



*Alzheimer's  
Prevention & Preparedness*

*November 2020  
In Collaboration with the California Master Plan for Aging*

# Brave & Bold

*These Recommendations are dedicated to those living with Alzheimer's today, and the millions of family and friends who caretake for them, in the past, present and future.*

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## *Introduction*

You have been my home for decades. In my 20s, I migrated from east to west to find independence, build my life, and pursue my dreams – just as so many others have done before me. Now, I’m in my 60s. I’m getting older, and so are you. As Governor Newsom said in his first State of the State address, “The Golden State is getting grayer.”

You’re home to more seniors than any other state. You’re also more expensive than ever, your fires burn hotter and longer, and your social safety net is straining. A lot of us have wondered if it’s still possible to grow old here with dignity and security. But California, I believe in you. I believe that you can be a place where everyone can thrive in every decade and stage of life.





So does Governor Newsom. During that address last year, he called for a new Master Plan for Aging to help better support and care for our seniors. And as he said, “We can’t talk about aging without focusing on Alzheimer’s.” That’s why the governor also announced a new Task Force on Alzheimer’s Prevention, Preparedness and the Path Forward.

As your former First Lady and a long-time champion for families touched by Alzheimer’s and other forms of dementia, and as someone whose own family has been forever changed because of this disease, I was honored to chair a team of distinguished doctors, researchers, labor representatives, and advocates. Together, Governor Newsom asked us to develop a plan to take on a disease that touches the lives of so many and poses severe policy, economic, and health challenges to families everywhere.

California, you’re more than just the land of youth and celebrity we see in the movies – the number of Californians over 65 years old is expected to grow from six to nine million within the next decade, and we have the second-longest life expectancy in the country. But that makes us particularly vulnerable to the ravages of Alzheimer’s. Of the [5.8](#) million Americans with Alzheimer’s, more live here than in any other state. And the rates of Californians developing the disease are rising. [690,000](#) people in this state live with the disease today – a number that will grow by [nearly 22%](#) in just the next five years – with [1.62](#) million serving as their caregivers. There are thousands who go undiagnosed and untreated. The toll falls particularly hard on women and people of color, who are disproportionately susceptible to developing the disease, and on caregivers and healthcare workers who are overburdened and under-supported.

But my dear California, while you are in some ways the epicenter of the Alzheimer’s crisis, you’re also uniquely suited to lead the nation in this fight. The Task Force challenged ourselves to develop a set of bold recommendations to help people with Alzheimer’s and dementia, the families and caregivers who support them, and communities more likely to get the disease who need access to better interventions and information early in life. Our recommendations were to be part of the Master Plan for Aging, and provide a clear strategy to ensure that all Californians can age with the dignity and security they deserve.

Those early days now feel like a lifetime ago.

In the months since our Task Force first got to work, people’s resilience has been tested in ways we couldn’t have possibly foreseen. Since March, we have battled a pandemic that has laid bare the vulnerability of our healthcare system, our economy, and our seniors.

*“California, you’re more than just the land of youth and celebrity we see in the movies...”*

Vast disparities in access to quality care, the urgent need for better research and testing, and the shortage of caregivers have all been thrown into stark relief. And sadly, as deaths due to Alzheimer’s

and dementia rose by more than [20 percent](#) over the summer, we have been reminded of how these failures in healthcare aren’t limited to COVID-19, but impact every single person who interacts with the system.

The pandemic has also led to one of the worst economic crises in modern history. California, you have certainly felt it: your economy went from [118 consecutive months of net job growth](#) to a near-instant implosion. Millions have lost their jobs, had hours or wages reduced, and struggled to balance family care with suddenly working from home.

Countless are feeling what it’s like to be responsible for taking care of the home, the children, and the chores, while doing the work that finances it all. Again, this burden falls disproportionately to [women](#).

*“People in every corner of our country are demanding justice for Black men and women killed by police...”*

As we grapple with the pandemic, Americans are also in the midst of an unprecedented reckoning with systemic racial injustice. People in every corner of our country are demanding justice for Black men and women killed by police, and confronting the ways racism has been woven into everything from public school funding to access to healthcare.



I hope this year will be a wake up call for us all. We can't afford to return to "business as usual," because it quite simply wasn't working for too many to begin with. Between an economy plagued by inequality, the insidiousness of systemic racism, and a broken healthcare system, we are all seeing the consequences of problems that have been allowed to fester for far too long.

*“Every 65 seconds, a person in America develops this disease – most of whom are women and people of color.”*

In other words, we are witnessing what happens when we let crises grow unchecked. When we fail to listen to science and take decisive action, when we pretend a problem is someone else's to solve, we all lose. When we don't plan ahead, when we ignore the fact that some systems were built broken, it's always the most vulnerable who suffer most.

The same is true for Alzheimer's. This is a crisis we cannot afford to ignore.

Every 65 seconds, a person in America develops this disease – most of whom are women and people of color. Alzheimer's is the [seventh](#) leading annual cause of death in the United States, including [COVID-19](#). It's [fourth](#) here, based on the latest publicly available information – affecting 1 in 3 of our seniors. This year, it will cost American

taxpayers [\\$305 billion](#). By 2050, it could be as much as \$1.1 trillion.

And this crisis is only getting worse. Between 2000 and 2017, deaths from Alzheimer's disease [increased 145%](#), even as deaths from other age-related diseases decreased. Upwards of [1.5 million](#) more Americans are living with Alzheimer's today than at the turn of the century, and scientists estimate that we will surpass [10 million cases](#) by 2040. But there still isn't enough funding or policy in place to provide a proportional response to the growing needs. This is an aggressive problem that demands aggressive solutions.

It's worth remembering that these numbers are a reflection of real people, and their lived experiences. No statistic can ever tell the story of what happens when this crisis reaches your own doorstep.

I know from personal experience how this disease can tear through a person's life and change it forever. My father, Sargent Shriver, was diagnosed with Alzheimer's in 2003 and I watched him go from someone who raced around Capitol Hill, testifying for his beloved Peace Corps and the War On Poverty programs he started, to someone who couldn't recognize his own daughter. He was my hero and my touchstone. His life spent in public service standing up for the issues he believed in was ripped away from him by this merciless disease.

He passed away in 2011, and the devastating memories of watching him battle Alzheimer's have stayed with me ever since. I remember how difficult it was for my mother, four brothers, and me to know what to do and how to help. There was so little information about treatment and care options. We were and are a very fortunate family, with access to resources that too few have.

*“That's why I'm so passionate about fighting this disease, and providing more support for those struggling with its effects.”*

But as I've said so many times before, it doesn't matter who you are or what your background is – when you're dealing with a loved one who has Alzheimer's or memory loss, you feel powerless.

That feeling is so difficult to overcome, though I've seen time and time again that the best antidote to feeling powerless is action.

That's why I'm so passionate about fighting this disease, and providing more support for those struggling with its effects. There is no cure for Alzheimer's. But California, there's a lot you can do to make it less costly, confusing, and heart-wrenching.

The good news? No state is more capable of rising to the challenge of taking on Alzheimer's than you are, California.

You are where the future is invented – as the Governor likes to say, California is America's coming attraction. You're where dreams come to life, whether it's on a Hollywood set or in a Silicon





Valley garage. You're a state full of freethinkers, challengers and innovators, with more patents filed here than anywhere else in the country. Californians have never shied away from tackling hard problems and we have extraordinary resources at our disposal: world-class universities, technological might, engaged citizens. We're storytellers, too. We have all of the tools we need to effectively inform people of the truth about Alzheimer's so that more people know what they can do to keep their brains healthy to prevent the development of this disease.

