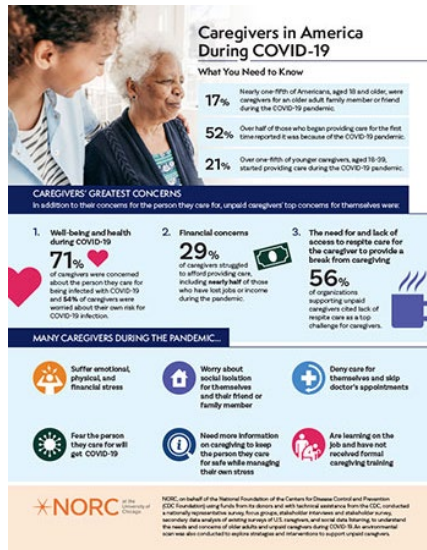
IN THIS SECTION

- NAM assesses dementia caregiver interventions
- NORC dissects needs for pandemic-related assistance
- AARP urges family caregiver payments
- COVID-19 strikes dementia patients harder
- Elderly 'prediabetes' get some good news
- Policy makers target Family Responsibilities Discrimination
- CHCS project supports states' family caregiver assistance programs
- Crisis Standards of Care concerns during COVID-19
- Medical home care delivery expands

NAM assesses dementia caregiver interventions

The National Academy of Medicine has [published](#) an extensive report examining the Challenge of Caring for Persons Living with Dementia and Their Care Partners and Caregivers. In accordance with the study charge, the committee's primary source of evidence was a systematic review of available evidence on care interventions for persons living with dementia and their care partners and caregivers commissioned and overseen by the Agency for Healthcare Research and Quality (AHRQ) and conducted by the Minnesota Evidence-based Practice Center. "(Our) review," the report concludes, "identified no interventions that met criteria for high-strength or moderate evidence of benefit and just two types of interventions supported by low-strength evidence of benefit: (1) collaborative care models, which use multidisciplinary teams that integrate medical and psychosocial approaches to the care of persons living with dementia; and (2) a multicomponent intervention aimed at supporting family caregivers known as REACH (Resources for Enhancing Alzheimer's Caregiver Health) II, along with associated adaptations." While the evidentiary assessment thus found limited proven beneficial interventions, NAM's more than 200-page report provides a rich journey into the dimensions of the dementia care crisis, the broad scope of efforts to confront it, and recommendations for how best to enlarge the universe of documented care successes. "The committee," the report observes, "also considered additional sources of evidence, including expert and stakeholder input and such resources as [Best Practice Caregiving](#), a database resulting from a joint project of the **Benjamin Rose Institute on Aging**, **Family Caregiver Alliance**, and the **Gerontological Society of America**. Best Practice Caregiving provides information derived from real-world implementation of interventions and was helpful in identifying interventions (or adaptations

thereof) evaluated in the AHRQ systematic review that had been implemented in practice settings.”



NORC dissects needs for pandemic-related assistance

NORC-University of Chicago has issued a wide-ranging 120-page [study](#) that addresses the maintenance of the physical and mental well-being of older adults and caregivers during a public health emergency such as the current COVID-19 pandemic. The final report “pays particular attention to subpopulations disproportionately impacted by COVID-19, including racial and ethnic minorities, individuals with disabilities, rural populations, tribal populations, populations with limited English proficiency, and socioeconomically disadvantaged populations. Among the many findings: Older adults expressed the need for three key types of assistance during the pandemic: food delivery services, help with technology, and accurate information about COVID-19. These needs differed by subpopulation. For example, older adults with low socioeconomic status needed help with getting household supplies; paying for basic expenses such as rent,

food, or health care; prescription drugs; and home energy costs. Older adults with disabilities needed assistance with exercise options, in-home care, and cleaning. Caregivers’ needs and concerns included their own physical and mental health, the care recipient’s physical and mental health, financial concerns, and the need for respite care to give them temporary relief from caregiving responsibilities. Our environmental scan focused on five key areas of interest: deconditioning, deferral of medical care, management of chronic conditions, social isolation, and elder abuse and neglect. The scan found that these areas can have a cascading, deleterious effect on older adults and caregivers during the COVID-19 pandemic. Social isolation has become problematic for older adults who must manage chronic conditions, given perceived threats of contracting the virus if they visit a health care setting or hospital. Misconceptions about COVID-19 and financial hardships resulting from the economic recession may motivate older adults to defer or forgo medical care. A reduction or loss of medical care for older adults — especially those with multiple chronic conditions — may result in negative long-term health consequences. Caregivers, too, face social isolation and financial stressors resulting from the pandemic, and COVID-19 has severely compromised their ability to effectively provide care for older adults as well as themselves.”

