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Family Caregiver Alliance®

National Center on Caregiving

CAREGIVING POLICY DIGEST

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“It’s obvious if you work in the aging field. It’s obvious if you work in the disability field. It’s obvious if you are any age and live with a disability. It’s obvious if you are a member of the growing direct care workforce. It’s obvious if you are a son or a daughter supporting an aging parent who needs help to remain at home. And now, finally, it’s obvious to the President of the United States. After nearly 20 years working in the field of aging, fighting to secure access to needed health and long-term care services for older adults, what a relief and revelation it was to hear the President’s words in his recent address to the joint session of Congress. ‘Democrat or Republican voters, their great concern is taking care of an elderly loved one.’ A simple and obvious statement that represents what could become the most profound and meaningful shift in aging policy in decades. President Biden has responded with a proposal to invest $400 billion in Medicaid home and community-based services (HCBS) — an investment that would fortify the foundation of our care infrastructure so that more people with disabilities of all ages can live at home and be connected to their communities, their jobs, their schools, their families, their friends; and so that direct care workers can have good jobs with just compensation. The Biden proposal would provide a 33% increase in HCBS spending annually. This is transformational! For comparison, in the period between 2011 and 2015 when complete

> *expenditure data was last available, HCBS spending only increased on average 5% a year. So a 33% increase is a very big deal."*
>
> — Kevin Prindiville, **Justice in Aging**

COVID-19, NURSING HOMES, AND PAID LEAVE

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Vaccinations tame the virus

"The primary objective," observed Dr. Amesh Adalja, an infectious disease specialist at Johns Hopkins University, "is to deny this virus the ability to kill at the rate that it could, and that has been achieved. We have in effect tamed the virus." Adalja's mid-May declaration followed the release of encouraging data indicating the dramatic impact of expanding vaccination rates. COVID-19 deaths in the United States have tumbled to an average of around 600 per day — the lowest level in 10 months, the Associated Press **reported** — with the number of lives lost dropping to single digits in well over half the states and, on some days, hitting zero. Confirmed infections have fallen to about 38,000 per day on average, their lowest mark since mid-September. While that is still cause for concern, reported cases have plummeted 85% from a daily peak of more than a quarter-million in early January. About 45% of the nation's adults are fully vaccinated, and nearly 59% have received at least one dose, according to the Centers for Disease Control and Prevention."

Victim aftereffects mount

The good news about coronavirus infection and death rates remained tempered by the growing evidence of the long-term health toll COVID-19 survivors are experiencing. "In one recent **study** published in Nature," **reports** The New York Times' Pam Bellock, "researchers looked at medical records of more than 73,000 people across the United States whose coronavirus infections did not require hospitalization. Between one and six months after becoming infected, those patients had a significantly greater risk of death — 60 percent higher — than people who had not been infected with the virus. The research, based on records of patients in the Department of Veterans Affairs health system, also found that non-hospitalized COVID survivors had a 20 percent greater chance of needing outpatient medical care over those six months than people who had not contracted the coronavirus. The COVID survivors experienced a vast array of long-term medical problems that they had never had before — not just lung issues from the respiratory effects of the virus, but symptoms that could affect virtually any organ system or part of the body, from neurological to cardiovascular to gastrointestinal. They were also at greater risk of mental health problems, including anxiety and sleep disorders. 'We found it all,' said an author of the study, Dr. Ziyad Al-Aly, chief of the research and development service at the VA St. Louis Health Care System. What's more, some of the patients' post-COVID medical issues — like diabetes, kidney disease and some heart problems — could become chronic conditions that would require treatment for the rest of their lives. 'We have hundreds of thousands of people with an unrecognized syndrome and we are trying to learn about the immune response and how the virus changes that response and how the immune response can include all the organ systems in the body,' said Dr. Eleftherios Mylonakis, chief of infectious diseases at Brown University's Warren Alpert Medical School and Lifespan hospitals. 'The health system is not made to deal with something like this.' In many cases, Dr. Mylonakis said, people experiencing new symptoms who were never acutely sick from the viral infection enter a confusing and balkanized medical world, where they seek help from primary care doctors and then are referred to various specialists who each try to figure out how to treat conditions that fall under their particular area of expertise. That helps explain why the study found that the COVID survivors had about one-and-a-half times more outpatient visits a month than patients in the general VA population."

CMS regulation mandates vaccination offer

CMS has issued a new **rule** regarding COVID-19 vaccinations in long-term and intermediate-care facilities. As summarized by Justice in Aging, the rule requires Long-Term Care (LTC) facilities and Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs-IID) to educate and offer the COVID-19 vaccine to all residents, clients, and staff, and to report weekly COVID-19 vaccination status data for both residents and staff. The new requirements align with existing requirements for influenza and pneumococcal vaccines in LTC facilities. In addition, CMS is requesting comment on extending the requirements to other congregate settings such as assisted living and group homes, and encourages these congregate settings to voluntarily adopt culturally and linguistically appropriate and accessible vaccination education and to support residents in accessing vaccines. **Comments are due** by July 12, 2021.

Nursing home indoor visitation guidance

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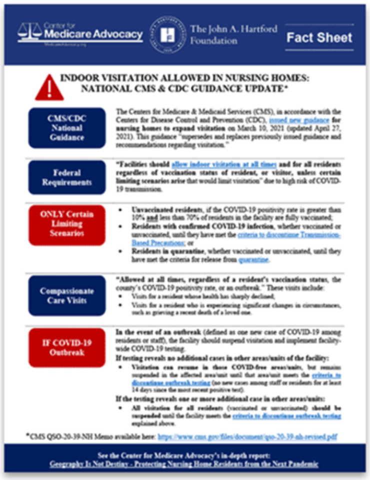

