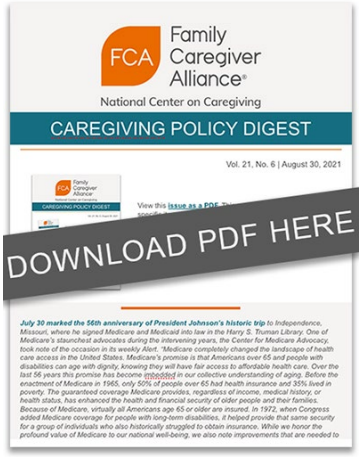
View as Webpage

Family Caregiver Alliance®

National Center on Caregiving

CAREGIVING POLICY DIGEST

Vol. 21, No. 6 | August 31, 2021



View this **issue as a PDF.** This option allows you to link to specific items or sections within Caregiving Policy Digest. After the PDF opens in your browser, access the document outline (a linkable table of contents) in the upper left corner. You can also download or print the document.

July 30 marked the 56th anniversary of President Johnson's historic trip *to Independence, Missouri, where he signed Medicare and Medicaid into law in the Harry S. Truman Library. One of Medicare's staunchest advocates during the intervening years, the Center for Medicare Advocacy, took note of the occasion in its weekly Alert. "Medicare completely changed the landscape of health care access in the United States. Medicare's promise is that Americans over 65 and people with disabilities can age with dignity, knowing they will have fair access to affordable health care. Over the last 56 years this promise has become imbedded in our collective understanding of aging. Before the enactment of Medicare in 1965, only 50% of people over 65 had health insurance and 35% lived in poverty. The guaranteed coverage Medicare provides, regardless of income, medical history, or health status, has enhanced the health and financial security of older people and their families. Because of Medicare, virtually all Americans age 65 or older are insured. In 1972, when Congress*

added Medicare coverage for people with long-term disabilities, it helped provide that same security for a group of individuals who also historically struggled to obtain insurance. While we honor the profound value of Medicare to our national well-being, we also note improvements that are needed to fully and fairly serve today's Medicare population. We continue to call for updates to the program — including adding an out-of-pocket cap, expanding Part B to include oral health, reducing barriers to covered care, and increasing low-income protections. At the same time, Medicare must maintain its leadership in identifying and addressing racial disparities and health equity in all Medicare policies and practices."

— **CMA Alert**)

In a moving post, two-time Super-Bowl winning coach Tom Coughlin talks *about taking care of his very ill wife as she continues to decline from a brain disorder that erodes her ability to walk, speak, think, and control body movements. "Judy's decline has been nothing but gut-wrenching and has placed me in a club with the tens of millions of other Americans who serve as a primary caregiver for a loved one. Admittedly, transitioning from being with an N.F.L. franchise to full-time caregiver wasn't easy. It's still not easy. The playbook is either changing by the minute or so numbingly repetitious, you lose track of time and self. I've learned firsthand caregiving is all-consuming. It is mentally and physically exhausting. When Judy is having a good day, then my day is good. But then there are dark days — those days that are so full of frustration and anger, they have me feeling like a failure and pondering the unfairness of the disease. I've spent my entire life preparing for some of the biggest games a person could play, but nothing can prepare you to be a caregiver who has to watch a loved one slip away. I do want the players I coached in college and in the N.F.L. who thought all my crazy ideas about discipline, commitment and accountability ended when they left the field to know that is not the case. The truth is, that is when those qualities matter most. To all those who are caring for a loved one, take a break when you need it and don't be too hard on yourselves. It's not easy. And for all those wondering how they can help, it's simple: Don't forget about the caregivers."*

— **The New York Times**

ALZHEIMER'S DISEASE, MEDICAID WORK REQUIREMENTS, TELEHEALTH, AND NURSING HOMES

IN THIS SECTION

- States enact SNF resident protection measures

Whether the country is on the verge of embarking on the greatest transformation of the federal safety net since LBJ's Great Society remains to be seen. As Congress works its way through the thorny budget process — given the unfolding Afghanistan tragedy and resurging COVID-19 infection rates — the coming fall political dynamics are increasingly uncertain. In the meantime, however, midsummer developments regarding a number of issues followed by Caregiving Policy Digest have continued to emerge.

ALZHEIMER'S DISEASE

Major hospital systems give thumbs down on aducanumab

The fallout from the FDA's approval of aducanumab continued apace with several major treatment centers **announcing** they would not administer the drug due to ongoing doubts about its efficacy and safety. Both the Cleveland Clinic and Mount Sinai Health System in New York were among the first very notable decliners. An even bigger blow to Biogen's hopes was struck by the Veterans Administration, which **declared** that "While VA acknowledges the recent FDA decision on aducanumab, given the lack of evidence of a robust and meaningful clinical benefit and the known safety signal, we recommend against offering this agent to patients with Alzheimer's dementia (mild or otherwise) or mild cognitive impairment. However, recognizing that there is an accelerated FDA approval, we also recommend that if it is to be used by exception then it should be utilized only in highly selected patients by experts and centers that have the necessary diagnostic and management expertise — and only by those with the needed resources for close monitoring to assure safety. As such, any use should be governed by stringent regulation, and safety and appropriateness of use monitored real time."

Medicare initiates national amyloid drug coverage determination

Meanwhile the biggest player of all — Medicare — **opened** a National Coverage Determination analysis, "a process that will allow the agency to carefully review and determine whether Medicare will establish a national Medicare coverage policy for monoclonal antibodies targeting amyloid for the treatment of Alzheimer's disease. NCDs are program instructions developed by CMS to describe the nationwide conditions for Medicare coverage for a specific item or service. This NCD analysis will be applicable to national coverage considerations for aducanumab, which was recently approved by the Food and Drug Administration (FDA), as well as any future monoclonal antibodies that target amyloid for the treatment of Alzheimer's disease. Currently, coverage determinations for aducanumab are being made at the local level by Medicare Administrative Contractors who represent 12 jurisdictions across the country. CMS's coverage decisions are based on careful analysis of the evidence and benefits a given therapy provides to Medicare beneficiaries. To determine whether a national policy is appropriate, CMS will follow a standard process that includes multiple opportunities for the public to participate and present comments through both listening sessions and the CMS Coverage website. The analysis will determine whether the evidence meets the Medicare law's requirements that items or services be 'reasonable and necessary for the diagnosis or treatment of illness or injury… .' To make this determination, CMS uses a formal process established by statute. Following this analysis, CMS will post a proposed national coverage determination, which will be open to a 30-day public comment period. After reviewing all comments received on a proposed determination, CMS will announce its final decision for a national policy which could range from Medicare coverage of this product type, coverage with evidence development, non-coverage, or deference to the Medicare Administrative Contractors. A proposed decision is expected to be posted within six months and a final within nine months."