Your diversity also gives us the perspective, background, and resolve to tackle the inequities associated with Alzheimer's prevention and care. You rank just behind Hawaii as the second most

racially diverse state in the nation. And more of your residents are immigrants than in any other state, with nearly 45% of Californians speaking a language other than English at home.

We still have a lot of work to do, but in many ways you're a model for the nation for how a diverse society can live together in a thriving multicultural democracy where we look out for one another and focus more on what unites us than divides us.

For all these reasons, I am convinced we can do more to help the 690,000 people here living with Alzheimer's, as well as those who love and support them, and create a model for the rest of the country to follow.

When the Task Force first came together last August, every member of the group brought to bear decades of diverse experience with Alzheimer's. Some have spent their careers caring for patients, seeing up close what this disease does to an individual's brain, health, and sense of self. Some have participated in internationally renowned research and bring unique understanding of this disease's development and brain health management prior to diagnosis. Others have been champions for those affected by the disease for decades, whether we've spent our careers advocating for people with dementia and their families, or worked for unions representing home care and nursing home workers.

Together, we hosted meetings throughout the state, first in person, and then, not missing a beat when COVID-19 hit, over Zoom. We met with dozens upon dozens of caregivers, faith-based organizations, leading researchers, scientists and doctors, as well as individuals and families who, like mine, were affected by the disease. We listened to their stories and perspectives, and learned more about what they think needs to be done to take on Alzheimer's.

No matter who we talked to or what their background was, we heard the same concerns across the board.

## **Alzheimer's is incredibly costly – emotionally and financially.**

Just as Alzheimer's presents a financial burden, caring for a family member, friend, or patient with the disease has a physical and emotional cost.

[Studies](#) show caregivers pay a steep price in terms of their own health due to increased stress, anxiety and depression, lost sleep, and immune-system deficiency. Take it from me. Helping my father – along with his professional caregivers and my mother – get in and out of bed, go to the bathroom, bathe, eat, and do all of the things that most of us do without a second thought, was hard. Our family was lucky to have the help of extraordinary caregivers, but it was hard to find experienced professionals who really understand this disease and how you have to evolve as the disease evolves and how important it is to preserve the dignity of the person grappling with it.

Everything got even harder after my mother died. My brothers and I made the difficult and painful decision to move my father to a facility down the street. We did it based on doctors' recommendations and because we thought that being surrounded by people, by activity and around-the-clock care, would be best for him. Yet it was still a complex and intensely personal decision. It taught me that none of us should ever judge how others make that decision for their own loved ones. To me, the weight of it felt heaviest during our visits. Had we made the



right choice? Should we have tried harder to keep him at home? But then I'd feel so grateful for the quality of care he received. Sometimes he would turn to me and ask who I was. I'd respond: "I'm your daughter, Maria." Those were the good days. On the bad days, it was like I wasn't even there. That emotional hurt and stress added up.

We heard similar stories during our Task Force meetings and the bottom line is that this disease takes something from everyone and everything it touches.

*“...receiving an Alzheimer’s diagnosis can be financially devastating...”*

Not only that, receiving an Alzheimer’s diagnosis can be financially devastating – studies say it costs the average affected family [\\$10,697](#) each year. But in truth – as everyone who lives through the ordeal will tell you – it costs way more, in lost paid work, daily indignities, and related healthcare challenges. And that cost is shared among taxpayers. In 2018, Californian taxpayers spent more than \$3.5 billion on Alzheimer’s-related costs, a number that is projected to exceed [\\$5 billion by 2025](#). Those numbers still don’t capture the full scope of the disease’s financial toll in the state because more than 80% of the help provided to people with Alzheimer’s comes from unpaid family, friends, and other caregivers. In this state alone, the value of

that care added up to [\\$24.25](#) billion last year. Plus, full-time workers who are also caregiving at home have lower earning power on the whole.

**Any recommendation the Task Force puts forward must, must, must put equity front and center.**

Like the COVID-19 pandemic, Alzheimer’s disproportionately impacts women and people of color. I’ve written about the impact of Alzheimer’s on women before. In fact, I dedicated a whole Shriver Report to it, and the findings are worth repeating: [Two-thirds](#) of both Americans with Alzheimer’s and [their often unpaid caretakers](#) are women. And on average, female caregivers [spend more time](#) giving care than their male counterparts, perhaps because women are [two and a half times more likely](#) to be living with the person they’re caring for. That means that everything I talked about earlier – the emotional, physical and financial burden – [primarily falls](#) on women. From being primary caregivers and taking on stress in every aspect of their lives, to actually being more likely to get the disease and need care at the end of their life, women are being crushed by this disease. Our state has a long way to go to ensure women have the help they need.

The picture is similarly bleak when it comes to race: older Black Americans are [twice as likely](#) to develop

Alzheimer’s as white Americans, and members of the Latinx community are up to [1.5 times](#) as likely. This is partially due to a [higher prevalence](#) within those communities of pre-existing conditions like cardiovascular disease and diabetes. The Alzheimer’s Association [reports](#) that socioeconomic inequities “including lower levels and quality of education, higher rates of poverty, and greater exposure to adversity and discrimination, also may increase risk” for developing the disease.

Black Americans with Alzheimer’s are also saddled with [1.7 times](#) as much in hospital care costs as white Americans, [likely due](#) to later-stage diagnoses, more pre-existing conditions, and delays in accessing timely care. There’s evidence that if you’re [Black](#) or [Latinx](#), you’re less likely to be correctly diagnosed in a timely manner. That means that fewer

Californians of color are getting the resources they need to properly care for their elders. And since Latinx Californians are on track to [become our majority ethnic group](#), these problems will only get more widespread unless we do more to give communities of color the support they need.

**While this disease is well-known, it’s still not well-understood.**

A survey conducted for the [WebMD and Shriver Report Snapshot](#): “Insight Into Alzheimer’s Attitudes and Behaviors,” found that big, dangerous myths about Alzheimer’s are still pervasive. People tend to think that if a relative had Alzheimer’s, they themselves are doomed to get it too; or if no one in their family has had it, then they’re in the clear. Neither of these are necessarily true. The risk





factors for Alzheimer's are much more complicated than that. Only [3%](#) of people actually know their personal risk for Alzheimer's.

Less than 40 percent of people know about treatment options for the disease, and [barely 11%](#) have ever asked their doctors about how to prevent it. More than [6 in 10](#) people don't know that it mostly impacts women, and [two-thirds](#) don't realize that it's more likely to impact Black Americans and Hispanics. And here's the most dangerous piece of misinformation: the idea that Alzheimer's is something that people don't need to prepare for until they're 60, 70, or 80 years old. In reality, the time to start thinking about it and developing healthy preventative habits is in your 30s and 40s or earlier. Dr. Nadine Burke Harris, our first California Surgeon General, reminds us that our focus on brain health should go all the way back to childhood and even the womb.

*“Less than 40 percent of people know about treatment options for the disease...”*

Thinking that Alzheimer's is a normal part of aging and that there's nothing we can do to prevent it – another dangerous myth – makes it even harder to take on this disease. It reduces the chances that people will plan ahead and invest in their own brain health early and effectively. This is why the Task Force came to the conclusion that more must be done to inform the public about Alzheimer's and the

ways to manage its impact on families and communities.

The way we care for our elders has not kept up with the changing American family; it's time to change that.