INDOOR VISITATION ALLOWED IN NURSING HOMES: NATIONAL CMS & CDC GUIDANCE UPDATE*

CMS/CDC National Guidance	The Centers for Medicare & Medicaid Services (CMS), in accordance with the Centers for Disease Control and Prevention (CDC), issued new guidance **for nursing homes to expand visitation** on March 10, 2021 (updated April 27, 2021). This guidance "supersedes and replaces previously issued guidance and recommendations regarding visitation."
Federal Requirements	**"Facilities should allow indoor visitation at all times and for all residents regardless of vaccination status of resident, or visitor, unless certain limiting** scenarios arise that would limit visitation" due to high risk of COVID-19 transmission.
ONLY Certain Limiting Scenarios	• **Unvaccinated residents**, if the COVID-19 positivity rate is greater than 10% **and** less than 70% of residents in the facility are fully vaccinated; • **Residents with confirmed COVID-19 infection**, whether vaccinated or unvaccinated, until they have met the criteria to discontinue Transmission-Based Precautions; or • **Residents in quarantine**, whether vaccinated or unvaccinated, until they have met the criteria for release from quarantine.
Compassionate Care Visits	**"Allowed at all times, regardless of a resident's vaccination status**, the county's COVID-19 positivity rate, or an outbreak." These visits include: • Visits for a resident whose health has sharply declined; • Visits for a resident who is experiencing significant changes in circumstances, such as grieving a recent death of a loved one.
IF COVID-19 Outbreak	**In the event of an outbreak** (defined as one new case of COVID-19 among residents or staff), the facility should suspend visitation and implement facility-wide COVID-19 testing. **If testing reveals no additional cases in other areas/units of the facility:** • **Visitation can resume in those COVID-free areas/units**, but remain suspended in the affected area/unit until that area/unit meets the criteria to discontinue outbreak testing (no new cases among staff or residents for at least 14 days since the most recent positive test). **If the testing reveals one or more additional case in other areas/units:** • **All visitation for all residents** (vaccinated or unvaccinated) **should be suspended** until the facility meets the criteria to discontinue outbreak testing explained above.

*CMS QSO-20-39-NH Memo available here: https://www.cms.gov/files/document/qso-20-39-nh-revised.pdf

See the Center for Medicare Advocacy's in-depth report:
Geography Is Not Destiny - Protecting Nursing Home Residents from the Next Pandemic

CMS issues HCBS guidance

CMS has also **published** extensive guidance to state Medicaid directors on using the enhanced funding for Medicaid home and community-based services (HCBS) provided through the recently enacted American Rescue Plan Act of 2021 (ARP). Under the ARP, states can receive a 10% increase to the federal medical assistance percentage (FMAP) for certain Medicaid HCBS expenditures from April 1, 2021 to March 31, 2022 (The Administration's much more expansive HCBS funding level — $400 billion — is contained in its proposed American Jobs Plan currently undergoing congressional debate).

Nursing homes face post pandemic challenges

As nursing homes emerge from their year-long COVID-19 nightmare, the challenges facing their ongoing existence continue to loom large. The pandemic laid bare the many fault lines in their structural, staffing, and financial elements. As The Washington Post's Nina A. Kohn **writes**, "Understaffing, for example, is possible — and profitable — because the U.S. regulatory system charged with ensuring that nursing homes provide safe care has failed. Federal regulations establish (on paper) a high bar for quality of care. Nursing homes must ensure that all of their residents receive individualized care in accordance with professional standards of practice and that no resident experiences avoidable harm or an avoidable decline in key abilities (such as mobility). States are deputized to enforce these rules — and must send surveyors into homes at least every 15 months — as part of that effort. But this enforcement scheme has largely failed to protect residents. Regulators rarely impose meaningful penalties such as fines, holds on new admissions, or payment suspensions. Usually when inspectors find that a nursing home has unlawfully endangered its residents, the facility is directed to fix the problem, and inspectors may not follow up to ensure that the problem has been corrected."

States enhance SNF quality controls

“Some states,” Kohn points out, “have begun to experiment with a new approach to ensuring that nursing homes meet the standards the federal government has set requiring them to spend a certain percentage of revenue on resident care. In September, Massachusetts announced that it would require nursing homes in the state to spend 75 percent of revenue on direct-care staffing costs. In October, New Jersey adopted legislation requiring nursing homes to spend 90 percent of annual aggregate revenue on direct resident care. The spending requirements ideally should be paired with financial transparency requirements so that facilities cannot hide profit as expenses. A bill being considered in California, for instance, would require facilities to disclose transactions with businesses owned by the same entities that own them. States are also finally showing interest in requiring the staffing levels necessary to achieve the positive outcomes that Washington mandates. In response to the pandemic, New Jersey passed legislation requiring that one certified nurse associate be on duty for every eight residents during the day shift (with somewhat lower requirements at night). Rhode Island is considering a more robust approach, with proposed legislation that would require nursing homes to provide the 4.1 hours of care (per resident per day) that researchers have found necessary for humane care. Such proposals, however, face stiff opposition from the industry, which helped scuttle a push for minimum staffing requirements in Virginia this year and helped develop legislation adopted by Arkansas in April that reduced penalties for understaffing and weakened the state’s existing staffing requirements.”

Congress questions private equity SNF investments

One aspect of the long-term care sector drawing increasing scrutiny is the role of private equity in SNF financing. “Democrats,” **writes** Modern Healthcare’s Jessie Hellmann, “want more information about the roles private equity and chain ownership of nursing homes play in patient outcomes, pointing to studies that show more deaths and worse care in facilities owned by investors. A proposal by House Ways and Means Committee Chairman Richard Neal, which will be reintroduced this year, would significantly increase the amount of information investors in the healthcare industry have to report to the IRS. With nursing homes in particular — an already fragmented sector of the healthcare industry — complex ownership structures make it hard for policymakers and families to know which facilities are owned by private equity investors or how profitable they are. ‘Examining the role of private equity in the healthcare system remains a top priority for the committee, especially in light of the last year, and we are actively accessing options for action here,’ said a Ways and Means aide.”

Blogger proposes compromise long-term care ‘fixes’

For Health Affairs **blogger** Robert Kramer SNF breakdowns, unleashed by the pandemic, may provide a fleeting opportunity to introduce some significant “fixes” — but only if “advocates from all corners see beyond traditional silos, listen to each other, and compromise. Failure to do so will likely lead to simplistic, fatally flawed quick fixes, or the favoring of one remedy over another. Among Kramer’s proposals: Tying increased funding to improved wages, benefits, and training for front line staff and addressing gaps in infection prevention and registered nurse coverage; pairing investments with meaningful transparency and accountability across providers’ ownership structures and finances; coupling transparency with some degree of liability relief for providers so that increased transparency does not simply invite frivolous lawsuits seeking settlements mandated by insurers regardless of the merits of claims; encouraging investment in digital technology, and driving improvements in areas such as communication, care delivery on site, and resident engagement; applying creative incentives, such as buyback programs, to help the industry close functionally obsolete buildings, convert multiple occupancy rooms to single occupancy, and enact numerous infrastructure improvements to meet the needs of today’s long-term care residents; and using regulation and funding to promote household or neighborhood models that use consistent staffing and even universal staffing. As we have seen in studies of the **Green House** model during the pandemic, these models perform better in both infection control and prevention, and resident/staff satisfaction.”