MEDICAID WORK REQUIREMENTS

CMS pulls the plug on Medicaid work requirements

After months of signaling its intent, President Biden's CMS has pulled the plug on state Medicaid work requirements that had been pursued by a number of states during the previous Trump administration. In a **letter** to South Carolina — also sent to Ohio and Utah — CMS's new administrator, Chiquita Brooks-LaSure, notified officials that "prior to the pandemic, most adult Medicaid beneficiaries who did not face a barrier to work were already working full- or part-time.

However, one in three working adult Medicaid beneficiaries was doing only part-time work prior to the COVID-19 public health emergency, often due to fewer opportunities for full-time employment. The pandemic is expected to exacerbate the challenges of finding not only full-time employment, but may create additional obstacles to securing even part-time work, due to shifting caregiving responsibilities and increased transportation barriers. The pandemic also has disproportionately impacted the physical and mental health of racial and ethnic minority groups, who already experience disparities in health outcomes. Racial minorities and people living in low-income households are more likely to work in industries that are considered 'essential services,' which have remained open during the pandemic. Additionally occupations with more frequent exposure to COVID-19 infections, and that require close proximity to others (such as personal care aides and bus drivers) employ Black individuals at higher rates than White individuals. As a result, Black people may be at higher risk of contracting COVID-19 through their employment. The pandemic's mental health impact also has been pronounced among populations experiencing disproportionately high rates of COVID-19 cases and deaths. Specifically, Black and Hispanic adults have been more likely than White adults to report symptoms of anxiety and/or depressive disorder during the pandemic. In summary, the short-to-long-term adverse implications of the COVID-19 pandemic on the economic opportunities for Medicaid beneficiaries, which have been aggravated further by challenges around shifting childcare and caregiving responsibilities as well as constraints on public transportation during the pandemic, heightens the risks of attaching a community engagement requirement to eligibility for coverage. In addition, the uncertainty regarding the lingering health complications of COVID-19 infections exacerbates the risk of potential coverage losses for Medicaid beneficiaries. The likely ramifications of losing timely access to necessary health care also can be long lasting. As such, CMS believes that the potential for coverage loss among Medicaid beneficiaries — especially from a requirement that is difficult for beneficiaries to understand and administratively complex for states to implement — would be particularly harmful in the aftermath of the pandemic and makes the community engagement requirement under the Healthy Connections Works demonstration impracticable." (One unresolved dispute over work requirements does remain in Georgia where the state and federal authorities are still sparring over the overall issue of Medicaid expansion.)

TELEHEALTH

Telehealth claims seesaw

Wither telehealth? The pandemic-induced rush to online medical consultation had been showing signs of ebbing, but the summer's Delta surge, according to **reporter** John Commins, appears to have brought a renewed, albeit small, uptick in claims. "Before May, telehealth as a percentage of medical claims had steadily fallen from February through April, according to Fair Health's regional tracker. The South (5.6%) and the West (4.8%) saw the largest increases in telehealth claims, while the Northeast and the Midwest saw declines of 5.4% and 1.7%, respectively. Substance use disorders were among the top five telehealth diagnoses nationally for the first time, coming in fifth place. The pattern was consistent with reports of increased misuse of opioids and stimulants during the COVID-19 pandemic."

Physicians fear renewal of state telehealth restrictions

StatNews' Katie Palmer **writes** that while telemedicine is here to stay, "it's free-for-all era may be coming to an end. State-issued emergency declarations and insurer policies that were issued at the start of the COVID-19 pandemic and that were meant to encourage the use of telemedicine are being phased out across U.S. states, one by one. And as they fade away, rules that make telemedicine more complicated — and costly — are setting back in. Experts say the moves, which come as vaccinations have ramped up and case counts have dwindled, are causing headaches among patients and providers alike. Doctors are scrambling to stay on top of rapidly-changing rules. Patients are contorting themselves to keep their virtual appointments — even driving into different states and taking calls from the side of the road so they can legally receive care. In the last year, Stephanie Titus, a primary care physician in Massachusetts, has treated patients located in Rhode Island, Vermont, New Hampshire, and even Maine virtually. That would normally require her to obtain a license in each of those states — a process that can take months and cost hundreds of dollars. But thanks to emergency orders from state governors and licensing boards, some of which expedited the application process or extended telehealth licenses to providers in neighboring states, that was no longer necessary. Many of Titus' far-flung patients now want to continue televisits whenever they're practical. 'For something as simple as blood pressure checks when they have a reliable blood pressure monitor at home,' said Titus, 'It doesn't make sense to have them travel.' But on July 1, Titus' network, Mass General Brigham, decided to end telemedicine appointments for patients in

states where their providers are not licensed, in anticipation of the lifting of temporary license allowances. Titus started asking her out-of-state patients to make a choice: come back into the office, or take their telehealth appointments within Massachusetts' borders. One of her patients from Rhode Island drove just across the border, parked in the lot outside of a BJ's superstore, and called in from her car. With behavioral health accounting for more than half of all telehealth visits during the pandemic, the end of license waivers could have a dramatic impact on patients. 'The restriction across states is bad for clients: bad for access to care and very much bad for continuity of care,' said Roy Huggins, a counselor and founder of Person Centered Tech, a consulting company that helps mental health providers navigate telehealth. 'Needing to switch a therapist is unhelpful at best, or harmful at worst,' he added."

400+ advocacy groups push for permissive federal telehealth policy

Lending their support to a federal fix, more than 400 advocacy groups representing a broad spectrum of stakeholders have urged congressional leaders in a **letter** to address the threats to continued telehealth options. "Congress must act to ensure that the Secretary has the tools to transition following the end of the public health emergency and ensure telehealth is regulated the same as in-person services. Secretary Becerra has recently asked for such authority, and we urge bipartisan action toward this goal. Specifically we ask that legislation focus on the following priorities: removal of obsolete restrictions on the location of the patient and provider; enhancement of HHS authority to determine appropriate providers, services, and modalities for telehealth; ensurance that Federally Qualified Health Centers, critical access hospitals, and rural health clinics can furnish telehealth services after the public health emergency; and removal of restrictions on Medicare beneficiary access to mental and behavioral health services offered through telehealth."

NURSING HOMES

HHS Inspector General spotlights lapse in standard nursing home state survey

Among the many unfortunate consequences of COVID-19, according to a new HHS office of Inspector General **report**: a backlog of standard state surveys of nursing homes. " We found that States' backlogs grew substantially during the COVID-19 pandemic. Nationally, 71 percent of nursing homes (10,913 of 15,295) had gone at least 16 months without a standard survey as of May 31, 2021. By State, the backlogs for standard surveys ranged from 22 percent to 96 percent of nursing homes. Standard surveys are comprehensive onsite inspections that evaluate the safety and quality of care provided by nursing homes. Surveyors cite deficiencies during these surveys when they observe a nursing home violating a Federal requirement. These deficiencies can result in CMS imposing remedies, such as civil monetary penalties, on the nursing home. In addition, surveyors discuss observations with nursing home staff throughout these surveys and may alert them to concerns with resident care, providing the nursing home with the opportunity to address these concerns by presenting additional information to the surveyors. In March 2020, to protect public health and address other concerns associated with the Public Health Emergency, CMS suspended standard surveys in nursing homes to reduce surveyor time on site. CMS shifted oversight to infection control surveys, which are more limited in scope than the standard surveys. Our updated analysis," the report concludes, "underscores the importance and urgency of our previous recommendation to CMS to clarify expectations for States to complete backlogs of standard surveys, including by issuing guidance on prioritization of surveys and required timeframes to complete these backlogs."