*“... the pressures put on families to care for loved ones, earn a paycheck, and balance other family responsibilities are well beyond what is reasonable.”*

The “Leave It To Beaver” model of the nuclear family – one working dad, one stay-at-home mom, two kids, and a dog, all in a house with enough space for grandma – is no longer a reality, if it ever was. For starters, women are more likely now than ever before to be their family's primary breadwinner. And California, you are home to single-parent families, households with two moms or two dads, grandparents serving as primary caregivers for their grandchildren, and relatives who have moved home to take care of aging loved ones. You also have the [second-highest](#) cost of living and [more elders living alone](#) than in any other state in the country.

To put it bluntly, the pressures put on families to care for loved ones, earn a paycheck, and balance other family responsibilities are well beyond what is reasonable. We are setting families and caregivers up to fail, and we're failing the sick and ourselves in

the process. Considering what goes into helping a loved one with cognitive impairment – including getting dressed and bathed and fed, and staying up-to-date on medical bills and doctor's appointments and being able to afford that care in the first place – the entire process of being a caregiver is simply unmanageable.

Over [40%](#) of caregivers nationally have a household income of \$50,000 or less, and [one in four](#) of them are “sandwich generation” caregivers – meaning that they care not only for their aging parent, but for their children. What's more, [22%](#) of these caregivers say that tending to a loved one with Alzheimer's has put them in debt. Half will spend [over \\$100,000](#) in the first five years, and 62% pay for expenses out-of-pocket. Some of the highest Alzheimer's costs in the nation are right here: a home health aide can cost nearly [\\$5,000](#) per month, and a private nursing home nearly [\\$10,000](#) per month. We must update

our elder care structure to reflect how costly it is for families to manage alone today.

**While Alzheimer's presents a huge and urgent challenge, it's not insurmountable.**

California, you can put solutions in place to improve care and ease the burdens weighing on people with Alzheimer's and their loving caretakers. You can invest in cutting-edge research. You can establish voluntary savings accounts for long-term care. And you can create a public awareness campaign that reaches beyond language and cultural barriers.

**We have the big ideas. Thankfully, we also have the courage to make them a reality**

More than once, in my advocacy around Alzheimer's and dementia I've had to dig down deep and find the energy to keep pushing for progress. I wrote a children's book about my father's decline at a time





when there was even more stigma attached to the disease than there is today. When I wanted to put my skills as a broadcast journalist to good use and report on the disease, I was told over and over again that no one wanted to hear about Alzheimer's. But we kept pushing, and finally HBO aired the most comprehensive television event ever produced on the subject. And I was proud to testify twice in front of Congress to help secure the passage of the 2011 National Alzheimer's Project Act and again to advocate for more funding for Alzheimers, which we so desperately needed to put it on a par with other major diseases.

In 2010, the Alzheimer's Association and I published The Shriver Report: A Woman's Nation Takes on Alzheimer's, which for the first time characterized Alzheimer's as disproportionately impacting women. We helped make it known that a woman in her 60s is [twice as likely](#) to get Alzheimer's as breast cancer, yet for decades women were left out of research trials and were not even considered when it came to crafting solutions. Pushing for women-centered research and care wasn't easy, but by digging into the data and doing comprehensive reporting, we changed the way the world thinks about Alzheimer's.

And in 2015, I worked with several amazing women to bring to the big screen the film "Still Alice," on which I was an executive producer. It was an all-too familiar story of one woman's struggle to stay connected to who she was before she started forgetting her words and received a diagnosis of younger-onset Alzheimer's.

*"... a woman in her 60s is twice as likely to get Alzheimer's as breast cancer..."*

Julianne Moore won an Oscar for her performance as Dr. Alice Howland, doing the important, heartbreaking work of embodying someone suffering from this disease. The film, like all the other work that came before, was all done to help raise awareness about Alzheimer's. Yet even after all these years of work, of climbing an uphill battle the size of Mt. Everest, there's so much more to do to spread the word about this disease and get the attention it needs.

I know that breaking new ground on an old disease can be difficult. But thanks to the diligent work of our Task Force, we have a game plan – a good one, full of ideas that are innovative and imaginative but also grounded in what's possible. It's comprehensive, looking at every aspect of living and caring for someone with memory loss.

This report isn't just a plan for Alzheimer's and other dementias. It's also a plan for chipping away at inequality in our healthcare system. It should come as no surprise that many of the issues that plague Californians struggling with the effects of Alzheimer's – unequal access to healthcare services, a lack of investment in medical research and distribution of information, the rising costs of care – are also the issues that have stressed our state and nation's ability to respond to COVID-19.

When COVID-19 first hit, the Task Force watched closely as the effects of the pandemic sank in and wreaked havoc on our economy, our healthcare system, and especially our frontline workers who care for the aging and for the sick. It raised the stakes around so much of what we had been discussing in our meetings and it refocused our attention on this important work for people living with Alzheimer's and their families.

And when Californians and people across the country spoke out about the urgent need to address systemic racism, we redoubled our determination to put equity at the center of our plans to address Alzheimer's.

We became all the more intent to put forward recommendations as bold as the Governor had asked for back in 2019, and as inclusive and intersectional as the current moment demands.



Even when the recession swept over the state, and many worried that budget constraints would mean a dead end for our recommendations, I was reminded of a passage in the 2010 Shriver Report: A Woman's Nation Takes on Alzheimer's:

*“You can tap into your energy and creativity to make this the best state in the nation in which to grow old.”*

“Let me say it before you do: ‘Who’s gonna pay for all these programs? We’re in a recession!’ Many states, including my own, are struggling with staggering budget deficits...But that’s exactly why we need a new kind of national conversation about Alzheimer’s and growing old in America – just like the conversations heard around kitchen tables all over the country. Families are sitting down to figure out how to pay their portion of the billions of dollars of unpaid care elders are receiving at home. American families are asking and answering the same questions we need to ask and answer on a state and national level: ‘How can we afford this care? How can we pay for it?’ and ‘Whose job is it – whose turn is it – to do the caregiving?’”

Ten years later, those words hold meaning once again. This time around, matters are much, much worse. We’re facing the worst economic downturn in [modern history](#), and state and local governments

[have been forced](#) to dramatically cut spending. Meanwhile, the inequality that exacerbated this crisis is only [growing wider](#), and families across the country are sitting down once more to talk about how to protect their health and futures.

Every day in this painful year, we’re seeing what happens when crises are allowed to build without being addressed decisively before they get out of control. We cannot make the same mistake with Alzheimer’s. That’s why the recommendations put forward by our Task Force are so important. They are a roadmap for the future that will not only help us take on Alzheimer’s, but will reinvigorate our commitment to caregiving, research, and the safety net. The benefits of acting now will ripple out across our healthcare system and for seniors everywhere.

Problems aren’t created in a vacuum, and they aren’t solved in a vacuum, either. We have the opportunity, if not the obligation, to take on the issues affecting people today by investing in our future and implementing solutions to tackle a range of problems at once, from the Alzheimer’s crisis to broader inequities in our healthcare system to racial injustice and economic inequality.

*“Problems aren’t created in a vacuum, and they aren’t solved in a vacuum, either.”*

There is no question that, unless we take action on Alzheimer’s right now, we are setting ourselves up for future tragedies. I don’t want to have to write another report in ten years where I’m quoting my prior warnings of what happens if we don’t address this formidable challenge that’s already coming for us. We cannot leave another generation to fend for itself from this disease.

My hope is that Governor Newsom and state leaders will take the torch from the Task Force on Alzheimer’s Prevention, Preparedness and the Path Forward and put these recommendations into action. I am so proud of the work our team has done and the solutions we have humbly put forward. They are ambitious and comprehensive, and represent a new model for taking care of those suffering from the disease.