Editors note: Click the image to download NORC's 8.5"x11" infographic

AARP urges family caregiver payments

The latest publication in AARP’s LTSS Choices series focuses on “Paying Family Caregivers to Provide Care during the Pandemic and Beyond.” The [report](#) includes a state-by-state analysis of family caregiver rules pertaining to “self-direction” programs serving older people and people with physical disabilities. When COVID-19 cases mounted during the spring of 2020, the report observes, “state Medicaid agencies swiftly expanded their self-direction programs to allow more family members to be hired and paid as caregivers. Such action was taken to protect continuity of care for vulnerable individuals, the majority of whom are older people and people with physical disabilities. Over 15 states issued temporary emergency rule changes permitting Medicaid waiver programs to give participants in self-direction programs the choice to hire family members to provide their care. Medicaid-funded self-direction programs are available in all states and the District of Columbia and offer a clear pathway that can enable states to allow family members to be paid to provide care to older family members and adult family members with disabilities. State Medicaid agencies should consider implementing permanent policies that encourage and facilitate paid family caregiving. While raising Medicaid reimbursement rates to attract more professional direct care workers may not be possible during a time of budget shortfalls, allowing family members to join the paid home care workforce expands access to cost-effective and safe HCBS for Medicaid beneficiaries who need it. States should also ensure that easy-to-understand information about their self-direction opportunities is available in a variety of formats to help expand access to these programs.”

COVID-19 strikes dementia patients harder

Case Western Reserve University researchers, [reports](#) The New York Times’ Pam Bellock, have documented yet another distressing risk of dementia: “People with dementia had a significantly greater risk of contracting the coronavirus, and they were much more likely to be hospitalized and die

from it, than people without dementia. Experts said the reasons for this vulnerability might include cognitive and physiological factors. ‘Folks with dementia are more dependent on those around them to do the safety stuff, to remember to wear a mask, to keep people away through social distancing,’ said Dr. Kenneth Langa, a professor of medicine at the University of Michigan.” UCSF neurologist Dr. Kristine Yaffe pointed to a “frailty element” affecting people with dementia, including a lack of mobility and muscle tone, that could affect their resilience to infections. And the Alzheimer’s Association’s chief science officer Maria Carrillo noted that coronavirus infection was associated with an inflammatory response that has been shown to affect blood vessels and other aspects of the circulatory system. Many people with dementia already have vascular impairment, which may be compounded or amplified by COVID-19. A cautionary observation from Dr. Langa: the data “reflected only people who have interacted with the health care system, so it doesn’t include more isolated and poorer patients that have a harder time getting to doctors. The study may be an underestimate of the greater COVID infection risk for those with dementia.”

Elderly ‘prediabetics’ get some good news

In this terrible time of COVID-19 any bit of good news is to be cheered. So, might the elderly have one less thing to worry about? Possibly, as Paula Span [reports](#), because “a new longitudinal study of older adults found that over several years, older people who were supposedly prediabetic were far more likely to have their blood sugar levels return to normal than to progress to diabetes. And they were no more likely to die during the follow-up period than their peers with normal blood sugar. ‘In most older adults, prediabetes probably shouldn’t be a priority,’ said Elizabeth Selvin, an epidemiologist at the Johns Hopkins Bloomberg School of Public Health in Baltimore and the senior author on the study. Prediabetes, a condition rarely discussed as recently as 15 years ago, refers to a blood sugar level that is higher than normal but that has not crossed the threshold into diabetes. It is commonly defined by a hemoglobin A1C reading of 5.7 to 6.4 percent or a fasting glucose level of 100 to 125 mg/dL; in midlife, it can portend serious health problems. UCSF geriatricians Kenneth Lam and Sei Lee argue for a case-by-case approach in older adults — especially if a diagnosis of prediabetes will cause their children to berate them over every cookie. For a patient who is frail and vulnerable, ‘you’re likely dealing with a host of other problems,’ Dr. Lam said. ‘Don’t worry about this number.’”

Policy makers target Family Responsibilities Discrimination

“An employee was approved for intermittent family leave to care for her mother. When she told her supervisor that she needed to use the leave to take her mother to a medical appointment, she was denied the day off. The employee nevertheless took her mother to the appointment and was terminated for ‘voluntarily abandoning’ her job. That vignette serves as an illustration of Family Responsibilities Discrimination (FRG), the subject of an extensive new [report](#) from The Center for WorkLife Law at UC Hastings College of the Law, AARP, The Commonwealth Fund, and The SCAN Foundation. Existing federal laws provide only limited protection from discrimination for employees who care for children, older adults, ill spouses, or other family members with a chronic, disabling, or serious health condition. Better protection may come from a lesser-known source: state and local laws. These laws specifically prohibit employment discrimination that occurs because of family caregiving. The laws vary in their scope, with most protecting only employees who care for minor children. Others have a broader reach and protect employees who care for any family member, including parents, parents-in-law, grandparents, and adult family members with disabilities. In addition to prohibiting discrimination, many of the laws let employees sue their employers in court for monetary damages and other relief — which makes the laws more useful to employees and more dangerous for employers to ignore. Delaware, for example, passed a law that broadly prohibits discrimination against employees because they care for adult family members. Three other states have laws that are more limited in protection but could be expanded to include family caregivers. Of local jurisdictions (cities, towns, villages, or counties), 191 have passed laws prohibiting workplace discrimination against family caregivers, but only 17 percent of these laws specifically include employees who care for adult family members.