CMS reinstates higher fines for nursing home quality failures

One oversight step that is sure to please long-term care patient advocates, **reports** The New York Times' Reed Abelson, is the administration's "quiet reversal of a controversial Trump policy that had limited the fines levied on facilities that endangered or injured residents. The policy favoring lower penalties, adopted in 2017 by the Trump administration, directed regulators at the Centers for Medicare and Medicaid Services to shift from fining a nursing home for each day it was out of compliance with federal standards. The relaxed policy reduced many penalties to a single fine, effectively lowering amounts from hundreds of thousands of dollars to a maximum of $22,000.
'It is the most obvious change the Trump administration made,' said Toby Edelman, a senior policy attorney at the Center for Medicare Advocacy. 'It's a much, much lower penalty amount.' Many of the nursing homes cited for poor infection controls, failing to protect residents from avoidable accidents, neglect, mistreatment and bedsores, are repeat offenders. Larger fines act as a deterrent and are

more likely to signal strong enforcement of the rules.' The main industry trade group, the American Health Care Association and National Center for Assisted Living, said in a statement that fines levied on a per-day basis 'only take precious resources away from an already underfunded industry, especially during an unprecedented time when nursing homes need every support to protect their residents.' But critics of the Trump policy say it offered a mere slap on the wrist for nursing homes, even those at the greatest risk for harming patients and workers."

Democrats introduce nursing home improvement legislation

Nursing homes' persistent challenges have not been lost on six Democratic senators who have introduced **The Nursing Home Improvement and Accountability Act of 2021**. "Families must have faith that loved ones receiving long-term care or care after a hospital stay will be safe and receive good-quality care," lead sponsor Sen. Ron Wyden said in a statement. "The pandemic, myriad reports of abuse, and critical failures during natural disasters have shattered that foundation of trust and safety." Some of the main provisions of the bill, **according** to the AP's Ricardo Alonso-Zaldivar, would:

- raise salaries and benefits for nursing home staff by giving states the option of an increase in federal Medicaid matching funds, available over six years. Low wages in the nursing home industry make for constant turnover, a critical problem even before the pandemic. The bill also starts a process for setting minimum staffing thresholds.
- require nursing homes to have an infection prevention and control specialist.
- require nursing homes to have a registered nurse available 24 hours a day, instead of the current eight hours.
- bolster state inspections of nursing homes and add more low-performing facilities to a 'special focus' program that helps them improve quality.
- forbid nursing homes from requiring residents and families to agree in advance to arbitration, thereby waiving their rights to go to court over disputes involving care.

The bill would also launch an experiment to see if downsized nursing homes lead to better care and quality of life for residents. Those facilities would have between five and 14 residents, make private rooms available, feature accessible outdoors areas, and involve residents and families in decision-making."

ABA supports move to Green House model SNFs

The American Bar Association's House of Delegates has taken a stand on the future direction of nursing home care, passing a **resolution** that calls for HHS to review the advisability and feasibility of phasing in size and design standards for nursing homes that would require small, household model facilities with single rooms and private baths; provide financial incentives for the development and operation of nursing homes meeting size and design standards developed pursuant to this review; and change Medicare and Medicaid regulations and payment policies to pay for single private rooms and bathrooms for all residents, with reasonable reimbursement rates for such rooms. "This policy resolution," the accompanying material concludes, "responds to consistent findings of COVID-19 research showings that the bed size and density (i.e., multiple residents per room) of nursing home buildings represents one of the most powerful risk factors fostering high rates of COVID-19 infection and death rates. The prevailing model of nursing home design and construction has failed to protect the lives, safety, and security of persons in need of nursing home care and needs to change if nursing homes are to provide safe and humane environments in the face of current and future public health challenges. Fortunately, this tragic design flaw is fixable. The report establishes that small household models, represented most visibly by Green House Homes, already exist. Green House and other small household model nursing homes have participated in Medicare and Medicaid and have been shown to be viable and significantly effective in preventing infection spread and death compared to traditional nursing homes."

SNF staff resist COVID-19 vaccinations

The upbeat accounts of spring and early summer nursing home family reunions in the wake of plunging infection and death rates have begun to be replaced by the specter of another bout of imposed isolation and a stressed caregiving environment. Fueling the anxiety: a combination of metastasizing COVID-19 variations, staffing shortages, and vaccination resistance. "Growing calls for vaccine mandates among health care workers," **report** The New York Times' Matt Richtel and Reed Abelson, "have gained urgency but also met resistance in the nursing home industry, where some homes say it will cost them staff members in an industry already plagued with high turnover. Only about 60 percent of nursing home staff members are vaccinated, and some states report an even

lower rate, with less than half inoculated. Staff immunization has been an issue in many states, especially as the highly contagious Delta variant races through regions with low vaccination rates. Some states and cities, not waiting for the nursing home industry, are imposing their own mandates for vaccinations on long-term care employees or operators may face penalties or additional testing requirements for unvaccinated staff. Massachusetts on Wednesday said all nursing-home staff must be fully vaccinated by Oct. 1, while California said health care workers must be immunized or be tested weekly for COVID. 'The bottom line is the vaccine is the No. 1, 2 and 3 thing we have to fight this pandemic, everywhere, but especially in nursing homes,' said Dr. Michael Wasserman, a geriatrician and former president of the California Association of Long Term Care Medicine, who has reluctantly come to believe mandates are necessary."

States, cities, and Medicare impose vaccine requirements

That is not to say that new COVID-19 waves will play out like the first. FDA's late August final status approval of the Pfizer vaccine came just days after Pres. Biden's announcement that Medicare would shortly require all staff members at nursing homes to be fully vaccinated against COVID-19 or those facilities would risk losing their Medicare and Medicaid funding. As **reported** by Yahoo's Brittany Shepherd, the president observed that "More than 130,000 residents in nursing homes have, sadly, over the period of this virus, passed away (but) vaccination rates among nursing home staff significantly trail the rest of the country."