So yes, California, you are getting grayer. But there’s no reason why you can’t meet this challenge. After all, you’re California! You can tap into your energy and creativity to make this the best state in the nation in which to grow old. Our history has proven time and time again that we are stronger than we think, and braver, too. The nation is looking to us, and we must dare to dream big, even if it feels impossible. There is no state more capable of emerging from this difficult time stronger than ever. That’s what this report is all about.

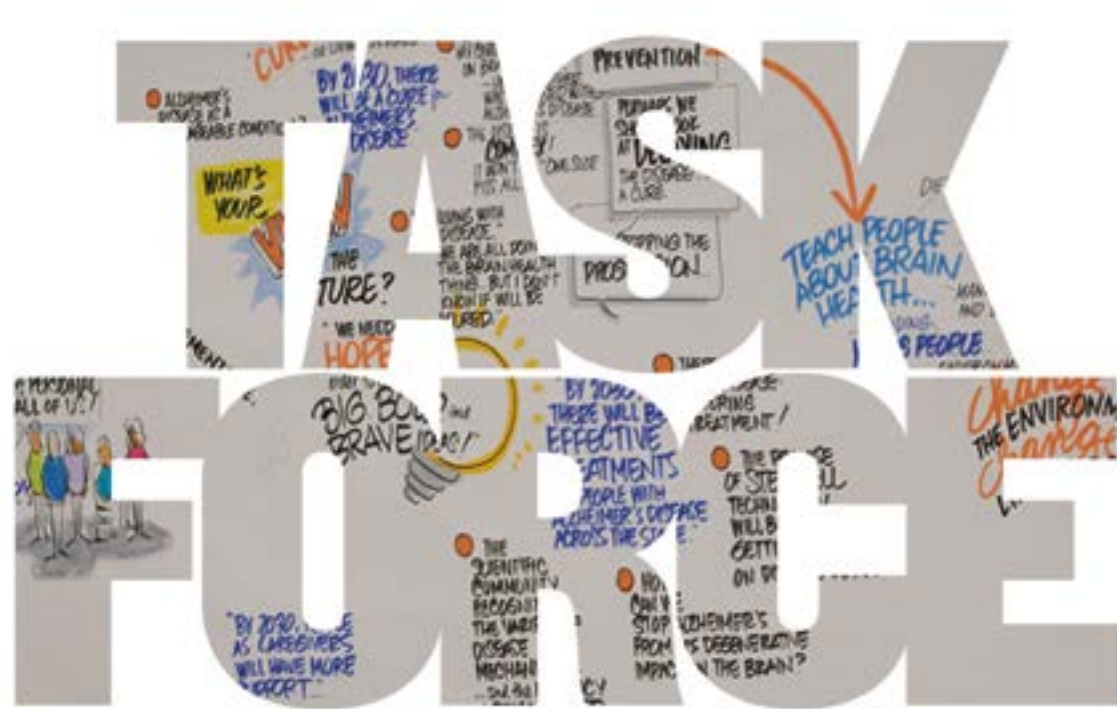
So let’s dig deep, muster up our courage, and get to work.

*Sincerely,*  
**Maria Shriver**





# Overview



## On Alzheimer's Disease Prevention and Preparedness

In 2019, Governor Gavin Newsom formed the Task Force on Alzheimer's Disease Prevention, Preparedness and the Path Forward because he recognized what so many Californians have discovered through their own experiences: We need to do more to help people and families living with Alzheimer's and related dementia.

Led by Maria Shriver, Former First Lady of California and a longtime advocate for women and people living with Alzheimer's, the Task Force is made up of a diverse group of consumers, caregivers, neuroscientists, researchers, health care providers, innovators, family members, education

systems, private-sector leaders, and media professionals.

As members of the Task Force, our goal is clear-cut: to deliver big, bold, brave recommendations on how California can prevent and prepare for the growing number of Alzheimer's cases and forge a path forward for families.

As we developed a set of recommendations to deliver to the Governor, we held meetings throughout the state, making sure to bring people of all ages, ethnicities, and experiences to the table. From the Sacramento Region in November 2019

to Southern California in January 2020 to the Bay Area in February 2020 to the Central Valley in June 2020, we met with hundreds of advocates, health care workers, members of the faith community, local government officials, nursing home workers, and other stakeholders.

Our mission is shaped by the unprecedented, complicated, and still-unfolding challenges facing California, America, and the world: a pandemic, an economic disaster, a climate crisis, and an overdue reckoning with racial injustice. Adding to those challenges is the reality that sustaining Alzheimer's programs and services will require real investments in a time when California's budget is already strained.

Even in the face of these headwinds, the Task Force's work has become more urgent by the day. For example, COVID-19 outbreaks and negligence at nursing homes in California and across the country have demonstrated how critical it is to strengthen the safety net for our most vulnerable communities, including the aging, the poor, communities of color, and caregivers. As our state becomes grayer, we need a deliberate, forward-looking plan for our aging population.

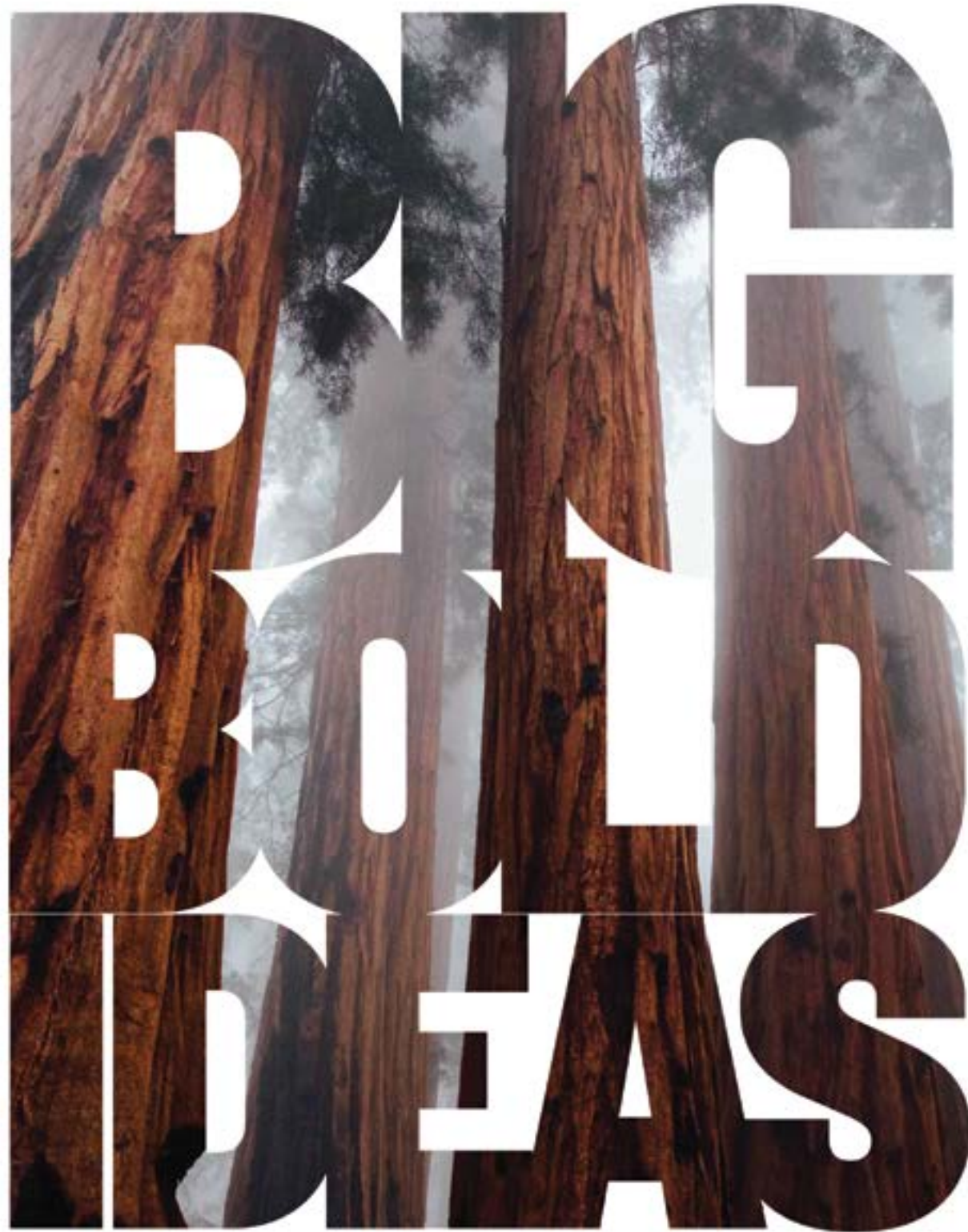
The recommendations we've developed take into account not only these challenges, but the unique opportunities California offers: diverse populations, extraordinary universities, and a