CHCS project supports states’ family caregiver assistance programs

The Center for Health Care Strategies (CHCS) has [announced](#) that eight states — Indiana, Iowa, Michigan, Minnesota, New York, Tennessee, Texas, and Washington — have been selected to join the second phase of Helping States Support Families Caring for an Aging America, a multi-state collaborative aimed at strengthening state-based opportunities to support family caregivers of older adults. Over two years, the participating states will receive technical assistance from CHCS and

leading experts as well as benefit from peer-to-peer learning opportunities to help develop and/or enhance strategies to assist family caregivers. Areas of focus include: strengthening family caregivers' capacity through use of new technologies, increased access to respite care, and formal training for family caregivers; establishing robust data collection strategies to enhance programs or inform policies to support family caregivers; and building formal cross-sector partnerships across aging, housing, transportation, and health plans in a deliberate and strategic way to better support family caregivers' needs. For more information, [visit here](#).

Crisis Standards of Care concerns during COVID-19

While receding in recent weeks, COVID-19's enormous strains on the availability of crisis hospital care spawned various state efforts to develop resource allocation policies that in some cases aroused advocates fears of denials of care to the elderly. Justice In Aging has now published a [report](#) summarizing its work in five states — Utah, Texas, Massachusetts, Oregon, and Florida — to address these issues.

Medical home care delivery expands

Spurred by COVID-19 risks of institutional exposure and the explosion of technology-enabled home care options, the momentum towards medical home health care delivery is accelerating:

- “Medicare patients seeking emergency care at Michigan Medicine’s University Hospital in Ann Arbor,” [reports](#) Modern Healthcare’s Jay Greene, “will soon have the option of returning home in a cutting-edge hospital at-home program. Over the last year, doctors at Michigan Medicine have been developing various programs and alternatives to hospitalization for patients with congestive heart failure, cellulitis, chronic obstructive pulmonary disease, pneumonia or urinary tract infections, said Dr. Grace Jenq, a geriatrics specialist and associate chief clinical officer for post-acute care at Michigan Medicine. The five health conditions were selected based on the ability to treat at home and because of the high readmission rates for the conditions. ‘The pandemic has driven the desire by patients to be at home whenever possible, and the need for hospitals to innovate in expanding our ability to care for patients with COVID-19 and those without,’ said Jenq. ‘We take great care to ensure that each patient who receives care under these programs can do so safely, and with the help of our skilled team members and partners.’ Patients discharged to home are monitored by Michigan Medicine physicians, nurse practitioners, nurses, paramedics, social workers and other remote-monitoring team members. Remote monitoring equipment for patients includes a special computer tablet for telemedicine conversations and a kit of Bluetooth home-monitoring tools that analyze blood pressure, blood-oxygen levels, weight, blood sugar, temperature and other vital signs. Some patients will decline because they might feel more comfortable in a hospital bed. ‘There are other patients who have experienced the hospital before, and may be more reluctant to go,’ Jenq said. ‘They may say, “I don’t really want to have to go into the hospital where I don’t get to see my family, I don’t get to be in my home. If you can bring me the medications and the nursing and the doctors out to my home, come to my house.”’”
- In another sign of the times, [writes](#) Modern Healthcare’s Nona Tepper, “Humana has partnered with in-home service provider DispatchHealth to offer in-home emergency and acute care to its 8.4 million Medicare members, as demand for out-of-office treatment rises during the COVID-19 pandemic, particularly among those living with chronic conditions. The Denver-based home healthcare provider offers patients 24/7 remote monitoring by an internal medicine physician specialized in ER training, a physician’s assistant and a nurse practitioner, along with daily visits from providers, including bedside nursing. Susan Diamond, president of Humana’s Home Business, said the agreement makes Humana the country’s first national payer to provide acute, hospital-level care in the home. ‘We’re going to see fewer readmissions and less post-acute care because Dispatch will really take a 30-day episode of care approach and provide more care than you’d see in just a traditional facility-based setting,’ In addition to meeting beneficiaries’ medical needs, DispatchHealth said it can address the social determinants of health, like food insecurity, social isolation and housing instability. The company can also coordinate members’ pharmacy deliveries, offer physical and respiratory therapy, imaging services and more.”
- Providing a conceptual, historical and modeling resource, the California Health Care Foundation has [published](#) Medical Care at Home Comes of Age. Models spanning the home- and community-based care continuum deliver a broad spectrum of services across primary, urgent, acute hospital, and post-acute levels of care. Some models provide longitudinal care (continuous over an extended period of time). Other models provide episodic care (primarily confined to a single incidence or time-limited episode of care over days to weeks), such as

community paramedicine, Hospital at Home, transitional care models, and rehabilitation at home. Given the diverse and often complex needs of the patients served, certain home-based medical models, such as home-based palliative care, may provide both longitudinal and episodic home-based medical care.