Advocates seek HCBS palliative care benefit

“In the wake of the emerging research on COVID-19 aftereffects,” **reports** The Washington Post’s Michael Ollove, “the National Hospice and Palliative Care Organization’s latest push in its talks with the Centers for Medicare and Medicaid Services (CMS) is to create a home- and community-based palliative care benefit. ‘Early on, it was clear to me that we are going to have a ton of seriously ill people, and almost none of them will qualify for hospice care,’ Edo Banach, the group’s president said. The contagiousness of the coronavirus also is an impetus for action since many people who might benefit from palliative care are particularly vulnerable to infection. They shouldn't risk a trip to the hospital during a pandemic if they can avoid it, he said. 'Anything that can bring home-based palliative care to patients who are not hospice eligible (or desiring) is essential,' said James Tulsky, co-director of the Harvard Medical School Center for Palliative Care. 'There are many patients with significant needs (medical, psychosocial) who are primarily homebound and could benefit from closer monitoring and more in-home services. Currently, the resources available for them are limited.' Others who are seriously ill now but who might recover, such as coronavirus long-haulers, also could benefit from palliative care. The proposal from Banach's group and their allies calls for the expansion of a demonstration that CMS has been funding since 2016 called the Medicare Care Choices Model. Under that model, patients with terminal illnesses who did not want to abandon medical treatments intended to prolong their lives can receive hospice services through participating hospice organizations. The model resulted in a 25 percent savings to Medicare, largely by reducing hospitalizations. Most caregivers also reported high satisfaction with the treatment provided."

Biden calls for big paid family leave program

On April 28 Pres. Biden unveiled his administration's American Families Plan. Among its ambitious components, detailed in the White House's **Fact Sheet:** "direct support to workers and families by creating a national comprehensive paid family and medical leave program that will bring America in line with competitor nations that offer paid leave programs. A lack of family-friendly policies, such as paid family and medical leave for when a worker needs time to care for a new child, a seriously ill family member, or recover from their own serious illness, has been identified as a key reason for the U.S. decline in competitiveness. The United States is one of the only countries in the world that doesn't guarantee paid leave. Nearly one in four mothers return to work within two weeks of giving birth and one in five retirees left or were forced to leave the workforce earlier than planned to care for an ill family member. Further, today nearly four of five private sector workers have no access to paid leave. Ninety-five percent of the lowest wage workers, mostly women and workers of color, lack any access to paid family leave. The program will ensure workers receive partial wage replacement to take time to bond with a new child, care for a seriously ill loved one, deal with a loved one's military deployment, find safety from sexual assault, stalking, or domestic violence, heal from their own serious illness, or take time to deal with the death of a loved one. It will guarantee twelve weeks of paid parental, family, and personal illness/safe leave by year 10 of the program, and also ensure workers get three days of bereavement leave per year starting in year one. The program will provide workers up to $4,000 a month, with a minimum of two-thirds of average weekly wages replaced, rising to 80 percent for the lowest wage workers. We estimate this program will cost $225 billion over a decade."

BRIEFING ROOM

Fact Sheet: The American Families Plan

APRIL 28, 2021 • STATEMENTS AND RELEASES

Today, President Biden announced the American Families Plan, an investment in our kids, our families, and our economic future.

In March, the President signed into law the American Rescue Plan, which continues to provide immediate relief to American families and communities. Approximately 161 million payments ↗ of up to $1,400 per person have gone out to households, schools are reopening, and 100 percent of Americans ages 16 and older are now eligible for a COVID-19 vaccine. The Rescue Plan is projected to lift more than five million children out of poverty this year, cutting child poverty by more than half. While too many Americans are still out of work, we are seeing encouraging signs in the labor market, as businesses begin to rehire and some of the hardest hit sectors begin to reopen.

Business leaders mobilize to support family caregivers

Some very high-powered support for caregiver assistance will be coming from the **Care Economy Business Council,** a newly formed coalition that will, as The New York Times' Alisha Haridasani Gupta **reports,** "argue that fixing the crumbling child and elder care systems is essential to the post-pandemic economic recovery. Led by Time's Up, the advocacy organization founded by powerful women in Hollywood, the council aims to bring executives together to share ways to improve workplace policies and to pressure Congress to pass policy changes that would help people — particularly women — get back to work. The council will push for federally funded family and medical leave, affordable child care and elder care, and elevated wages for caregiving workers. The issue is 'bigger than something we can solve on our own,' said Christy M. Pambianchi, the chief human resources officer at council member Verizon."

RESEARCH AND RESOURCES

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- CMA laments disappearing home health care services, again

Researchers confirm COVID-19 brain risks

The COVID-19 post-acute symptom phenomenon received attention in new research regarding two vital bodily parts: the brain and lungs. In a **study** published in The Lancet Psychiatry, **reported** STAT's Elizabeth Cooney, "Six months after being diagnosed with COVID-19 1 in 3 patients also had experienced a psychiatric or neurological illness, mostly mood disorders but also strokes or dementia. About 1 in 8 of the patients (12.8%) were diagnosed for the first time with such an illness, most commonly anxiety or depression. Compared to control groups of people who had the flu or other non-COVID respiratory infections, first-ever neuropsychiatric diagnoses were almost twice as high. The study used real-world health data on millions of people to gauge the incidence of 13 brain disorders. Anxiety, mood, and substance-use disorders were most common, but the researchers also found worrying, if lower, rates of serious neurological complications, especially in patients who had been severely ill with COVID-19. At the same time, Allison Navis, assistant professor in the division of neuro-infectious diseases at the Icahn School of Medicine at Mount Sinai, sounded a note of caution. 'It does highlight that there is something unique going on with COVID,' she told STAT. 'And the 12.8% who have a new diagnosis of something neuropsychiatric can sound very sensational. That 12.8% encompasses depression and anxiety, so it's extremely important to not minimize that and not make that sound like a lesser diagnosis at all, but the more severe things like strokes are still fairly uncommon. I don't want people thinking that 1 in 10 people get a stroke with COVID.' What does appear new is the distinction between neurological and psychiatric complications. People with very severe COVID-19 had a higher risk of complications like stroke or dementia, but people who developed anxiety or depression spanned the spectrum of illness severity."