deeply held commitment to lifting up those who are disproportionately impacted by issues like Alzheimer's, including women and the Black and Latinx communities.

The recommendations in this report are born out of an extensive collaborative process and rooted in the unique needs of Californians. For example, people with Intellectual/Developmental Disabilities (IDD), especially Down syndrome, face the greatest risk of Alzheimer's, with 70% dying of this disease. Our recommendations are optimized to serve California's diverse populations, including those with IDD as well as people from different regions of the state, from all walks of life.

Our state is facing unprecedented circumstances. But it has never been more important to stay the course in preparing and implementing a set of big, bold, and brave recommendations we believe are key components of California's Master Plan for Aging. Families in every corner of our state are counting on us to take action.





*10 Recommendations for  
Alzheimer's Prevention, Preparedness  
and the Path Forward*

1

**APPOINT A SENIOR  
ADVISOR ON ALZHEIMER'S**

.

4

**BUILD A CALIFORNIA  
CARES (DIGITAL PORTAL)**

.

7

**INTRODUCE A NEW  
CAREGIVER TRAINING  
AND CERTIFICATION  
PROGRAM**

2

**KEEP CALIFORNIA  
AT THE FOREFRONT  
OF CUTTING-EDGE  
GLOBAL RESEARCH**

.

5

**ESTABLISH CALIFORNIA  
VOLUNTARY SAVINGS  
ACCOUNTS FOR  
LONG-TERM CARE**

.

8

**LAUNCH A CALIFORNIA  
BLUE ZONE CITY  
CHALLENGE**

.

10

**MODEL A STATEWIDE  
STANDARD OF CARE TO  
THE NATION**

3

**CREATE AN ALZHEIMER'S  
DISEASE PUBLIC  
AWARENESS CAMPAIGN**

.

6

**INVEST IN CAREER  
INCENTIVES FOR  
ALZHEIMER'S HEALTH  
CARE WORKFORCE**

.

9

**LAUNCH A CALIFORNIANS  
FOR ALL CARE  
CORP PROGRAM**



# 1

## Appoint a Senior Advisor on Alzheimer's



*“Appointing a Senior Advisor to address aging issues in our state is extremely important and could make all the difference for the progression of our state.”*

~ Debra Cherry, Ph.D., Orange County  
Brain Trust Member

The recommendations made by the Task Force will undoubtedly outlive the Task Force itself. Our goal is to create long-term solutions that will reach all Californians. This will require a sustained and concerted effort to coordinate the various stakeholders, agencies, departments, and advocates that intersect with Alzheimer's disease. This cabinet-level or Governor's Office position will ensure sufficient leadership and oversight to successfully implement and coordinate these recommendations. The need for this position will only grow as the state ages.

### Recommendation

Appoint a Senior Advisor on Alzheimer's who will lead the State of California in implementing the recommendations of the Task Force on Alzheimer's Prevention, Preparedness and the Path Forward to:

- Coordinate the implementation of the Task Force's recommendations and ensure that the Task Force's work remains on schedule and aligns with the Governor's vision.
- Seek advice and guidance from California's Alzheimer's Disease Centers and other public and private collaborators and councils.
- Keep all stakeholder communities informed and engaged over the short-, medium-, and long-term horizon by implementing recommendations.
- Highlight the economic, interpersonal, and societal impacts of scaling Alzheimer's prevention with the public and among lawmakers.
- Measure outcomes and report to the governor and the public on how the Task Force's recommendations are being implemented and what changes (if any) are made in response to evolving circumstances in the coming years.
- Link and leverage related work in the Master Plan for Aging, Future of Work, Mental Health Advisory Council, Alzheimer's Disease and Related Disorders Advisory Committee
- Convene people from aging, Alzheimer's, mental and behavioral health, and other relevant areas to make necessary recommendations and decisions.
- Create work groups that bring various stakeholders to the table to make decisions around coordination and implementation related to Alzheimer's.

# 2

## Keep California at the Forefront of Cutting-Edge Global Research



*“California is the most diverse state in the nation, so we are well-poised to establish a pipeline of diverse and underrepresented scholars in Alzheimer's research, investigators who mirror the diversity of the population and can conduct research that is inclusive.”*

~ Dr. Oanh Meyer, Task Force Member,  
UC Davis School of Medicine

Research is one answer to preventing and preparing for the rising number of Alzheimer's disease cases and other dementias. Targeted research to uncover how Alzheimer's, dementia and other age-related neurodegenerative diseases disproportionately impact certain population groups, women, Asian Pacific Islanders (API), Black, Latinx, LGBTQ+ and Native American communities. Identifying causes, risk factors, prevention measures and biomarkers need to be a priority focus. Overall, research investigating Alzheimer's disease through these and other dimensions such as behavioral and lifestyle factors is under-resourced and under-investigated. The best research in the nation to address Alzheimer's disease and related dementias is being done in the State of California; it started here first with the 10 California Alzheimer's Disease Centers and, collectively, they can move the field forward.

Our state can accelerate progress worldwide through statewide collaboration and sustained investments in California's robust research

infrastructure. As a state home to diverse populations, there is an opportunity to create revolutionary programs that look at Alzheimer's with a unique lens. We've done it before. In 2001, when President George Bush banned federal funding for research on newly created human embryonic stem, California stepped up and taxed itself to lead the way in this vital research. California can lead the way again by reimagining Alzheimer's research that reflects the unique Californian experience, such as rapid climate changes that disproportionately impact migrant workers, innovation at our fingerprints with Silicon Valley and the birthplace of biotech – the opportunities are endless.

### Recommendation

Keep California at the Forefront of Cutting-Edge Global Research:

- Accelerate investigation into Alzheimer's by increasing funding to keep California at the forefront of research that focuses on populations historically underrepresented,

including women, communities of color, and the LGBTQ+ community. Expanding research into these populations will help address health inequities, including toxic stress resulting from Adverse Childhood Experiences (ACEs), exposure to climate-induced toxins such as smoke from fires, and the unique role of women's health.

- Prioritize what California can uniquely contribute to Alzheimer's research, including funding of novel questions and trials involving our highly diverse population of black, brown, and Asian women, migrant workers, people living in poverty, as well as looking at how health-conscious environments might provide "blue zones" that promote healthy life styles, including brain health.
- Double down on existing and new research topics that underscore innovation and diversity, such as how Alzheimer's affects individuals differently within the Latinx population, depending on which continent someone's ancestors hailed from, or how lifestyle changes may stop or reverse the progression of early-stage Alzheimer's disease.
- Commit funding to cutting-edge, novel research questions and clinical trials, expand in-person and virtual access to research studies and support underrepresented and innovative investigators.
- Extend research opportunities to and enlist a diverse array of leaders in the life and

bioscience disciplines and sectors so that all research reflects all Californians, inclusive of their gender, gender identity, race, ethnicity, or sexual orientation.