MEDIA WATCH

- Kate Washington articulates caregiving stresses
- Katie Engelhard explores pandemic's toll on dementia sufferers
- Younger disabled COVID-19 patients seek vaccine access
- Rabbi Kukla counters treatment of 'disposable' people
- 'Wrongful life' lawsuits attack disregard of advance directives
- 'Citizen scientists' tackle COVID-19 research gaps
- Barron's dives into Alzheimer's crisis
- Financial advisors focus on Alzheimer's wealth destruction
- Dr. Vais takes on her patients' isolation
- The need for human touch suffers severe deprivation

Kate Washington articulates caregiving stresses

Kate Washington, whose new [book](#) on caregiving will be published March 16, previews it in a fervent call-out for help on behalf of families with sick loved ones. Five years ago, she [writes](#) in The New York Times, "I stood in a tiny hospital room wondering how I was going to care for the man I loved most without succumbing to despair. For four months, my husband, Brad, had been recovering from a stem-cell transplant that saved his life from aggressive lymphoma. The hospital administration said he must go home, but he needed a level of support that, I thought, only a hospital could provide. I became painfully familiar with caregiving's challenges during Brad's months of chemo in 2015, but it was his 2016 stem-cell transplant — a last-ditch treatment for relapsed cancer — that showed me just how broken our system is. When he was discharged, he was immunocompromised, blind, too weak to walk unassisted, and unable to eat more than half his calories. 'He'll need attendance 24 hours a day,' his oncologist told me. I stared, panic rising. 'How am I supposed to do that? We have two kids,' I said. 'Well, usually family steps in, and it works out fine,' the doctor replied, waving away my concerns. Brad came home with 35 medications that had to be administered on a mind-boggling schedule, as well as intravenous nutrition that I had to hook up, a complex procedure that I learned to perform in a hasty training session from a nurse. He needed blood sugar tests and assistance with toileting, showering and other intimate acts at which even close friends might well balk. Even though I had support systems and family to help, and we could afford supplemental care, my husband's long medical ordeal was almost unbearably stressful. Supporting a catastrophically ill person will never be easy — but in the United States today, it's far harder than it needs to be. Our system largely abandons those with less privilege than I have to struggle alone caring for those we love most. The result for many is burnout, bankruptcy and profound suffering."

Katie Engelhard explores pandemic's toll on dementia sufferers

Katie Engelhard, another new [author](#), turns her attention in a New York Times [op-ed](#) to the particular impact of COVID-19 restrictions on dementia sufferers. "The death toll," she writes, "tells one story. Even compared with others in their vulnerable age group, people with dementia are more likely to get COVID-19 and are significantly more likely to die of it. Dementia responds well to routine: rigid, time-blocked schedules and familiar faces. But the pandemic has shown us, and warned us, how quickly the fragile channels of dementia care — the muddled blend of formal and informal networks that sustain those routines — can collapse under strain. When a daily routine falls apart, a person with dementia can seem to fall apart, too. Around the country, geriatricians describe an acceleration of decline — one that they say has not yet been captured and construed by academic literature, but that they see play out in the bodies and minds of their patients. People with dementia are losing things faster than they should: weight, words, functional abilities, their remaining sense of self. There's a question among geriatricians about what our COVID-era response to dementia care says about the future of dementia care: whether all the suffering and the deaths and the aloneness bodes poorly for patients and future patients, or whether the pandemic might inspire a change of direction. There has been so much attention on nursing homes and their failures — on elder care and its burdens. Where people come down on this question depends in part on whether they accept the chancy idea that

‘awareness’ of the problem, having been raised, will make a difference.”

Younger disabled COVID-19 patients seek vaccine access

Amid the chaos of the COVID-19 vaccine rollout, [writes](#) San Francisco’s KQED reporter Matthew Green, advocates from within the disabled community have made their voices heard concerning the vaccine distribution’s priority list. “When Alice Wong found recently that younger people with disabilities in California may have to wait many more months to receive the COVID-19 vaccine, her heart sank. ‘This really took my breath away,’ said Wong, a San Francisco-based disability rights activist and host of the [Disability Visibility podcast](#). Wong has a rare neuromuscular disease that requires her to use an electric wheelchair and ventilator. ‘I’m so angry, so sad and so scared. Not just for myself, but for the many people in my community that I care about.’ Added Andy Imparato, executive director of Disability Rights California, ‘I think a lot about very young, disabled, critically ill and immunocompromised people who could die before it’s their turn to be vaccinated. Our message is not to make people over 65 wait. Our message is don’t make everybody else wait while you’re doing people over 65. People with disabilities who are most at risk should be prioritized alongside farmworkers, teachers and people over 65. We’re not trying to supplant those other groups, we want to have access at the same time as those other groups.’ State health officials, however, have consistently pushed back, arguing that there’s little reliable data showing people with disabilities are at significantly higher risk for hospitalization or death from COVID-19. Meanwhile, the data showing risk for people over 65 is unequivocal. ‘People 85 years or older have a 630 times higher death rate,’ said epidemiologist Dr. Erica Pan. ‘Those over 75 years of age have a 220 times rate higher, and then 90 times higher mortality rate for 65 and up.’ Disability advocates say the state is trading in equity in its quest for efficiency. ‘Just because something might pose unique challenges, does not mean that it is not a worthy goal that we must, must, must go after,’ said Alyssa Burgart, a medical ethicist at the Stanford Center for Biomedical Ethics. ‘We cannot abandon this population.’”