Post-COVID lung damage and transplants

Meanwhile pulmonary physician Daniela J. Lamas **posted** some disturbing observations concerning COVID-19 post-acute lung damage. "Here in my hospital, we are caring for a new population of patients who have cleared the virus but are left with severe lung disease, trapped on ventilators and lung bypass machines. Try to imagine: You go to the E.R. with a cough. You're not even sure that you will be admitted. Days later you are intubated. Consciousness ceases. A month or two pass, and then you wake up with hoses in your neck, and you learn that a transplant and all that comes with it is your only option to stay alive. How does someone who has never known what it is to have a chronic disease, whose only frame of reference is a healthy life before COVID-19, come to terms with this reality? These questions are only going to become more immediate. We are seeing the first wave of COVID lung transplants, caring for patients who are on the cusp of death, for whom a transplant is the only option to live. But a larger, second wave is coming, this time of coronavirus survivors who have made it out of the hospital but are left with lungs that are irrevocably scarred. Some will continue to improve over time. But for those who do not, a handful of hospitals throughout the country have started to consider one of medicine's most aggressive interventions: lung transplant. These transplants are already raising thorny ethical questions about equitable access to a scarce resource, and how we define a good transplant candidate — for which we do not have any easy answers."

Council recommends COVID-19 brain damage countermeasures

Targeting attention on the impact of COVID-19 on brain health, the Global Council on Brain Health, an AARP collaborative, **offers** 10 recommendations to decrease the pandemic's mental threats. Vaccination tops the list followed by physical activity, a balanced diet, maintenance of social connections and regular sleep, brain stimulation through reading, crossword puzzles and listening to music, keeping necessary medical appointments, pursuing less stressful, more relaxing activities, paying attention to sudden confusion, and monitoring changes in brain health. “While the pandemic has affected everyone in different ways,” the report states, “it has brought a great deal of uncertainty and forced us all to adapt to new ways of life. It has raised awareness for many about what is truly important, even bringing positive feelings in some cases, such as gratitude for friends and family. More troublingly, it has unleashed a host of new stressors into all of our lives, along with a range of emotions, some of which can be harmful. For those with mental health conditions such as anxiety, depression, and obsessive-compulsive disorder, the uncertainties have been felt even more acutely. For those who have suffered job loss and economic hardship, or are grieving from the loss of a loved one, the instability may feel overwhelming.”

Milken guide seeks better dementia detection and diagnosis

The Milken Institute has issued a 43-page **guide** to broadening access to dementia detection and diagnosis. Emanating from the organization’s Alliance to Improve Dementia Care, the report aims to equip health-care professionals with proven tools and resources to detect and diagnose dementia in a timely manner, encourage individuals to pursue cognitive screenings to track their brain health, and offer guidance for policymakers on best practices and existing solutions. “Achieving these goals,” the report finds, “will entail such efforts as

- promoting routine utilization of structured cognitive assessments during the Medicare Annual Wellness Visit;
- accelerating incorporation of available and recognized trainings and toolkits into primary care team clinical workflows to augment detection and diagnosis;
- addressing stigma surrounding dementia by raising awareness of the benefits to early detection and diagnosis and creating consumer demand for and expectation of routine cognitive assessment; and
- facilitating expansion of and access to cognitive assessment strategies to include age-friendly clinical and non-clinical home- and community-based settings.”

AD drug trial stirs some hopes

“Hope springs eternal” has thus far been the sentiment that the search for a drug to combat Alzheimer’s disease has necessitated, but a ray of such hope may soon be warranted. The cause: the results of TRAILBLAZER-ALZ, a phase 2 **clinical trial** of donanemab, an antiamyloid monoclonal antibody, in early Alzheimer’s disease. Disease-modifying treatments for Alzheimer’s disease have mostly targeted the amyloid plaques that are a hallmark of the disease, but repeated trial failures have led many to question this choice of target. “In this trial,” **comments** Emory University’s Dr. Allan I. Levey, “257 participants with early Alzheimer’s disease were randomly assigned to receive donanemab or placebo intravenously every 4 weeks for approximately 1.5 years. The prespecified primary outcome goal was met: treatment with donanemab resulted in 25 to 30% less decline than placebo in the score on the Integrated Alzheimer’s Disease Rating Scale, a composite measure of cognition and the ability to perform instrumental activities of living. Although encouraging, these findings, which amounted to a 3-point difference on a scale ranging from 0 to 144, barely showed significance (P=0.04), and the clinically relevant secondary outcomes of dementia severity, cognition, and functional abilities all failed to show treatment effects. Nevertheless, the results warrant further study of donanemab. Treatments for Alzheimer’s disease will require a transformation of health care practice. Early and specific diagnosis is an essential first step, because a treatment benefit is expected only when treatment is started at the very early stages of disease. Many people with dementia never receive a diagnosis of the underlying cause or receive one only after many years of symptoms. This trial of donanemab provided encouraging results that support a potential role for amyloid immunotherapies for mild Alzheimer’s disease. However, the need for additional research has never been clearer.”

NAM calls for universal primary physician access

In a 449-page **report** the National Academy of Medicine has issued a fervent call for providing every American with access to a primary care physician. The report, **writes** Kaiser Health News’ Noam N. Levey, calls for a broad recognition that primary care is a “common good” akin to public education. “The authors recommend that all Americans select a primary care provider or be assigned one, a landmark step that could reorient how care is delivered in the nation’s fragmented medical system. And the report calls on major government health plans such as Medicare and Medicaid to shift money to primary care and away from the medical specialties that have long commanded the biggest fees in the U.S. system. ‘High-quality primary care is the foundation of a robust health care system, and perhaps more importantly, it is the essential element for improving the health of the U.S. population,' the report concludes. 'Yet, in large part because of chronic underinvestment, primary care in the United States is slowly dying.' Only about 5% of U.S. health care spending goes to primary care, versus an average of 14% in other wealthy nations, according to data collected by the Organization for Economic Co-operation and Development. 'If we increase the supply of primary care, more people and more communities will be healthier, and no other part of health care can make this claim,' said Dr. Robert Phillips, a family physician who co-chaired the committee that produced the report. This idea of formally linking patients with a primary care office — often called empanelment — isn't new. Kaiser Permanente, consistently among the nation's best-performing health systems, has long made primary care central. But the model, which was at the heart of managed-care health plans, suffered in the backlash against HMOs in the 1990s, when some health plans forced primary care providers to act as 'gatekeepers' to keep patients away from costlier specialty care. More recently, however, a growing number of experts and primary care advocates have shown that linking patients with a primary care provider need not limit access to care. 'If you don't have empanelment, you don't really have continuity of care,' said Dr. Tom Bodenheimer, an internist who founded the Center for Excellence in Primary Care at the University of California-San Francisco and has called for stronger primary care systems for decades. Bodenheimer added: 'We know that continuity of care is linked to everything good: better preventive care, higher patient satisfaction, better chronic care and lower costs. It is really fundamental.'"