- Leverage the strengths of California's academic institutions and tech and data-gathering companies through strategic collaboration and multi-site initiatives coordinated between Alzheimer's research centers. An Alzheimer's Senior Adviser could manage this critical effort that largely leverages existing resources, including consulting with the 10 California Alzheimer's Disease Centers on research priorities.
- Enable translational research that accelerates the transition from "bench to bedside" and incorporates results into the standard of care.
- Partner with populations most disproportionately affected by Alzheimer's, including women, API, Black, Latinx, LGBTQ+, and Native American communities to identify needs and shape research of critical issues that must be addressed to eliminate health disparities and to develop strategies for overcoming barriers to participation in clinical trials, such as trust.
- Ensure funded researchers and doctors are as diverse as the populations they serve.
- Identify research opportunities that are unique to California due to the diversity of its residents.

# 3

## Create an Alzheimer's Disease Public Awareness Campaign



*"We know very little of the brain health and brain aging of Latinos, and of Californios in particular. These gaps in knowledge will make it harder to address the impact of Alzheimer's disease. Given that Latinos form the largest ethnic/racial minority in the U.S. and the plurality of Californians, more research on this population should be a public health priority."*

*~ Hector M. Gonzalez, Ph.D., San Diego  
Brain Trust Member*

While California is known for its "youth culture," the state has the second-longest life span in the nation: 80.8 years. With age comes greater risk for Alzheimer's disease and all dementias. It is also true that no other state has the media-savvy or industry our state has, meaning California is uniquely positioned to dispel myths about aging and de-stigmatize Alzheimer's disease. Widespread misinformation, lack of understanding and negative perceptions in the population about dementia, Alzheimer's disease and other age-related diseases present a major barrier to policy change and health system transformation. Designing an "Alzheimer's Public Awareness Campaign" that educates the public about the different neurodegenerative diseases, their prevention, symptoms, diagnosis and treatments is essential.

### Recommendation

Create an Alzheimer's Disease Public Awareness Campaign that is multilingual, multicultural and intergenerational, designed

to shift public perceptions and reduce social stigma. The public awareness campaign will:

- Target four groups: 1) youth, 2) at-risk populations, 3) pre-symptomatic individuals and 4) people living with the disease now, focusing on populations disproportionately affected by Alzheimer's, including women, communities of color, and LGBTQ+ people.
- Incorporate a targeted messaging strategy that recognizes the unique impacts on racially, ethnically and geographically diverse populations throughout our state. Develop campaigns that engage trusted faith-based, educational and community leaders in designing and disseminating culturally appropriate messages.
- Focus on debunking fake news and stigmas using evidence-based education related to Alzheimer's disease prevention, preparedness, and healthy aging.
- Clearly define the differences and similarities between Alzheimer's, aging,



dementia, and brain health for the public and health professionals alike.

- Inform the public about prevention, risk reduction, the 12 proven modifiable lifestyle interventions, and the realities of late-stage Alzheimer's and end-of-life care.
- Connect messaging to curriculum development across schools to shape intergenerational perceptions of aging and Alzheimer's disease.
- Link the service-minded with the California Connections Corp program to connect volunteers with people and families affected by Alzheimer's.
- Drive concerned Californians to threshold language accessible, culturally competent assistance by phone, online and in-person, e.g. CA Cares.
- Explore new ways to reach Californians in retirement through campaigns targeting existing pension programs, e.g. University of California, CalPERS and CalSTRS.
- Implement a statewide communications campaign to bolster the message of service as a means to address challenges.
- Drive the public to helpful resources to directly access and pay for Alzheimer's care.
- Partner with private, public and philanthropic organizations to help fund this vital work, including an evaluation.
- Promote the voluntary state tax check-off fund for Alzheimer's through the PSA Campaign and partner's networks.



## 4

### Build a California Cares ~ Digital Portal



*“We can change communities. We won’t just help people live better.  
We can change communities, if we get these workers out of poverty.”*

*~ April Verrett,*

*Task Force Member, President of SEIU Local 2015*

Information and resources related to Alzheimer's, dementia and other age-related conditions are fragmented and difficult to navigate. Information is not in one centralized place, spanning dozens of federal, state and county departments, and does not sufficiently support decision-making across the lifespan.

Information could better support the needs of people with Alzheimer's disease and their families, especially those who speak a language other than English, as they move from screening and diagnosis to planning and coordinating care.

#### **Recommendation**

Create a California Cares digital portal to:

- Function as a one-stop-shop for all information (shaped by the California Standard of Care described below) and services related to screening and diagnosis of Alzheimer's disease and the planning and coordinating care.
- Address the fragmentation of information resources (through vetting and curation) and help individuals, families and caregivers navigate resources as Alzheimer's and dementia progresses over time. Collaborate with public and private partners to coordinate content and ensure the needs of the community are met.
- Make information and resources (e.g., such as the opportunity to join online support communities) easily accessible and on the go with a web portal optimized for both computer and mobile access to information and services.
- Evolve into a referral service that connects families with paid caregivers and other service providers who meet the highest quality of care and workplace standards, including competitive wages, benefits, and training.
- Protect vulnerable populations from exploitation by offering a state-curated portal in the public domain that serves as a trusted and reliable resource.
- Provide linguistically and culturally competent services for all Californians.
- The state's portals, such as [response.ca.gov](https://response.ca.gov) for fire season and [covid19.ca.gov](https://covid19.ca.gov) for COVID-19, serve as a model and best practice for what is achievable.

# 5

## Establish California Voluntary Savings Accounts for Long-Term Care



*“[Caregivers] are saying ‘we need help today.’ And that is some help we can get literally to every caregiver in California in the next year.”*

*~ Dr. David Lubarsky, Task Force Member,  
Vice Chancellor and CEO of UC Davis Health*

Individuals (and their families) need relief from out-of-pocket costs not covered by Medicare, Medicaid, Social Security, or Veteran’s Administration benefits. New financing models for long-term care are needed; reliance on uncompensated family caregivers is not sustainable. With new financing models, individuals and families could avoid bankruptcy.

Employers could see productivity gains and those in need of assistance could access the help they need to live with dignity. With age still the most significant risk factor for Alzheimer’s disease, special financial consideration must be given to older women who represent nearly two-thirds of all individuals age 65 and over living in poverty, with women of color, LGBTQ women, and single women suffering impoverishment most acutely according to Justice in Aging.

### Recommendation

Create California Voluntary Savings Accounts for Long-Term Care to:

- Address affordability and access by exploring new, sustainable revenue streams that prevent the need for individuals and

families to spend down to poverty to qualify for Medicaid.

- Enable tax-advantaged savings with a new “565 pre-tax account” for long-term care financing, particularly for health care as out-of-pocket, unreimbursed expenses increase as Alzheimer’s disease progresses. The college savings plan, referred to as a 529 Scholar Share Plan, can serve as a model.
- Address long-term care affordability and health access for Californians by creating voluntary savings accounts that would help finance support services for those needing long-term care (e.g., home modifications, adult day care, transportation).
- Pay for non-clinical costs incurred by individuals living with Alzheimer’s, including in-home caregiving services to assist with daily living activities like eating, bathing, and helping with medications to delay or avoid costly institutional care.
- Create a participatory retirement savings model, reduce the financial burden on families, mitigate caregiver strain, productivity losses, and bankruptcy risks.