SNF residents fear return of isolation

The latest visitation and interactive restrictions often fall short of those implemented earlier in the pandemic, which barred almost all visitation and left residents communicating through windows and cellphone screens. But the restrictions are a setback for families who hoped the worst was behind them after a mass-vaccination campaign sent cases plummeting earlier this year, and many rules were relaxed. "Mary Ellen Dayan-Varnum," The Wall Street Journal's John Kamp and Arian Campo-Flores **reported**, "had been taking her 85-year-old mother, Jody Dayan, to a salon to get her hair done twice a week, but new restrictions at Ms. Dayan's nursing home in Blountstown, Fla., have ended those outings. Most visitation is canceled, and group activities like bingo, movies and communal dining have been suspended, leaving residents largely confined to their rooms. Ms. Dayan-Varnum can still visit her mother, who has dementia, under what is known as an essential-caregiver exemption. But she worries about the high case counts and low vaccination rates in the area. 'Every day I have to explain to my mom why she can't leave her room, why nobody is visiting her, why she can't visit her friend across the hall,' she said. 'There is no light at the end of the tunnel right now.'"

States enact SNF resident protection measures

Many states have taken stock of the pandemic's initial toll on nursing home living conditions and enacted a slew of protective measures aimed at avoiding a repeat response. "When the coronavirus hit Martha Leland's Connecticut nursing home last year," **wrote** Kaiser Health News' Susan Jaffe, "she and dozens of other residents contracted the disease while the facility was on lockdown. Twenty-eight residents died, including her roommate. 'The impact of not having friends and family come in and see us for a year was totally devastating,' she said. 'And then, the staff all bound up with the masks and the shields on, that too was very difficult to accept.' She summed up the experience in one word: 'scary.' Twenty-three geographically and politically diverse states have passed more than 70 pandemic-related provisions affecting nursing home operations. States have set minimum staffing levels for nursing homes, expanded visitation, mandated access for residents to virtual communications, required full-time nurses at all times and infection control specialists, limited owners' profits, increased room size, restricted room occupancy to two people and improved emergency response plans." Under a law Connecticut enacted in June nursing home residents will be able to designate an 'essential support person' who can help take care of a loved one even during a public health emergency. Connecticut legislators also approved laws this year giving nursing home residents free internet access and digital devices for virtual visits and allowing video cameras in their rooms so family or friends can monitor their care. 'I don't think anybody would have ever dreamed that we would be telling people that they can't have someone come in to check on them,' said Julie Mayberry, a Republican Arkansas state representative and the lead sponsor of the No Patient Left Alone Act, an Arkansas law ensuring that residents have an advocate at their bedside. 'This is not someone that's just coming in to say hello or bring a get-well card,' she said. Jacqueline Collins, a Democrat who represents sections of Chicago in the Illinois State Senate, was also concerned about the effects of social isolation on nursing home residents. 'The pandemic exacerbated the matter, and

served to expose that vulnerability among our long-term care facilities,' said Collins, who proposed legislation to make virtual visits a permanent part of nursing home life by creating a lending library of tablets and other devices residents can borrow. Gov. J.B. Pritzker is expected to sign the measure. In addition, states increasingly have established either a minimum number of hours of daily direct care for each resident, or a ratio of nursing staff to residents. For every eight residents, New Jersey nursing homes must now have at least one certified nursing aide during the day, with other minimums during afternoon and night work shifts. Rhode Island's new law requires nursing homes to provide a minimum of 3.58 hours of daily care per resident, and at least one registered nurse must be on duty 24 hours a day every day. Next door in Connecticut, nursing homes must now provide at least three hours of daily direct care per resident next year, one full-time infection control specialist and one full-time social worker for every 60 residents."

RESEARCH AND RESOURCES

IN THIS SECTION

NAM proposes 10-year dementia reduction strategy

While the recent focus regarding Alzheimer's disease and dementia-related illnesses has remained on the controversial approval of aducanumab, the National Academy of Medicine has **published** a new study with a far longer vision — 10 years to be exact. "The committee's report, Reducing the Impact of Dementia in America: A Decadal Survey of the Behavioral and Social Sciences, offers a broad research roadmap for the behavioral and social sciences over the next decade, noting promising interventions and programs that require additional confirmatory evidence. The report also describes social and behavioral research that can provide the foundation for the development of programs and policies, as well as ethical safeguards that would serve the needs of all Americans affected by dementia. Family caregivers receive their share of attention: Although much is known about interventions that can effectively support caregivers, there are also significant gaps in the existing research. Important aspects of the caregiving experience and its effects on both caregivers and people living with dementia have not yet been studied; an example is the need for better research on differences in caregiver needs across diverse populations. Among other areas, research is needed to identify the highest priority needs for resources and support for family caregivers, including supplemental skills and training, and other resources to enhance their capacity to provide care while maintaining the safety and well-being of both care recipients and caregivers."

The recent news about cognition problems hasn't all been about aducanumab —

COVID-19 loss of smell signals cognitive impairments

"Research findings link cognitive impairment and COVID-19-induced loss of smell (anosmia)," MedPagesToday's Judy George **reports**. "Severity of cognitive impairment was significantly correlated with severity of olfactory dysfunction but not with the severity of acute COVID-19, Gabriel de Erausquin, M.D., Ph.D., M.Sc., of the University of Texas Health Science Center at San Antonio, reported at the 2021 Alzheimer's Association International Conference. In the study, de Erausquin and co-researchers evaluated olfactory dysfunction and chronic cognitive impairment after COVID-19 infection in 233 older adults from the Andes Mountains of Argentina, comparing them with 64 matched controls with no history of COVID. More than half of people showed persistent, severe problems with forgetfulness. Roughly a quarter had additional problems with cognition, including language and executive dysfunction. 'The only predictor of cognitive impairment,' de Erausquin said,

'was anosmia that persisted for at least 3 to 6 months. We're starting to see clear connections between COVID-19 and problems with cognition months after infection. It's imperative we continue to study this population, and others around the world, for a longer period of time to further understand the long-term neurological impacts of COVID-19.'"

Cardiologist doubts statin-dementia link

"Do statins increase or decrease the risk of dementia? Cardiologist Christopher Labos **ponders** that question in the wake of some PET scan findings identifying differences in brain metabolism between statin users and non-users. When observational studies show a link between statin use and dementia, you always have to ask: Is this a true causal link or is it simply that people prescribed statins tend to be older, and older patients are more likely to get dementia? Teasing out such distinctions is never easy and probably explains why results in this area have been so variable. For every study suggesting a link, we have another showing no association between statin use and dementia, mild cognitive impairment, or cognitive decline. In fact, there is good reason to think that the opposite would be true, that statins could prevent at least one form of dementia. We tend to lump all dementia types together and sometimes, rather erroneously, refer to everything as Alzheimer's disease. In reality, Alzheimer's disease is just one disease that can cause dementia; other pathologies, like Lewy body dementia, frontotemporal dementia, or vascular dementia, could be responsible. A large stroke, or more commonly a series of small strokes, can also lead to decreases in cognitive function. Statins have been shown to decrease the risk for stroke, and so it seems to be a very reasonable assumption that by preventing strokes, especially the small repetitive strokes that accumulate over time, you would prevent the onset of dementia. Whenever you have multiple studies with differing results, the final conclusion is generally that there is no large effect one way or the other. All this is to say that I am not excessively worried about dementia risk with statins. For now, most readers can rest assured that if there is any impact on cognitive function, it is probably small and probably not clinically significant."