Lown Institute calls out unnecessary tests and procedures

Is your hospital performing unnecessary tests and procedures? Yes, the **Lown Institute** says, much too often. "The Institute's second annual Hospitals Index," **reports** Modern Healthcare's Lisa Gillespie, "found that in the U.S., for-profit, non-teaching and Southern hospitals were associated with the highest rates of overuse. Hospitals like Houston Methodist Sugarland Hospital, CHI St. Luke's Health Memorial Livingston in Tennessee, and Adventist Healthcare Fort Washington Medical Center in Maryland all scored in the bottom 50 hospitals as having the most Medicare claims for 12 unnecessary tests, procedures and surgeries. 'These are things that are generally low-value tests and procedures that you don't really see health improvements or functional improvements,' said Dr. Vikas Saini, president of the Lown Institute. 'These are the tip of the iceberg of overuse, because this is the stuff that are very black and white.' The rankings are from over 3,100 hospitals of more than 1 million tests and procedures from Medicare claims in a two-year period between 2016 and 2018. The Lown Institute looked at claims, for example, for patients who had hysterectomies without a cancer diagnosis. Among the 12 low-value services measured, hysterectomy for benign disease, the placement of coronary stents for stable heart disease, and diagnostic tests like head imaging for fainting, were all widespread, with more than 90% of hospitals overusing these tests or procedures. The institute also found that 64% of all hysterectomies, 44% of carotid endarterectomies and 24% of coronary stent procedures met criteria for overuse nationwide."

Researchers tie high SNF staff turnover rates to lower quality of care

Throughout the more than 12 months of severe nursing home COVID-19 distress, SNF staffing needs and the perceived failure to meet them became a major theme of the crisis. Now an intriguing **study** by UCLA and Harvard researchers used recently available CMS SNF payroll data to measure nursing turnover rates as an indicator of nursing home quality during the pandemic. "The results," the researchers write, "suggest that nursing staff turnover at U.S. nursing homes is higher than previous work typically suggests, highly variable across facilities, and strongly correlated with specific organizational characteristics. We identified several organizational characteristics that were correlated with total nursing staff turnover. Turnover rates were higher in regions with lower per capita income. This may reflect nursing staff being more likely to depart from their positions because of inadequate pay in these regions. We also found that for-profit status and chain ownership were associated with higher turnover rates. This may reflect for-profit nursing homes failing to support the needs of nursing staff and chain-owned facilities imposing stricter standardization and oversight on their employees. Finally, we found that a higher Medicaid census was also associated with greater nursing staff turnover. Because Medicaid reimbursement rates are generally lower than those of Medicare and private payment, it is likely that facilities with a greater share of Medicaid residents are less financially capable of paying staff higher wages and offering benefits, which could contribute to higher turnover. Policy makers may wish to consider reporting facilities' staffing turnover rates on the Nursing Home Compare website, as well as incorporating turnover rates into the five-star staffing rating system used by Nursing Home Compare. Residents and their families could use these measures to seek out facilities with more stable nurse staffing. In turn, facilities could be financially incentivized to implement practices to reduce turnover."

Justice in Aging and AARP weigh in on HCBS

Home and Community Based Services (HCBS), long the lodestar of advocates for the elderly and disabled, find themselves on the cusp of a major infusion of federal stimulus funds. Some of it is already on the statute books and much more will accrue if the Biden Administration succeeds in enacting its ambitious HCBS proposals. Two recent contributions to the HCBS information library have come from Justice on Aging and AARP

From Justice in Aging:

Medicaid Home- and Community-Based Services for Older Adults with Disabilities: A **Primer,** includes a state-by-state chart of recent HCBS spending, emphasizing the major remaining gaps and inequities. "Access to HCBS varies widely from state to state and even within states because many HCBS programs are operated through waivers of federal law. In addition, because federal Medicaid law does not require states to provide HCBS to all populations who need LTSS, signifcant race and population-based inequities arise and often intersect. For example, half of Michigan's population lives in 10 counties in the southeast part of the state. In one of those, Wayne County, 40% of older adults are non-white. However, only one-third of the state's total HCBS waiver slots are available in those 10 counties. In other words, there is only one waiver slot for every 58 eligible individuals in those counties compared to one slot for every 20 eligible individuals in the rest of the state. An underlying barrier in access to HCBS that exists in every state and every community is affordable and accessible housing. When a Medicaid enrollee resides in a nursing home or other institution, Medicaid covers the costs of room and board, in addition to the health care and LTSS costs. However, aside from a few limited demonstration programs, Medicaid does not pay for housing or housing modifcations for people who are receiving or need HCBS. Individuals who are unhoused, including a growing number of older adults, face the ultimate barrier to accessing HCBS and are more likely to be forced into an institution. Like other barriers to HCBS, the housing barrier is disproportionately greater among people of color with limited wealth."

From AARP:

AARP calls for expanded "presumptive eligibility" for Medicaid HCBS to provide consumers more long-term care options. The **AARP report** details several states' varying approaches to presumptive eligibility and addresses general concerns about potential financial risks in undertaking such coverage. "Individuals who cannot afford to pay for in-home services out of pocket can apply for Medicaid HCBS waiver or state plan service. However, in all but a few states, the individual must wait until a final Medicaid eligibility determination before Medicaid will start. The time period between application and final approval of a Medicaid HCBS eligibility can be particularly perilous for individuals with limited resources who want to stay at home. Individuals who need care and wish to avoid a nursing home admission must either privately pay for services or rely on family caregivers during that period. Most family caregivers work part or full time, and many do not have access to workplace flexibilities that would allow them to take extended leave for caregiving duties. Given these constraints, timely care is essential to ensure consumers receive appropriate care in the setting of their choice.