Rabbi Kukla counters treatment of ‘disposable’ people

Disabled San Francisco Bay Area Rabbi Elliott Kukla argues that the state-sanctioned callous treatment of some of us as disposable has put everyone at risk. “Many people,” he [writes](#), “aren’t very bothered by the deaths of people like me, but this callousness is contrary to their own self-interest. Anyone could become disabled in the split second it takes for a tire to blow out on the freeway, or to inhale a microbe. The extreme fatigue, debilitating headaches, confusion and memory loss of long-haul COVID-19 sound remarkably like the symptoms of my chronic neurological illness. Furthermore, the virus does not recognize boundaries of the body; COVID-19’s blaze through vulnerable populations has sparked outbreaks across the country, infecting people across all demographics. At my synagogue in Oakland, members can join remote services by video conferencing from their hospital beds after surgery. Wheelchair users can now work remotely instead of having to arrange for unreliable accessible transportation. In this increasingly common virtual space, disabled and older people are not kept out, segregated and hidden from view. The limitations and accommodations of pandemic life are a profound reminder of our shared humanity, the centrality of care work and the terrifying fragility of our bodies. I have no desire to get back to a time in which we had forgotten how inextricably linked we are to one another.”

‘Wrongful life’ lawsuits attack disregard of advance directives

Is there any recourse after a carefully and explicitly drafted advance directive is disregarded by medical personnel in life-threatening situations? As The New York Times New Old Age blogger Paula Span [observes](#), “Lawsuits charging negligence or malpractice by hospitals and doctors typically claim that they have failed to save patients’ lives. More recently, though, some families have sued if providers failed to heed patients’ documented wishes and prevented death from occurring. ‘In the past, people have said, ‘How have we harmed you if we kept you alive?’ said Thaddeus Pope, a professor at the Mitchell Hamline School of Law in St. Paul, Minn. ‘Now, courts have said this is a compensable injury.’ In Montana, a jury delivered what is believed to be the first verdict in a wrongful life case, awarding \$209,000 in medical costs and \$200,000 for ‘mental and physical pain and suffering’ to the estate of Rodney Knoepfle in 2019. Debilitated by many illnesses, Mr. Knoepfle had a do-not-resuscitate order and a POLST form in his records at St. Peter’s Health, Helena’s largest hospital. ‘He’d suffered more pain than anyone should in a lifetime and was comfortable with going, if it was his time to go,’ said Ben Snipes, one of his lawyers. But a medical team resuscitated Mr. Knoepfle — twice. Tethered to an oxygen tank, he lived another two years before dying at age 69. ‘The last few months, he was almost incoherent with pain, living in a hospital bed, getting morphine crushed into his pudding,’ Mr. Snipes said. ‘Such awards and rulings, and news coverage, have led

more families to seek legal remedies and have encouraged lawyers to take such cases,' said Mr. Pope. Now similar suits are pending in Georgia, Maryland and New Jersey, in addition to two malpractice cases brought against Montefiore in New York."