AD smart phone predictor gains FDA 'breakthrough' status

Can a smart phone app predict the future onset of Alzheimer's disease? The FDA appears to think it might, awarding "breakthrough" designation to **Altoida**'s predictive system. "The system," **reports** FierceBiotech's Andrea Park, "is the product of more than 20 years of cognitive research. It comprises a slate of neurological tests for users aged 55 and up and AI software to analyze the results of those tests. The assessment portion of the system takes 10 minutes to complete and can be accessed on a user's own smartphone or tablet. It focuses on measuring 11 specific areas of the brain research has suggested are linked to the onset of Alzheimer's. The augmented reality tests are designed to feel like video games. In one, users are asked to hide three virtual items around the room they're in, then relocate them at random. Another tasks users with learning the tools and actions needed to simulate a fire evacuation, and the third main activity has them simultaneously locate virtual tools in their environment while a dynamic sound plays intermittently. Once the tests are complete, Altoida's AI assesses the results to score the user's risk of developing Alzheimer's within the next year. It produces a full cognitive report based on hand and gait movements and errors, eye tracking and pupil dilation, voice parameters and more. 'Altoida's device could enable predictive diagnosis of neurodegenerative disorders at the population level, which can in turn enable preventative and therapeutic intervention in the earliest stages to delay onset and improve clinical outcomes,' said Ioannis Tarnanas, Ph.D., Altoida's chief scientific officer. If ultimately approved by the FDA, Altoida's device would be the first diagnostic tool cleared to predict Alzheimer's onset before symptoms arise, but there are plenty of other tech developers hot on its tail. Just last month, Boston-based startup Linus Health raised $55 million to continue building its own early diagnosis software, which offers a digital version of the traditional clock-drawing test as well as a suite of tools to monitor the progression of a patient's cognitive decline over time.

Neuroscientists fight AD with light and sound therapy

At the Alzheimer's Association's July International Conference in Denver, **NPR reports**, "... brain waves were among the targets of future Alzheimer's treatments. Targeting the waves with light and sound therapy is an idea being pursued by a team of scientists at MIT that has been studying electrical pulses in the brain called gamma waves. These waves play a critical role in learning and memory. The researchers noticed that these waves become weaker and less synchronized in people with Alzheimer's. So they thought they might be able to slow down the disease by boosting gamma waves. 'To find out, the team exposed mice to lights and sounds that caused the gamma waves in their brains to strengthen and synchronize,' says Li-Huei Tsai, a professor of neuroscience at MIT

and director of the Picower Institute for Learning and Memory. 'What really surprised us is that this approach produces profound benefits in mice engineered to model Alzheimer's disease.' After treatment, their brains started clearing out both amyloid and tau proteins, the brain's immune cells began to function better, and the mice improved on tests of learning and memory. 'The next step was to try the approach on humans,' says Dr. Diane Chan, a neurologist at Massachusetts General Hospital who also works in Tsai's lab. So the team built a portable device that could generate light and sound pulses at just the right frequency: 40 hz. 'We sent the device home with people who had mild Alzheimer's dementia to let them use these devices an hour a day every day,' Chan says. After three months, the team checked participants' brains for signs of atrophy, which is usually found in people with Alzheimer's. 'We found that the group that used the active setting at 40hz light and sound actually did not see any atrophy over this time period.' In contrast, people who'd been using an inactive, placebo device did have brain atrophy.The results came from a study of 15 people that was designed to make sure the device was safe. Next, the scientists hope to confirm the results in a larger study. 'This,' Tsai says, 'is completely noninvasive and could really change the way Alzheimer's disease is treated.'"

Leading Edge envisions professionalized direct care workforce

Leading Age has **published** Feeling Valued Because They *Are* Valued: A Vision for Professionalizing the Caregiving Workforce in the Field of Long-Term Services and Supports. Why is it necessary to reimagine the direct care workforce, the white paper asks. "Despite the valuable work they do, direct care professionals are not valued by our society or its health care system. Too many of these caregivers earn low wages, receive inadequate benefits, and endure poor working conditions while carrying out an extremely labor-intensive job. Given these conditions, inevitable staffing shortages and workforce instability will lead to lower-quality care, lower-quality of life for consumers and their families, and unmet needs among care recipients. What would a reimagined direct care workforce look like? LeadingAge envisions a direct care workforce that is a professionalized workforce. The white paper proposes six strategies for achieving that goal: an expanded pipeline of potential caregivers; enhanced education and training; facilitated career advancement; increased compensation; preparation of universal workers who could become direct care professionals in nursing homes, assisted living communities, and home and community-based settings; and reform of the LTSS financing system."

Kaiser surveys HCBS programs and options for Medicaid SDOH support

The Kaiser Family Foundation published two issue briefs in August covering early findings on state Medicaid Home & Community-Based Services (HCBS) programs' response to COVID-19, as well as legal options for Medicaid to address social determinants of health (SDOH).

- Kaiser's **survey brief on HCBS programs** finds that "the Medicaid HCBS provider infrastructure declined during the pandemic, with two-thirds of responding states reporting a permanent closure of at least one provider. Most of these states reported permanent closures among more than one HCBS provider type. States most frequently cited workforce shortages as the pandemic's primary impact on in-home and group home services, while closures due to social distancing measures was the most frequently reported primary impact on adult day health and supported employment programs. Over half of responding states reported early plans for the new ARPA temporary enhanced federal funds for Medicaid HCBS. The most frequently reported activities were provider payment rate increases and workforce recruitment."

- With respect to Medicaid and social determinants of health, Kaiser's **second brief** points out that "Though health care is essential to health, research shows that health outcomes are driven by an array of factors, including underlying genetics, health behaviors, social, economic, and environmental factors. While there is currently no consensus in the research on the magnitude of the relative contributions of each of these factors to health, studies suggest that health behaviors and social and economic factors are primary drivers of health outcomes, and social and economic factors can shape individuals' health behaviors. There is extensive research that concludes that addressing social determinants of health is important for improving health outcomes and reducing health disparities. While new funding to provide targeted assistance related to food and housing security as well as economic supports to individuals have a direct impact on helping to address SDOH, health programs like Medicaid can also play a supporting role. Although federal Medicaid rules prohibit expenditures for most non-medical services, state Medicaid programs have been developing strategies to identify and address enrollee social

needs both within and outside of managed care since long before the COVID-19 pandemic."