"Presumptive eligibility is a strategy several states have pursued to fast-track access to Medicaid and other publicly funded HCBS. Presumptive eligibility, AARP observes, "allows applicants who appear likely to be eligible for Medicaid to start receiving HCBS when a need arises. In states with presumptive eligibility, an individual can receive services in his or her home while his or her Medicaid application is being processed; the financial risk that someone will ultimately be found ineligible is either fully assumed by the state or shared with HCBS providers. This flexibility ensures individuals have access to critical services in the setting of their choice without having to go into a nursing home. However, presumptive eligibility, in isolation, is not necessarily sufficient to guarantee consumer choice. Other structural, external factors impacting consumer choice must also be addressed. These include current caps on HCBS waiver slots, lack of HCBS providers in some areas, challenges quickly matching individuals with appropriate social and health service providers that can support the consumer's goals, and community design features such as adequate transportation and housing options. Presumptive eligibility is an important prerequisite to consumer choice, but, ultimately, presumptive eligibility can only expedite eligibility and connect individuals to the services that exist and are available in that community. Without adequate alternatives, consumers will still lack the meaningful choices they deserve."

Seniors embrace communication tech

AARP's attention was also drawn to older adults' growing attachment to online technology in the pandemic's wake. In its 2021 annual **Tech Trends and the 50-plus,** AARP found usage increasing across the technological spectrum. "Older adults are streaming movies and TV shows, video-chatting with loved ones and colleagues, and buying new smart devices, such as TVs, phones, watches, tablets, home assistants, and home security. Adults 70-plus have a particular fondness for tablets, with more than half (53%) owning one, up from 40% in 2019. Spending is up significantly as well, with older adults spending on average $1,144 on tech, up from $394 in 2019. The top three tech purchases are smartphones, smart TVs, and Bluetooth headsets/earbuds. Barriers, however, haven't been completely eliminated. Older adults cited cost, knowledge gaps, and privacy concerns as top reasons they may be hesitant to adopt technology. More than half (54%) admitted they want a better grasp of the devices they've acquired, while more than one in three (37%) said they lacked confidence when using the technology that has otherwise become so much more prevalent in their lives."

Milken explores long term care insurance options

Middle income access to affordable long-term care insurance (LTCI) has long proved elusive. Seeking to propose some new and innovative solutions, the Milken Institute convened a series of high-powered expert panels in late 2020. The Institute's resulting **report** observes that "as the U.S. population ages, the need for long-term care rises proportionally. Of particular concern is the risk of a catastrophic health event that necessitates a high level of expensive care over an extended period. This looming risk is front and center for most middle-income Americans, who have been priced out of private care and cannot qualify for public aid. Meanwhile, the private long-term care insurance industry itself has shrunk under cost burdens, and federal and state budgets have been hit hard by COVID-19. Urgent action is needed, and effective solutions to these challenges will require public-private cooperation and collaboration. One possible approach: a technology-focused Medicare Advantage demonstration project to show improved care delivery and lower costs. We also offer ideas to scale and hone two of the most promising integrated care programs, PACE and SNPs (Special Needs Plans). Perhaps most important is an initial roadmap to coordinate public and private efforts to develop complementary LTCI programs and products that ensure seamless coverage and shared financial risk."

Ecstasy and magic mushrooms near psychiatric go-ahead

"The psychedelic revolution is coming," **writes** The New York Times Andrew Jacobs, "and psychiatry may may never be the same. After decades of demonization and criminalization, psychedelic drugs are on the cusp of entering mainstream psychiatry, with profound implications for a field that in recent decades has seen few pharmacological advancements for the treatment of mental disorders and addiction. The quest to win mainstream acceptance of psychedelics took a significant leap forward in early May when the journal Nature Medicine **published** the results of a lab study on MDMA, the club drug popularly known as Ecstasy and Molly. The study, the first Phase 3 clinical trial conducted with psychedelic-assisted therapy, found that MDMA paired with counseling brought marked relief to patients with severe post-traumatic stress disorder. The results came just weeks after a New England Journal of Medicine **study** highlighted the benefits of treating depression with psilocybin — the psychoactive ingredient in magic mushrooms. The nation's top universities are racing to set up psychedelic research centers, and investors are pouring millions of dollars into a pack of start-ups. States and cities across the country are beginning to loosen restrictions on the drugs, the first steps in what some hope will lead to the federal decriminalization of psychedelics for therapeutic and even recreational use."

The question for many, Jacobs writes, "is how far — and how fast — the pendulum should swing. Even researchers who champion psychedelic-assisted therapy say the drive to commercialize the drugs, combined with a growing movement to liberalize existing prohibitions, could prove risky, especially for those with severe psychiatric disorders, and derail the field's slow, methodical return to mainstream acceptance. Numerous studies have shown that classic psychedelics like LSD and psilocybin are not addictive and cause no organ damage in even high doses. And contrary to popular lore, Ecstasy does not leave holes in users' brains, studies say, nor will a bad acid trip lead to chromosome damage. But most scientists agree that more research is needed on other possible side effects — like how the drugs might affect those with cardiac problems. Dr. Michael P. Bogenschutz, a professor of psychiatry who runs the four-month-old Center for Psychedelic Medicine at NYU Langone Health, said most of the clinical studies to date had been conducted with relatively small numbers of people who were carefully vetted to screen out those with schizophrenia and other serious mental problems. That makes it hard to know whether there will be potential adverse reactions if the drugs are taken by millions of people without any guidance or supervision. 'I know it sounds silly but, kids, don't take these at home. I would just encourage everyone to not get ahead of the data.'"

Obesity drug shows promise

Long resistant to a pharmaceutical remedy, America's severe obesity epidemic may be on the verge of gaining some medicinal relief. The reason for cautious optimism: incretins, the main ingredient in semiglutide, a drug whose weight loss of efficiency was demonstrated in a recent New England Journal of Medicine **report**. "Incretins," **writes** The New York Times Gina Kolata, "appear to elicit significant weight loss in most patients, enough to make a real medical and aesthetic difference. But experts hope that the drugs also do something else: change how society feels about people with obesity, and how people with obesity feel about themselves. If these new drugs allow obesity to be treated like a chronic disease — with medications that must be taken for a lifetime — the thought is that doctors, patients and the public might understand that obesity is truly a medical condition. The drugs will not banish obesity or make people truly thin. But people who take them can look and feel very different. For some, the medications lead to weight loss approaching that of bariatric surgery. Like other obesity specialists, Dr. Rudolph L. Leibel, a researcher at Columbia University who conducted many of the pivotal studies showing obesity is a disease, deplores society's bias against his patients. But he has his doubts that perceptions will change with new treatments. 'My guess is that bias will persist and might even be exacerbated by the availability of an easy way out,' he said. Northwestern University clinician Dr. Robert F. Kushner is more hopeful and points to the example of statins, which lower cholesterol and became available in the late 1980s. Until then, doctors could only suggest that patients with high cholesterol cut back on eggs and red meat because they could at last treat this condition. 'More powerful incretins,' he added, 'could have the same effect on the medical profession.'"