'Citizen scientists' tackle COVID-19 research gaps

With the COVID-19 pandemic severely taxing both the diagnostic and treatment capabilities of the world's health care systems, one resource that is assuming greater prominence and impact is the community of those most directly affected, namely, those who have fallen victim to the viral infection. "A month after her COVID-19 diagnosis last March," [writes](#) The Wall St. Journal's Amy Dockser Marcus, "Lisa McCorkell wanted to know why she was still struggling with a cough, shortness of breath and other debilitating symptoms. Her doctors didn't have answers, so she and a group of other COVID patients took matters into their own hands. They formed a research group on a Slack channel and launched their own study. 'I was looking for validation, that my experience was reflected in the others,' said Ms. McCorkell, 28, of Oakland, Calif. The work of the Patient-Led Research for COVID-19 group — including a rapid survey and analysis of 640 patients and a detailed paper tracking symptoms in thousands of patients who have been sick for over 28 days — is helping to drive a larger reckoning about how science values and uses knowledge produced by outsiders. 'Citizen science,' the name given to a range of scientific projects in which patients participate, covers myriad experiences. Some patients create and run their own experiments, sharing consumer DNA and blood test results and tracking body temperature, heart rate and other biological measures. COVID citizen scientists have generated information about symptoms, such as neurological issues, that didn't garner a lot of attention at the start of the pandemic. 'Patients who want to lead COVID research projects often must navigate tension between their sense of urgency and the traditional scientific process, which typically requires a long peer review process before publication in a journal,' said Emily Sirotych, a Ph.D. student at McMaster University in Canada. On March 12, the day the WHO declared COVID a pandemic, Ms. Sirotych joined a Twitter conversation between rheumatology patients and doctors, who were on equal footing when it came to COVID: No one understood the disease. The patients and doctors formed the COVID-19 Global Rheumatology Alliance on a Slack channel. They decided to create two data-generating sources, a physician-directed international registry of rheumatic patients with COVID and a patient-driven experiences survey. Patients created overview summaries of the raw data that they immediately disseminated to support groups for use in personal decision making. The physicians and patients also co-wrote and submitted articles with more detailed data analysis to peer-reviewed journals and conferences. Ms. McCorkell, who never anticipated turning into a COVID citizen scientist, said traditional science still takes too long to help patients. 'We helped catapult COVID research way ahead of where it would have been had we not been doing this work.'"

Barron's dives into Alzheimer's crisis

"The Coming Alzheimer's Crisis — and What to Do About It" leads off a special Barron's Magazine series on how the disease will increasingly burden the nation's caregiving resources. "Alzheimer's is a disease of greater prevalence and greater lethality than COVID-19," says George Vradenburg, who co-founded the advocacy and research group UsAgainstAlzheimer's. "This is an ongoing pandemic. Its cost to America in terms of direct medical costs is significantly higher than cancer." Scientific developments are reason for hope, but even biotech executives say that a cure is always away. As a result, Barron's Reshma Kapadia [writes](#), "care will continue to be at the center of Alzheimer's treatment, and fixing the U.S. caregiving system needs to be a top priority. Unlike cancer or heart disease, much of the cost related to Alzheimer's disease comes from caregiving. An army of family and friends — often women in their prime earning years — shoulder roughly two-thirds of the care for those with Alzheimer's. Many interrupt their careers, give up promotions, cut back on hours, or quit jobs. The average caregiver spends about five years on care for a dementia patient. 'That indirect cost can total roughly \$500,000 per person, based on models that account for lost wages, promotions, and benefits, as well as the obstacles most people face when trying to re-enter the workforce in their 50s or 60s,' says Norma Coe, associate professor of medical ethics and health policy at the Perelman School of Medicine at the University of Pennsylvania. 'The indirect costs are likely to be higher in the future, as a larger share of the next cohort of caregivers are primary breadwinners or single. The hit to their Social Security, for example, may be even greater than for some in the current cohort who may be able to claim spousal benefits on their higher-earning partner's record. Rising female labor-force participation played a big role in the last economic recovery, especially as male labor participation has fallen. The absence of these women could further hamper economic growth.' The financial costs can cascade through multiple generations as caregivers compromise their own finances and retirement security. At the local level, Medicaid

budgets are crowding out investments in youth education. Says Vradenburg: “We are seeing right before our eyes the intergenerational impact. Millennials make up a sixth of those caring for people with Alzheimer’s.”

Financial advisors focus on Alzheimer’s wealth destruction

Barron’s particular specialty — finance and wealth management — is reflected in Beverly Goodman’s [guide](#) to how financial advisors can help families navigate Alzheimer’s. “Financial advisors are often the first to spot the signs of dementia, for two reasons: They’re less likely to be in denial about the symptoms, and trouble with finances is often one of the first problems. ‘Managing your finances is a big frontal-lobe thing,’ says Carolyn McClanahan, a financial advisor in Jacksonville, Fla., who is also a physician. ‘It requires a lot of brain flexibility, and it slips the easiest.’ Because of the unique nature of the disease, the first line of defense is, unfortunately, financial rather than medical. Alzheimer’s disease is typically diagnosed when people are age 75 or older, but the disease often begins some 20 years before signs of dementia manifest themselves — and that is when planning should begin. Since there is virtually no medical treatment, Alzheimer’s expenses are largely caretaking-related, and not covered by insurance or Medicare — meaning costs for a family, on average, are more than \$350,000, twice as much as what’s incurred by caregivers of people with other conditions. Alzheimer’s disease is such a big destroyer of wealth that advisory firms are starting to get involved. The Alzheimer’s Association is developing a financial-literacy program for caregivers with the help of a steering committee that includes TIAA, Raymond James, Wells Fargo, and Edward Jones, along with AARP, the Consumer Financial Protection Bureau, and others. Some firms are creating internal resources: Merrill Lynch, for instance, has a gerontologist on staff, and provides its advisors with education and tools to work with clients, such as a ‘family album’ they can use with clients to document not only vital account and legal information, but also their hopes about retirement, thoughts about health care, and end-of-life planning. regulators have started to create some protections for advisors. In 2018, the Financial Industry Regulatory Authority, or FINRA, implemented two provisions: One requires broker-dealers to ask a customer for a trusted contact who can be called if an advisor suspects dementia; the other allows brokers to place a temporary hold on funds if there is reason to believe the client is being exploited.”