Researchers caution about unique COVID-19 symptoms in older patients

Researchers have sounded a cautionary note when it comes to recognizing COVID-19 infection in aging adults. As The New York Times Paula Span **reports**, "COVID can look different in older patients. 'People expect fever, cough, shortness of breath,' said Allison Marziliano, lead author of the study. She is a social and health psychologist at the Feinstein Institutes for Medical Research, part of the large Northwell Health system across New York State. But when her team combed through the electronic health records of nearly 5,000 people, all over the age of 65, who were hospitalized for COVID at a dozen Northwell hospitals in March and April of 2020, they found that one-third had arrived with other symptoms, unexpected ones. About one-quarter of older patients reported a functional decline. 'This was falls, fatigue, weakness, difficulty walking or getting out of bed,' Dr. Marziliano said. Eleven percent experienced altered mental status — 'confusion, agitation, forgetfulness, lethargy.' About half the group with atypical symptoms also suffered from at least one of the classic COVID problems — fever, trouble breathing, coughing. 'We're not necessarily surprised by this,' said Dr. Maria Carney, a geriatrician and an author of the Northwell study. 'Older adults don't always present like other adults. They may not mount a fever. Their metabolisms are different. Diagnosing COVID quickly in older patients can make a world of difference. 'We have things to offer now that we didn't have in the first wave,' said Dr. Eleftherios Mylonakis, chief of infectious diseases at Warren Alpert Medical School of Brown University, who led a Providence nursing home study. 'We have better understanding, more treatments, better support.' Among the improvements: using anticoagulant drugs to prevent clotting and using monoclonal antibodies that strengthen the immune system. Dr. Mylonakis added, 'It's paramount to start any kind of treatment early.' Understanding that something as vague as weakness, confusion or appetite loss might signal a COVID infection can also help protect friends and family, who can then isolate and get tested themselves. 'It not only helps the individual, but also can contain the spread of the virus.' A COVID diagnosis can also ward off needless tests and procedures. 'We can avoid unnecessary testing, poking and prodding, CT scans,' Dr. Carney said. CT scans are expensive, burdensome and take time to schedule and analyze; a nasal swab for COVID is quick, relatively cheap and now widely available. With widespread vaccination, the symptoms of COVID-19 in older adults may become even more subtle. 'Fevers are easy to measure, and difficulty breathing will send anyone to an emergency room,' Dr. Carney pointed out, whereas 'we don't necessarily notice if someone has stopped eating.' Her counsel, for older patients and their caregivers and doctors, is to stay alert for changes that occur quickly, over a matter of days. 'When there's a change in behavior, physical or cognitive, it may not look like an infection, but keep COVID at the top of your list.'"

MEDIA WATCH

IN THIS SECTION

U.S. healthcare system scores last among 11 high income countries

The dazzling medical centers, the bustling research labs — all the many manifestations of the U.S. healthcare system — do not, in the view of the latest **Commonwealth Fund assessment,** keep that system from placing last among 11 high-income countries. As **reported** by The Washington Post's Claire Parker, "Researchers compared the health care systems of 11 high-income countries: Australia, Canada, France, Germany, the Netherlands, New Zealand, Norway, Sweden, Switzerland, the United Kingdom, and the United States. The research relies on 71 performance measures, based on surveys conducted in each country and administrative data from the Organization for Economic Cooperation and Development and the World Health Organization. The measures analyzed fell under five themes: access to care, the care process, administrative efficiency, equity, and health care outcomes. 'No country is at the top in every area and,' said Eric Schneider, the Fund report's lead

author, ‘every country has something to learn from the others.’ But Norway, the Netherlands and Australia were the top-performing countries overall. The high performers stand apart from the United States in providing universal coverage and removing cost barriers, investing in primary care systems to reduce inequities, minimizing administrative burdens, and investing in social services among children and working-age adults. The latter is particularly important for easing the burdens on health systems created by older populations, according to Schneider. ‘These sort of basic supports throughout younger age groups reduce, we think, the chronic disease burden that’s higher in the U.S.,’ he said. The United States was rated last overall, researchers found, ranking ‘well below’ the average of the other countries overall and ‘far below’ Switzerland and Canada, the two countries ranked above it. In particular, the United States fell at the end of the pack on access to care, administrative efficiency, equity, and health care outcomes. On care process — which measures things like preventive care and engagement with patients — the United States performed well in the latest iteration, coming in second place behind New Zealand. The United States has high rates of mammography screening and flu vaccination, for example, and a greater percentage of adults talk with their doctors about topics such as nutrition, smoking, and alcohol abuse. ‘We have almost two health care systems in America: one for people with means and insurance, and another one that falls short for people who are uninsured or don’t have adequate insurance coverage,’ Schneider said. ‘Those inequities contribute to poor health outcomes among marginalized or lower-income groups.’ The United States ranked last on health-care outcomes among surveyed countries, with the highest infant mortality rate and lowest life expectancy at age 60. The U.S. rate of preventable mortality is more than double that of Switzerland, the highest-performing country in that category. Lessons from the three top performers we highlight in this report — Norway, the Netherlands, and Australia — can inform the United States and other countries seeking to improve. As the COVID-19 pandemic has amply shown, no nation has the perfect health system. Health care is a work in progress; the science continues to advance, creating new opportunities and challenges.”

Nursing shortages vex hospitals

“Cyndy O’Brien, an emergency room nurse at Ocean Springs Hospital on the Gulf Coast of Mississippi, could not believe her eyes as she arrived for work,” **writes** The New York Times’ Andrew Jacobs. “There were people sprawled out in their cars gasping for air as three ambulances with gravely ill patients idled in the parking lot. Just inside the front doors, a crush of anxious people jostled to get the attention of an overwhelmed triage nurse. ‘It’s like a war zone,’ said Ms. O’Brien, who is the patient care coordinator at Singing River, a small health system near the Alabama border that includes Ocean Springs. ‘We are just barraged with patients and have nowhere to put them.’ The bottleneck, however, has little to do with a lack of space. Nearly 30 percent of Singing River’s 500 beds are empty. With 169 unfilled nursing positions, administrators must keep the beds empty. Nursing shortages have long vexed hospitals. But in the year and a half since its ferocious debut in the United States, the coronavirus pandemic has stretched the nation’s nurses as never before, testing their skills and stamina as desperately ill patients with a poorly understood malady flooded emergency rooms. ‘We’re exhausted, both physically and emotionally,’ Ms. O’Brien said, choking back tears. The staffing shortages have a hospital-wide domino effect. When hospitals lack nurses to treat those who need less intensive care, emergency rooms and I.C.U.s are unable to move out patients, creating a traffic jam that limits their ability to admit new ones. In Mississippi, health officials are warning that the state’s hospital system is on the verge of collapse. The state has 2,000 fewer registered nurses than it did at the beginning of the year, according to the Mississippi Hospital Association. With neighboring states also in crisis and unable to take patient transfers, the University of Mississippi Medical Center in Jackson, the only Level 1 trauma unit in the state, has been setting up beds inside a parking garage. ‘You want to be there in someone’s moment of need, but when you are in disaster mode and trying to keep your finger on the leak in the dike, you can’t give every patient the care they deserve,’ said Dr. LouAnn Woodward, the medical center’s top executive.