- Examine new public financing models based on actuarial data to expand universal access to long-term services and supports such as the Washington state program.
- Explore how the program can be expanded to create a federally tax-advantaged savings account. California has the authority to create a savings plan that impacts state taxes but will need federal approval to waive federal income taxes. California’s comparatively high state tax rate still makes the “565 pre-tax account” viable and advantageous for participants, but expanding to be federally taxed advantaged would

significantly increase participants’ potential benefits and incentives.

- This recommendation will build off of key learnings from the CalABLE and CalSavers savings program.

This recommendation will be presented to the Governor along with the Master Plan for Aging’s Long-Term Services and Supports Subcommittee stakeholder recommendation for a universal LTSS benefit potentially funded by a payroll tax, ensuring that the Governor has a menu of options of how best to tackle this issue.

# 6

## Invest In Career Incentives for Alzheimer’s Health Care Workforce



*“COVID has caused a raised unemployment and is drastically impacting the trajectory of new grads (from college and high school). Now more than ever, we have the opportunity to tap into people’s power to care for vulnerable older adults.”*

*~ Nihal Satyadev & Norma Bostarr, Los Angeles  
Brain Trust Member*

Amid an unprecedented health crisis, California has an opportunity to incentivize people to pursue careers in health fields such as direct care staff, nurses, gerontologists, social workers, mental health practitioners, among others.

Through a variety of incentives – student loan forgiveness, educational internships,

student/residency stipends, and above-average wages – California can increase its “health care capacity” by steering people into careers in the aging ecosystem to meet a critical lack of supply as demand continues to grow. Similar incentives provided to law school students decades ago steered newly minted lawyers away from traditional private firms and into public interest practices that



served low-income, marginalized clients where shortages existed. Furthermore, in California, Proposition 56 was passed in 2016, which increased the excise tax rate on cigarettes and electronic cigarettes, which funded a Physicians and Dentists Loan Repayment Act Program for recently graduated physicians and dentists. California can continue this pioneering model by incentivizing health care work in Alzheimer's, brain health and aging.

### Recommendation

Create Career Incentives for Future Alzheimer's Health Care Workforce:

- Create competitive wage and benefit incentives for all health care workers as California remains one of the nation's most expensive states to call home. Offering above-average compensation would entice national and possibly world-leading experts to bring their skills and expertise to California.
- Offer loan forgiveness to students who commit to completing their healthcare degree and commit to serving in California's healthcare field post-graduation and certification. This recommendation would be modeled after similar programs offered to physicians, nurses and other healthcare workers.
- Diversify the workforce to ensure access to linguistically appropriate, culturally competent care for all Californians. We will focus on recruitment efforts on expanding outreach to diverse communities to attract and retain people of color in the health care workforce.
- Expand career exploration avenues by creating educational internships starting at the high school level to encourage youth to consider a health care community path. Additionally, partnering with universities and colleges to establish internship programs offering college credit or internship hour fulfillments.
- Provide residency stipends, as most clinical or residency periods are unpaid and students are often placed in different cities or states than the student's current residency place. This recommendation would offer a stipend for students pursuing their advanced degrees in the healthcare world that complete their residency within California.
- Examine funding through the Office of Statewide Health Planning and Development with an "aging lens" to bring equity to geriatrics, gerontology, gynecology, psychology and psychiatry programs. In coordination with public and private partners, establish benchmarks and formal milestones to measure progress
- Set a wage floor above minimum wage for direct care staff, including benefits (health insurance and paid time off), access to training and career ladder opportunities to overcome workforce shortages and reduce turnover.

# 7

## Introduce A New Caregiver Training and Certification Program



*"Far too many Californians have seen the crushing grip of Alzheimer's on our loved ones," Newsom said in a news release identifying the full membership of his Alzheimer's Prevention and Preparedness Task Force. "It is one of the leading causes of death among Californians with particularly severe impacts on our mothers, wives and daughters. It's time we take meaningful action for those living with Alzheimer's and for the people who love and care for them."*

~ Governor Newsom

The direct care workforce – primarily women of color, who serve as front line employees working in the home, in the community, and in licensed long-term care facilities, need dementia training, certification programs and career ladders. Augmenting the paid workforce are 1.7 million California family caregivers who provide the vast majority of care and support to loved ones living with Alzheimer's or dementia. Projections for both paid and unpaid caregivers show alarming shortfalls. The availability of both formal and informal caregivers is likely to shrink due to changing demographics. Informal and family caregivers are the backbone of California's long-term care system, providing far more direct care and support than formal, paid caregivers. COVID-19 has uncovered new training topics urgently needed for in-home and long-term care staff to address social isolation, infection control, virtual communication, alternative activities and more.

### Recommendation

Create a California Caregiver Training and Certification Program to:

- Elevate the care in all communities by expanding access to evidence-based education and training for formal and informal caregivers.
- Support all caregivers (informal, formal and IHSS) with education and training to ensure quality and safety.
- Elevate the job quality of paid, direct care staff by defining comprehensive employment benefits, training, scheduling, safety regulations and appropriate compensation levels for work performed, acknowledging increased knowledge and skills with higher wages.
- Engage with state-supported partners (e.g. California Alzheimer's Disease Centers, Family Caregiver Alliance) to explore new

caregiver training models accessible to underserved communities.

- Build on the nationally acclaimed, evidence-based research and training of the California Long-Term Care Education Center focused on In-Home Supportive Services (IHSS) workers, the California Independent Training Center.
- Meet the demands of a growing population by exploring initiatives to embrace undocumented workers and attract foreign caregivers.

- Collaborate with community partners, including labor, educational institutions, health systems, and nonprofit organizations to design curriculum and deliver culturally competent dementia training where students can earn caregiver certification upon completing the program.
- Expand online course offerings in languages other than English and pursue respite funding to allow family caregivers to participate in training.

## 8

### Launch a California Blue Zone City Challenge



*“The California Blue Zones Challenges set Californians up for better brain health by optimizing their surroundings to make the healthy choice the easy choice.”*

~ Dan Buettner,  
Task Force Member, Blue Zones Founder

Many interacting factors are influencing healthy aging – one’s genetic makeup, cellular biology, lifestyle behaviors, personal perspectives about aging, social engagement, and the environment – aging is a culmination of all these factors.

California’s Surgeon General notes the harmful effect of toxic stress over time, especially among low-income families and people of color. There is strong evidence that healthy lifestyles significantly reduce the risks of Alzheimer’s and other age-related

diseases by up to 70%. Long-term place-based interventions – as opposed to ephemeral behavior change strategies – have been shown to transform cities by strengthening social ties among communities, expanding access to healthy food, creating opportunities for physical movement, designing activities that maximize social engagement, and supporting healthy behaviors that can reduce health care costs, expand life spans, and improve quality of life.