Dr. Vais takes on her patients’ isolation

From the front lines of the pandemic, family medicine intern Dr. Simone Vais [ponders](#) the new role COVID-19 has thrust upon her. “In the past few months, as I’ve learned to catch and care for babies, select elegant antibiotics, and titrate methadone, I’ve also learned that bearing witness to my patients’ isolation and its repercussions is now part of my job, too. The absence of loved ones at the bedside means that as our patients endure illness, there is no one beside them to ask questions, advocate for further testing, notice subtle changes in appetite or behavior, or insist that the problem that brought them to the hospital be solved before they’re sent home. So these roles — noticing, advocating, accompanying — are my job now, too. I must fill the gaps left by the absence of loved ones. And as in all aspects of my job, I am still learning. I feel,” writes Vais, “the weight of your isolation. I carry the burden of knowing that while I can enter and exit the hospital freely, you and your loved ones cannot. I see you early in the morning as I pre-round, and again as I prepare to head home for the night. Each time, I notice that you are alone, and it weighs on me. And yet as I get caught up in learning a system that is new to me in a world that is new to everyone, I sometimes forget that doing something about that isolation is my job now, too. Isolation during illness is not new, but its effects and inequities are magnified by this pandemic. Visitor restrictions are reasonable public health measures, but they are inherently inequitable. People with the means to care for loved ones at home do not suffer the consequences of these rules as severely. Those with smartphones and data plans can connect in spite of the rules. In our hospital service bundles and checklists, we systematically review important but easily overlooked details every day, before we sign every note. Diet order, deep-vein thrombosis prophylaxis, code status, emergency contact. I believe it’s time to add isolation to these checklists. We need to think proactively about how isolation will affect our patients’ experiences and health, so that we don’t inadvertently bend the rules only for people who understand the system and have been empowered to self-advocate within it.”

The need for human touch suffers severe deprivation

“It has been 11 months since anyone hugged Larry,” [writes](#) the Economist magazine. “The 62-year-old accountant lives alone in Chicago, which went into lockdown last March in response to COVID-19. He has heart problems, so he has stayed at home since then. The only people to touch him have

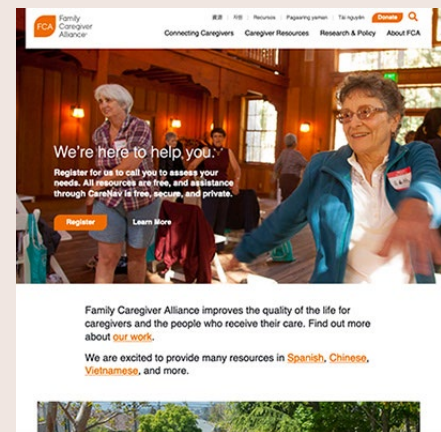
been latex-sheathed nurses taking his blood pressure. The pandemic has been an exercise in subtraction. There are the voids left by loved ones who have succumbed to COVID-19, the gaps where jobs and school used to be, and the absence of friends and family. And then there are the smaller things that are missing. To stop the spread of COVID-19 people have forsaken the handshakes, pats, squeezes and strokes that warm daily interactions. The loss of any one hardly seems worthy of note. And yet touch is as necessary to human survival as food and water, says Tiffany Field, director of the Touch Research Institute at the Miller School of Medicine, part of the University of Miami. It is the first sense to develop and the only one necessary for survival. We can live with the loss of sight or hearing. But without touch, which enables us to detect such stimuli as pressure, temperature and texture, we would be unable to walk or feel pain. Our skin is the vehicle through which we navigate the world. But in the age of distance, the skin-hungry must make do with what they can. Between February 10th and 13th, 2020, sales of massage chairs in China were 436% higher than in the same period in 2019, according to suning.com, a big retailer. Others are turning to technology to simulate caresses. CuteCircuit weaves haptic sensors into shirts which, it claims, can transmit the sensation of a hug using Bluetooth technology to corresponding shirts. Between April and December, traffic to its online shop surged by 238%. In 2015 Madelon Guinazzo and Adam Lippin founded Cuddlist, a company which trains 'cuddle therapists.' 'The pandemic has made many more people aware of their craving for touch,' says Ms Guinazzo. Her business has suffered, but once COVID-19 ebbs she expects demand to surge. People need to touch people, not just screens."

FAMILY CAREGIVER ALLIANCE ANNOUNCEMENTS

FCA'S new look!