CMA laments disappearing home health care services, again

Home health care coverage has been a persistent cause for concern at the Center for Medicare Advocacy. In its latest **Issue Brief**, CMA once again focuses on what it perceives as an ongoing conflict between reality and the law. "Unfortunately," the brief observes, "people who legally qualify for Medicare coverage frequently have great difficulty obtaining and affording necessary home care. There are legal standards that define who can obtain coverage, and what services are available. However, the criteria are often narrowly construed and misrepresented by providers and policy-makers, resulting in inappropriate barriers to Medicare coverage for necessary care. This is increasingly true for home health aide services — the very kind of personal care services vulnerable people often need to remain safely at home. In the past, this level of home health aide coverage was actually available. Currently, however, this level of coverage and care is almost never obtainable. Data demonstrate this dramatic change in coverage. In 2019 the Medicare Payment Advisory Commission (MedPAC) reported that home health aide visits per 60-day episode of home care declined by 88% from 1998 to 2017, from an average of 13.4 visits per episode to 1.6 visits. As a percent of total visits from 1997 to 2017, home health aides declined from 48% of total services to 9%."

*TVs "**Last Week with John Oliver**" recently delivered some very straight talk about what ails American long-term care. Oliver took reviewers on an unvarnished trip through nursing homes, assisted living and home care, stopping along the way to underscore staffing shortages, inadequate staff reimbursement rates and oversight challenges.*

MEDIA WATCH

IN THIS SECTION

The New York Times tours post-vaccination reunions

Pages of pictures, punctuated by family members' accounts of long-awaited nursing home reunions with mothers, fathers and grandparents, make for a poignant NY Times **tableau** of post vaccinated long-term care residences across the nation. "For many families, the joy of reuniting has been a balm on a deep wound. Marie Fabrizio, 95, for example has been in assisted living at Reformed Church Home in Old Bridge, N.J., since 2017. During the pandemic, she saw her family for limited visits through a window or outdoors at a distance. When her son, Dan Fabrizio, 59, surprised her with a visit last month, it was the first time they had been able to embrace in more than a year.

- MARIE FABRIZIO: Of course I miss my family. It's lonely. Thank God, I have friends who are here. We play bingo. We have arts and crafts. Seeing my son, it was a surprise. I was crying, and he cried with me. It was such a beautiful feeling. I didn't want him to leave. It's hard to let go.
- DAN FABRIZIO: It was like a year in review — all the things that went through my mind in the past 14 months. Thinking, what if my mom passed away? Thinking about the things we wish we could have done, the things we sacrificed. We have a beach house down at the Jersey Shore. I take her down personally three times a year — Memorial Day, July 4 and Labor Day. Thinking that she would not have had that chance, and just being hopeful she has the chance to do that this summer. Hearing my mom's voice in person — it just felt like, it wasn't a recording. It wasn't the telephone. It wasn't a Zoom. It was live. She got through this. I sat in my car, and I cried."

Therapist confronts sibling caregiving rivalries

"Nothing," **writes** psychologist Barry Jacobs, "reveals the fault lines in sibling relationships like the seismic shift caused by an aging parent's sudden decline. While their adult relationships may have been marked by decades of chummy phone calls and warm holiday dinners, brothers and sisters can quickly become locked in conflict about what's best for Mom and Dad. Struggles ensue over who has the right to make decisions, as well as who should make sacrifices on their parents' behalf. Old pecking orders, ancient rivalries, and latent feelings of entitlement reassert themselves. In the case of client Diane, Jacobs reports, structured mediation over three sessions proved beneficial: she and her siblings began communicating on a listserv, a more equitable family caregiving plan was discharged, Diane continued to participate actively in Mom's daily care, and her brothers and sisters began applauding her efforts. She came to acknowledge that her siblings cared for Mom in their own ways, and she was glad that they were becoming increasingly involved. In the end, their mother didn't go to a retirement community, but received more intensive help in her home because her children were working together as a team. Because of the siblings' greater collaboration, Mom thrived, and the family became stronger."

Editor's note: FCA's Client Services Director Christina Irving, along with Jacobs, is quoted in another **article** on sibling caregiving conflicts — this time in The Washington Post.

Radiologist eases patient fears

Radiologist **Doug Lake** believes he knows how to improve the doctor-patient relationship. Facing patients that are about to hear possibly life-altering imaging results, "I made it a priority to reach out to patients to ask, 'Where are you with this? How does it make you feel?' My process began to change when considering an issue that often brings patients to my office for an esophagram: trouble with swallowing food and the sometimes terrifying feeling of having food stuck in the esophagus. I know how it feels, both physically and emotionally. I've snuck away from Thanksgiving dinner while a vise grip squeezed my chest. I've had the thought, Am I having a heart attack? I know the symptoms can be a signifier of cancer. I've felt like there is nothing that can be done about the discomfort. The first time I said to a patient, 'You know, I've had a similar problem for years,' the technologist in the room swung her head around, wide-eyed. I believe that she had not seen or heard such a thing in her experience. Physicians make a common error in believing that their patients hear and understand them. The truth is, patients don't retain everything. In high-stakes situations — like a new cancer diagnosis — data show that patients remember just half of the conversation. I've found that framing some of the information in personal terms helps patients better understand my message. I share information when I can be reassuring, letting patients know when I don't see anything that alarms me. For example, when I've done an esophagram, the first words out of my mouth after we finish are often 'I don't see anything that looks bad — no esophagus or stomach cancer.' Cancer is the least likely result, but it is what patients have on their mind. I watch shoulders relax, hear long exhales, or see eyes brighten every time. Why make them wait a few days or a week? A patient will get a full rundown from their primary doctor, but I can bring immediate practical relief when possible. Concrete information helps, and patients are eager for it. But it's still second to what happens when I say, 'I know something about what you're going through because I've been through it too.' As social creatures, we respond deeply to the simple message 'You are not alone.'"