“With staffing shortfalls plaguing hospitals coast to coast,” Jacobs writes, “bidding wars have pushed salaries for travel nurses to stratospheric levels, depleting staff at hospitals that can’t afford to compete. Many are in states flooded with coronavirus patients. Texas Emergency Hospital, a small health system near Houston that employs 150 nurses and has 50 unfilled shifts each week, has been losing experienced nurses to recruiters who offer $20,000 signing bonuses and $140-an-hour wages. Texas Emergency, by contrast, pays its nurses $43 an hour with a $2 stipend for those on the night shift. ‘That’s ridiculous money, which gives you a sense of how desperate everyone is,’ said Patti Foster, the chief operations officer of the system, which runs two emergency rooms in Cleveland, Texas, that are over capacity. Ms. Foster sighed when asked whether the hospital offered signing bonuses. The best she can do is pass out goody bags filled with gum, bottled water and a letter of appreciation that includes online resources for those overwhelmed by the stress of the past few

weeks. On Friday, Cassie Kavanaugh, the chief nursing officer for the hospital's network, was dealing with additional challenges: Ten nurses were out sick with COVID. She had no luck renting ventilators or other breathing machines for her COVID patients. Many of the new arrivals are in their 30s and 40s and far sicker than those she saw during previous surges. 'This is a whole different ballgame,' she said. Ms. Kavanaugh, too, was running on fumes, having worked 60 hours as a staff nurse over the previous week on top of her administrative duties. She was also emotionally wrought after seeing co-workers and relatives admitted to her hospital. And her anguish only mounted after she stopped at the grocery store: 'Almost no one,' she said, 'was wearing masks.'"

Financial and driving difficulties: a dementia signal?

"Learning your odds of eventually developing dementia," **writes** The New York Times Paula Span, "requires medical testing and counseling. But what if every day behavior, like overlooking a couple of credit card payments or habitually breaking while driving, could foretell your risk? A spate of experiments is underway to explore that possibility, reflecting the growing awareness that the pathologies underlying dementia can begin years or even decades before symptoms emerge. 'Early detection is key for intervention, at the stage when that would be most effective,' said Sayeh Bayat, the lead author of a driving study funded by the National Institutes of Health and conducted at Washington University in St. Louis. 'It's all about finding people soon enough to intervene and prevent or delay the onset of the disease,' said Emily Largent, a medical ethicist and health policy researcher at the Penn Memory Center in Philadelphia, which undertakes many such studies. A GPS device in someone's car could monitor driving behavior almost continuously at low cost, providing so-called digital biomarkers. 'Studies have shown that driving changes in people with symptomatic Alzheimer's,' Ms. Bayat said. 'But some changes occur even earlier.' Another study analyzing medical records and consumer credit reports for more than 80,000 Medicare beneficiaries showed that seniors who eventually received a diagnosis of Alzheimer's disease were significantly more likely to have delinquent credit card payments than those who were demographically similar but never received such diagnoses. They also were more likely to have subprime credit scores. 'We were motivated by anecdotes in which family members discover a relative's dementia through a catastrophic financial event, like a home being seized,' said Lauren Nicholas, the lead author and a health economist at the University of Colorado School of Public Health. 'This could be a way to identify patients at risk.'"

Dr. Rockey extols face-to-face doctor-patient encounters and writes a poem

Dr. Paul H. Rockey laments the loss of compassionate face-to-face doctor-patient encounters — and he's written a poem to drive it home. "Compassion," he **writes**, "is more than empathy or sympathy. Empathy and sympathy are feelings. Being compassionate requires personal action. The admonition for doctors to really care about patients, to show actual compassion is not new. Before 20th-century, bioscientific advances, compassion was often the only healing action available to physicians. In an address the celebrated clinician, researcher, and educator Francis W. Peabody, M.D., gave to Harvard medical students in 1926 he said, 'One of the essential qualities of the clinician is interest in humanity, for the secret of the care of the patient is in caring for the patient.' Compassion occurs in profound human-to-human interactions. A colleague recently noted that at least two Chicago health systems advertise that their institutions provide 'compassion.' But how can sprawling medical complexes be compassionate? Large medical institutions have become adept at doing tests; not so good at providing face-to-face care. Sixteen years ago, while still providing patient care, I wrote a poem entitled Stethoscope. I wanted to capture how we doctors face patients, listen to their stories, speak to them, touch them, and engage them with both verbal and non-verbal communication, showing we care, comforting them, creating trust, and opening the door for them to accept our advice.

Stethoscope
Face-to-face, the curtain drawn,
your smoker's voice, like iced gravel,
tells me of a close friend's death,
'Sudden,' you say, 'from a heart attack.'
With a two-tailed snake in my ears,
I stand, warm its head in my hand,
cup the bell and touch your chest,
bringing your heart in to me.
To complete our mortal circle,
my left hand holds your shoulder.

I say, 'Your heart sounds normal.'
and I feel your muscles relax.

"All physicians should strive to demonstrate compassion in speech and actions. Those in certain specialties will have more opportunities for compassion during face-to-face encounters with patients. But can compassion be shown in full in this technological age, where many patients and doctors, and many teachers and students are not face-to-face? Can you feel your patient's muscles relax on Zoom?"

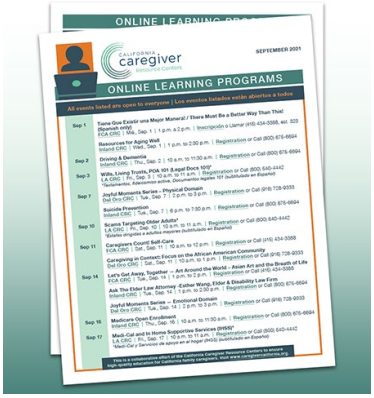
FCA ANNOUNCEMENTS

FCA's clinical services director quoted in Vox article on caregivers

America isn't taking care of caregivers. 48 million people provide unpaid care to their loved ones in the US. Here's how to help them. That is the headline of a recent **Vox article** focusing on the collateral health effects of the Covid-19 pandemic in the United States. FCA's Christina Irving, clinical services director, is generously quoted and offered this takeaway: "Irving advocates for a more comprehensive connection of services among health care, social service, and government systems. 'It doesn't mean they're going to provide all the supports — just so that caregivers don't fall through the cracks.'"