A bright spot for FCA during this pandemic year has been the opportunity to develop a new look for the organization. We retired our 35-plus-year-old "nautilus" logo with a clearer and brighter brand and logo. We are in the process of updating our materials and communications, including Caregiving Policy Digest, and we rebuilt FCA's website, caregiver.org, using responsive design to accommodate mobile devices, an important and overdue upgrade.

The website beta version launched in the second week of February. We anticipate both family caregivers and professionals will find it easier to navigate, read, and connect with the new caregiver.org. **Look for a formal announcement of the launch this month.**



If you have any thoughts or comments, contact us at the email addresses listed under CREDITS.

Winners of the Innovations in Alzheimer's Caregiving Awards

SAN FRANCISCO, February 25, 2021 — In celebration of the 14th year of the **Innovations in Alzheimer's Caregiving Award**, The Rosalinde and Arthur Gilbert Foundation, the Helen Daniels Bader Fund, A Bader Philanthropy, and Family Caregiver Alliance are pleased to announce three winning organizations — each delivering a state-of-the-art program that addresses the needs of caregivers and those they care for with Alzheimer's disease or a related condition. Each model program will receive \$20,000 for their work in the following categories: Creative Expression — **Caregiver/Storyteller podcast**; Diverse/Multicultural Communities — **Culturally Responsive Caregiver Support and Dementia Services**; and Public Policy — **California Task Force on Family Caregiving: Picking up the Pace of Change in California**. View detailed information on the [winning programs here](#).

Providers: Connect your patients' or

clients' caregivers to 1:1 support
Designed for health care and social service
providers, FCA's Provider e-News Update offers
resources to support the caregivers who care for
providers' patients and clients. Here's the [latest
issue](#). Archive [here](#). Subscribe [here](#).



Online classes from the California Caregiver Resource Centers

Family Caregiver Alliance (FCA) hosts a monthly calendar of online classes, workshops, and events — compiled from the 11 California Caregiver Resource Centers (CRCs) — open to family caregivers across the country. To view the monthly calendar of listings visit the CRCs' [webpage](#). A downloadable listing of the monthly events can be found on the same page by clicking the SEE ALL UPCOMING EVENTS HERE! button.

The [California Caregiver Resource Centers](#) (CRCs) serve families and caregivers of adults affected by chronic and debilitating health conditions — FCA is the San Francisco Bay Area CRC.

best practice caregiving

*Guiding organizations
to dementia programs
for family caregivers*

[Best Practice Caregiving](#), is a **free** online database of more than 40 vetted, proven dementia caregiving programs that allows organizations to identify, compare and adopt best-fit programs for their clientele and community. It is a product of the collaboration among three leading organizations in the field of aging and caregiving: Benjamin Rose Institute on Aging, Center for Research & Education; Family Caregiver Alliance: National Center on Caregiving; and The Gerontological Society of America. Project funders are The John A. Hartford Foundation, Archstone Foundation, and RRF Foundation for Aging. Visit the database at [bpc.caregiver.org](#). Stay in touch with BPC e-News and [subscribe here](#). The latest e-News is [available to read here](#).

CREDITS

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

FCA TWEETS @CaregiverAlly

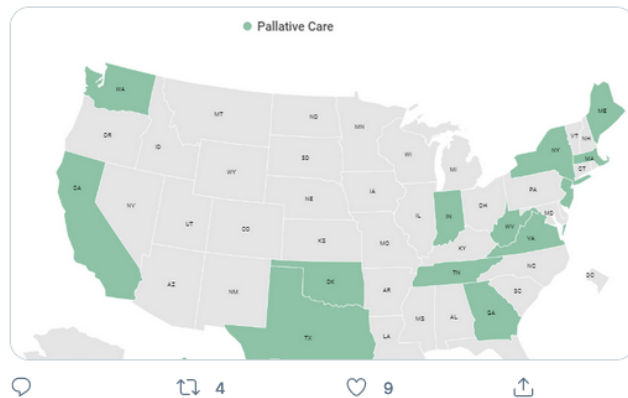
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6 of 15 states provided funds for palliative care programs and education, and several passed laws that create or expand state palliative care advisory councils or task forces.

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/ National Center on Caregiving on Twitter [@CaregiverAlly](#) and Executive Director Kathleen Kelly [@KKellyFCA](#).

REGISTER YOUR RESEARCH

Professional Research

- [Life Enhancing Activities for Family Caregivers \(LEAF\) \(SP0044459; NCT03610698\)](#)
- [Social Connection During COVID-19](#)
- [The Impact of Emotions on Social Distancing among spousal caregivers for Alzheimer's disease or related dementias during the COVID-19 Pandemic](#)

Graduate Student Research

- [Compassion Fatigue Among Family Caregivers of Individuals with End-stage Heart Failure](#)
- [Complete a 30-minute survey at home!](#)
- [Developing Support Strategies in Stroke Caregiving](#)
- [Exploring the impact of compassion fatigue and burnout among family caregivers: Consider taking the PROQOL](#)
- [Pilot study of an education and skills training program for caregivers post-stroke](#)

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