A Post-COVID Mother's Day

"Only a year ago, my stocky, 84-year-old mother could hike with me up steep San Francisco hills. But since the pandemic hit, she has shriveled, become wobbly on her feet, even fallen a few times. It has been a year since my parents' assisted living facility went on lockdown, meaning it had been a year since she and I had seen each other in person. Around Thanksgiving, when it was clear we wouldn't be able to gather for the holidays, we started to meet on FaceTime to exercise, which we refer to in her native Japanese as 'taiso.' Sometimes she embellishes my moves, fluttering her fingers like a silly ballerina. When she is in a particularly good mood, she will wave her arms toward the ceiling, demanding a faster song. 'Ma,' I say. 'Can you do your washing machine imitation?' She used to be a masterful mimic. Without hesitation, she will jiggle her trunk sideways, hands flailing at her sides, deadpan. No doubt, she still has it. I see many stories in my mother's face: her childhood in a shattered Japan during World War II; the youngest and only girl of four siblings; losing her beloved mother to illness when she was 10; doing factory work in America to support my father's teaching career at Rutgers; getting taunted by co-workers for her accent and for eating rice balls for lunch. If it weren't for COVID, I never would have learned that my mother and I can have fun together without actually being in the same place. Recently, we have started to work her sea lion moves into the beginning of Madonna's Open Your Heart. *She is the mama sea lion, and I am the baby, and we are connected no matter what. We slap our hands together. 'Am I doing it right?' I say, and she nods. For a year, this was all we had. But this Mother's Day, we'll finally have so much more. A day together. In person."*

— **Erika Shimahara**, The New York Times

FAMILY CAREGIVER ANNOUNCEMENTS

Journaling for Caregivers

In this hands-on **webinar**, participants will explore journaling as a way to relieve stress, find the meaning and purpose that often gets lost in day-to-day activities, and find new ways to share love with the one we care for. The objectives of the Journaling for Caregivers webinar are to:

- learn how to write with no judgments.
- say what you need to and see how it changes the way you feel.
- find or re-discover hope.

Presenter **B. Lynn Goodwin** rediscovered journaling while caring for her mother who had undiagnosed Alzheimer's. She owns **Writer Advice**. Goodwin is the author of *Never Too Late: From Wannabe to Wife at 62* (memoir), *Talent* (YA), and *You Want Me to Do WHAT? Journaling for Caregivers* (self-help).
When: Wednesday, May 26, 11 a.m. (PST)
Registration: **Click here**

Provider E-News Update: read and subscribe!

FCA publishes Provider e-News Update every one to two months for medical offices/groups and social service organizations seeking to support the needs of family caregivers. Update offers quick links to FCA resources, including fact sheets and videos; a listing of classes and events for caregivers; and timely news of interest to providers. You can read the latest **issue here**. To subscribe, **click here**.

Newly launched: e-news for Spanish-speaking caregivers from FCA

FCA is proud to announce ¿Qué Pasa? — a new monthly newsletter for Spanish-speaking caregivers. Check out the May 2021 **issue here**. And **click here** to subscribe! FCA is unique among national caregiver organizations by providing direct support to family and friend caregivers as the **Bay Area Caregiver Resource Center**, and is one of 11 caregiver resource centers in California.

Monthly Online Learning Programs from the California Caregiver Resource Centers

The 11 **California Caregiver Resource Centers** (FCA is the Bay Area Caregiver Resource Center) publishes a monthly linkable and downloadable calendar of online learning programs and events. Caregivers across the country can participate in these programs. To download the May 2021 calendar **click here**. To subscribe, visit **www.caregivercalifornia.org** and scroll to the subscribe box at the bottom of the homepage. To learn more about the California Caregiver Resource Centers, this **video** offers a short overview.

Credits

Editor: Alan K. Kaplan, (attorney and health policy consultant)
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Layout: Francesca Pera (communications specialist)

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

FCA TWEETS @CaregiverAlly

Visit **Best Practice Caregiving** — an easy-to-use, data-rich resource that offers providers detailed information on more than 40 proven dementia


FCA

FamCaregiverAlliance @CaregiverAlly · May 14

Grab this 1-pg, print-ready infographic on Telenovela Mirela – one of 44 proven dementia caregiving programs in Best Practice Caregiving – for a quick program snapshot and overview.
ow.ly/sX1A50EM1ej

best practice **caregiving** | *Guiding organizations to dementia programs for family caregivers*

A partnership between Benjamin Rose Institute on Aging and Family Caregiver Alliance

Program Snapshot **Telenovela Mirela**

WHAT IT IS

Telenovela Mirela is a dementia caregiving program featuring a video series developed for Hispanic/Latino caregivers of those

INSTANT ACCESS FOR HISPANIC CAREGIVERS

The series of 18 videos is available for caregivers to stream directly via Amazon Video and Vimeo for

caregiving programs located across the U.S.

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REGISTER YOUR RESEARCH

Professional Research

- **UCSF Movement and Mindfulness Research Study for Caregivers And Those With Memory Loss**
- **Care2Sleep Education Program**
- **Caring for COPD Caregivers**
- **Wanted for Online Research Study: Caretakers of People with Dementia**
- **Well-Being and Service Needs in Dementia Caregivers**
- **The Impact of Emotions on Social Distancing among spousal caregivers for Alzheimer's disease or related dementias during the COVID-19 Pandemic**
- **Life-Enhancing Activities for Family Caregivers (LEAF) (SP0044459; NCT03610698)**
- **Social Connections During COVID-19**

Graduate Student Research

- **Understanding Eating and Health**
- **Family Caregivers of Relatives with Dementia: Health and Support Study**
- **Asian American Family Caregivers for Stroke**
- **Study on Vehicle Accessibility for Non-Driving Individuals with Disabilities and their**

Families/Caregivers

- **Family Views on Quality of Life for TBI Survivors**
- **Informal Caregivers Providing Wound Care**
- **Volunteers Needed for Research Study about Helping Older Adults**
- **Chinese American Family Caregivers for Alzheimer’s or Other Dementia**
- **Relationship Between Subjective Stress and Cognition in Alzheimer's Disease Spousal Caregivers**
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