New 'BPC Approved' badge for dementia caregiving programs

Is your organization seeking a vetted program for families and friends caring for loved ones with dementia? Look no further than the user-friendly database **Best Practice Caregiving.** Each program in BPC meets the criteria for inclusion enabling them to add the badge to their websites. Best Practice Caregiving is a product of collaboration among: Benjamin Rose Institute on Aging, Family Caregiver Alliance, and The Gerontological Society of America. Project funders are The John A. Hartford Foundation, the Archstone Foundation, and RRF Foundation for Aging. For further information about BPC along with infographics for three of the programs check out the recent **BPC newsletter.**



Free online programs for caregivers

The **California Caregiver Resource Centers (CRCs)** are proud to provide regular educational and informative events to family caregivers. This is a coordinated effort to offer a wide range of free, virtual programs in multiple languages and with topics of interest to family caregivers. These programs are open to ALL family caregivers in California. A downloadable calendar listing of monthly events is available in a linkable PDF at **https://bit.ly/SepCRC.** View the PDF in your browser or download to Adobe reader. You can also view the calendar on the CRC website **here.**

The American Society on Aging's 12-part series — **The Legacy Interviews** — features pioneers in the aging field. FCA is a co-sponsor and we are excited to share the four interviews have been conducted to date. Don't miss the following interviews offering diverse perspectives, insights, and wisdom.

Paul Nathanson, J.D., founder of Justice in Aging shares how his early legal career in the 1970s took a left turn by leaving a prominent law firm to devote his life to achieving social justice for those aging and the impact that decision has had on elders, communities and society.

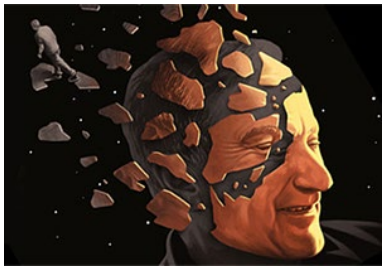
Imani Woody, Ph.D., the force behind Mary's House, herself a victim of poverty, homophobia, ageism and racism, describes how – for nearly 50 years - she has battled to create a more equitable and inclusive world for everyone.

Linda Fried, M.D., M.P.H., geriatrician, epidemiologist (and aikido black belt), and the first female dean of Columbia University's Mailman School of Public Health, reflects on the public and personal paths to a healthy and purposeful aging.

Jennie Chin-Hansen, R.N., M.S., former president of AARP explains that after facing many serious challenges as a young minority woman, she abides by a three-legged stool of social justice, democratic means, and capitalism.

Let's Get Away Together

One of the free online programs FCA sponsors is the Let's Get Away Together series. These weekly events offer, in collaboration with **The Hummingbird Project,** storytelling, music, poetry writing, or a simple craft while virtually traveling (Zooming) to a specific country and culture. The programs are interactive and intended to be an enjoyable activity for caregivers and the person receiving their care. Visit **Let's Get Away Together** for more information. Registration is available **here.** To learn more about the series, a Q&A with the project manager and director of The Hummingbird Project can be **read here.**



SPARK film screening and panel discussion

Following a special screening on June 30 of the documentary, *SPARK: Robin Williams and his Battle with Lewy Body Dementia,* FCA hosted a **panel discussion** in partnership with the Lewy Body Dementia Association and the Brain Support Network. SPARK tells the story of Mr. Williams' battle with undiagnosed Lewy body dementia; delves into the known science behind the disease; and highlights the disease's impact on the person with LBD and their family caregiver. The panel discussion featured: Robin Riddle, Board Member and CEO of **Brain Support Network;** Bruce L. Miller, M.D., Director, **Memory and Aging Center,** University of California, San Francisco; and two family caregivers. Among the topics covered during the discussion were: the nature of Lewy body dementia and what's known about it; the caregivers' experiences while caring for family members who were diagnosed with Lewy body dementia; and families' interactions with health care providers. In addition, FCA spoke with **LBDA** executive director Todd Graham prior to the screening to learn how the film is contributing to greater understanding, detection, diagnosis, and quality care management of LBD. The interview is available **here.**

Credits

Editor: Alan K. Kaplan, (attorney and health policy consultant)
Contributor: Kathleen Kelly (executive director)
Layout: Francesca Pera (communications specialist)

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

FCA TWEETS @CaregiverAlly

Follow Family Caregiver Alliance / National Center on Caregiving on Twitter **@CaregiverAlly** and Executive Director Kathleen Kelly **@KKellyFCA**.

REGISTER YOUR RESEARCH

Professional Research

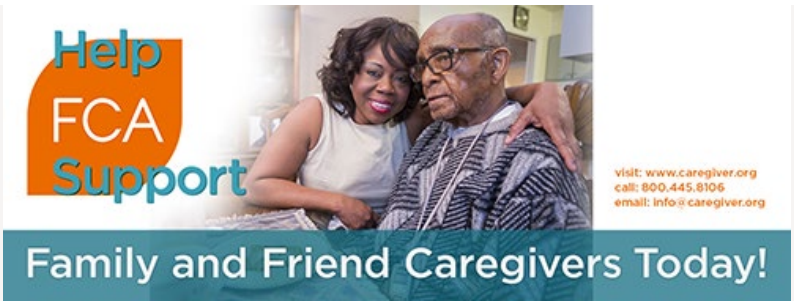
- **Aging with Pride: IDEA (Innovations in Dementia Empowerment and Action)**
- **Balancing Work and Caregiving**
- **Care2Sleep Education Program**
- **Equality in Caregiving: Facilitating Caregiver Mastery Among LGBT Caregivers**
- **Free Assistive Technology for Caregivers**
- **Life Enhancing Activities for Family Caregivers (LEAF) (SP0044459; NCT03610698)**
- **Survey of Black New Yorkers' Caregiving & End of Life Experiences**
- **The Taking Care of Us (TCU) Program (NCT04737759)**
- **UCSF Movement and Mindfulness Research Study for Caregivers And Those With Memory Loss**

Graduate Student Research

- **ACHIEVE Study**
- **Caregivers of LGBTQ+ Older Adults of Color**
- **Chinese American Family Caregivers for Alzheimer's or Other Dementia**

- **Evaluating a text-messaging intervention to improve caregiver wellbeing**
- **Exploring End of Life Experiences in Diverse Communities**
- **Understanding Eating and Health**
- **Working Age Stroke Caregiver Survey**

SUPPORT FCA



Help support FCA/NCC's continuing advocacy efforts today with a donation through **Network for Good**.

Amazon shoppers: Please consider supporting FCA through AmazonSmile. Amazon will donate to FCA based on your purchase. Use the following link when you shop: **smile.amazon.com/ch/94-2687079**.

Subscribe

Subscribe to **Caregiving Policy Digest** and **Connections** (for family caregivers) **here**.

Archive

Read past issues of **Caregiving Policy Digest** **here**.

Family Caregiver Alliance®
National Center on Caregiving

Visit FCA's website @ **caregiver.org**

Stay connected on social media with FCA