### Recommendation

Create the first California Blue Zone City Challenge to:

- Issue a challenge by the Governor for California cities that are most prepared and willing to address dementia in their community. Cities must demonstrate that both the private sector (Chamber of Commerce, local CEO’s) and the public sector (Mayor, City Manager, City Planner, City Council, Superintendent of Schools, Food Council etc.) understand the project and will commit to minimum requirements. A handful of the “readiest” cities are chosen for the initial pilot projects.
- Promote the project’s core tenants by optimizing the environment to promote low-intensity physical activity, healthy and whole food options, socializing, reduce smoking and alcohol abuse, while increasing volunteerism and improving mental health.
- Ensure the challenge addresses health, economic and racial disparities to fully embrace Californians at greatest risk of Alzheimer’s and other chronic conditions in program design.
- Deploy specialized staff, with support from the national Blue Zones office, to pilot cities to coordinate project development and implementation.
- Create an advisory group of academics and policy experts who will collaborate to create policy “menus” that favor better brain health that aligns with the core tenets.
- Certify establishments such as schools, restaurants, grocery stores, workplaces, churches, temples, etc. as “Blue Zones” once they adopt a minimum threshold of best practices outlined by the program.
- Establish a “Blue Zones Ambassador” program for individuals who want to lower their dementia chances or want to help fight dementia in their communities.
- Model the ideal (evidence-based) California Blue Zone that is inclusive and addresses the unique needs and challenges that people with dementia, Alzheimer’s, and other age-related diseases face.
- Provide resources to one or more California cities and California Alzheimer’s Disease Centers to pilot the California Blue Zone City Challenge.
- Integrate the population-based, public health work of the Healthy Brain Initiative in select California counties as a start.
- Build capacity in under-resourced communities.



# 9

## Launch A Californians For All Care Corp Program



*“The role of lifestyle changes could help prevent Alzheimer’s disease. We are conducting the first randomized trial to determine if intensive lifestyle changes may stop or perhaps even reverse its progression in its early stages.”*

~ Dr. and Author Dean Ornish, San Francisco  
Brain Trust Member

Initiatives such as the Californians for All Care Corp are needed to expand short-term service opportunities to support people living with dementia, Alzheimer’s disease, and other age-related neurodegenerative diseases, especially as we continue to navigate the current pandemic.

California can lead the nation in creating intergenerational connections, addressing social isolation, attracting future workforce, and lifting communities by creating a service culture.

### Recommendation

Create the Californians for All Care Corp, connecting Californians of all ages to service opportunities in their communities to:

- Create innovative, structured service opportunities for people of all ages and life stages to contribute meaningful public service while tackling pressing community challenges.
- Build local and statewide infrastructure and operational capacity to support service and

volunteer opportunities at scale, including adequate training and safeguards.

- Invest in technology platforms to easily connect Californians to service opportunities (and to pro bono financial planning, legal services and so on) in every community.
- Promote skill building and career exploration for students by offering opportunities to serve those affected by Alzheimer’s.
- Honor Californians For All Care Corps service members with a Governor’s Badge of Service, modeled after President John F. Kennedy’s “Badge of Honor.”
- Engage community and faith-based leaders and educational institutions such as school districts, high schools, community colleges and universities to recruit members for the Care Corp.

# 10

## Model A Statewide Standard of Care to The Nation



*“Caregiver training opportunity for leaders in the faith community is vital and I am delighted to see a faith focus in the recommendations.”*

~ Leeza Gibbons, Los Angeles  
Brain Trust Member

According to the California Department of Public Health, Alzheimer’s is the second leading cause of death in our state; yet, health professionals routinely dismiss the symptoms of Alzheimer’s as “normal aging,” despite the proven value and benefit of early detection and diagnosis. The variation in diagnostic standards alone reveals the urgent need for a statewide standard of care to bring evidence and equity to treatment and care decisions throughout Alzheimer’s disease progression. Early intervention can enhance quality of life and save the state money. California families are unlikely to see a health professional who understands how to identify, screen, or diagnose dementia. Especially within communities of color, where patients often go undiagnosed or diagnosed so late in the disease, there is decreasing value or benefit.

### Recommendation

Model a Statewide Standard of Care to the Nation:

- Ensure doctors have access to a set of evidence-derived cognitive screening questions that would identify Alzheimer’s symptoms and trigger further assessment if warranted.

- Develop a formal, networked “hub and spoke” model that leverages the detection, diagnosis, treatment and care planning expertise of the 10 California Alzheimer’s Disease Centers (CADCs). Enlist essential multilingual, culturally competent care team members in the model, including family caregivers.

- Integrate the standard of care throughout all payer models, including Medicare, Medi-Cal, Covered California and commercial insurance. Ensure health providers are reimbursed for the time it takes to assess a patient, provide a diagnosis, and offer a plan of care.

- Pursue quality initiatives within managed care plans to drive adoption of the statewide standard of care and produce improved health outcomes

- Extend the geographic reach of the 10 CADCs to ethnically and racially diverse, underserved, and marginalized communities throughout the state.

- Incentivize cross-collaboration and interdisciplinary initiatives across the 10 CADCs focused on detection, diagnosis, treatment and care planning.

- Lead the nation to equitable treatment by focusing outreach and participatory action for individuals and communities disproportionately impacted by Alzheimer’s disease as a result of toxic stress, Adverse Childhood Experiences (ACEs), and persistent gender, gender identity, sexual orientation, racial and ethnic disparities in disease prevalence among women, API, Black, Latinx, LGBTQ+, and Native American people.
- Adopt a “behavioral health first” approach that leverages the Governor’s Behavioral Health Task Force to build state of the art “behavioral health services” for older adults, their family members and chosen caregivers who face daily and intensive decisions about care/services, managing acute anxiety, depression, fears and other behavioral symptoms related to memory impairment, dementia, Alzheimer’s, and related health or mental health conditions.
- Emphasize neuropsychiatric symptoms in later stages of dementia being addressed by doctors and more training to treat psychiatric symptoms at all dementia stages.
- Incorporate family caregivers into the diagnostic process and care planning to ensure all family caregivers have access to health education, dementia training, and emotional support directly through the CADCs and collaborate with government and community partners.
- Champion person and family-centered care planning. Patients should be documented in charts, but so should a family caregiver assess and have a bearing on the care plan. Both patients and their unpaid caregivers should have a recognized, implicit role in care planning and implementation.
- Promote home and community-based options to support individuals and families with a real choice in determining their living environment while assisting in placement in the lowest level of long-term care when – and if needed.
- Promote innovative acute care models, e.g. ACEP accredited Geriatric Emergency Departments and Age-Friendly Health Systems focused on the four “M’s” – what Matters, Medication, Mobility and Mentation. Pioneering work underway in California could significantly reduce ER visits and hospital readmissions among patients with dementia.
- Ensure telehealth visits remain after COVID-19 as it is another tool to reach patients and families.
- The standard of care will include models of cutting edge developments, including access to dementia care managers who are trained social workers or nurses who assist, educate and guide patients and families over the course of Alzheimer’s disease. Several models of this role include nationally recognized ones developed or implemented in California at UCLA, UCSF, the Cal MediConnect demonstration, and others.

“So much of Alzheimer’s Disease is defined by what we cannot do – the memories and cognitive ability that are taken away from us and our loved ones. The work of this Task Force was to listen, to investigate and to recommend groundbreaking solutions that prove there is much we can do now to take on Alzheimer’s Disease.”

~ Maria Shriver



An aerial photograph of San Francisco at sunset. The city skyline is visible in the background, with the Golden Gate Bridge and the bay. The foreground shows a winding road on a hillside with some vegetation. The sky is filled with soft, golden light from the setting sun.

## Epilogue

# California, it's time to rethink our approach to Alzheimer's

By  
Dr. Nadine Burke Harris

*California Surgeon General and member of the Task  
Force on Alzheimer's Prevention, Preparedness  
and the Path Forward.*

One of the biggest myths about Alzheimer's is that it's not something we need to worry about until we're older. The truth is that in order to fully understand this disease, we need to start much earlier.

As a pediatrician, a toxic stress researcher, and a mother, I spend a lot of time thinking about the ways children's experiences will shape their entire lives. I've seen how traumatic stress in childhood can lead to the chronic overactivation of the stress response, which is associated with increased risk of long-term health problems like heart disease, cancer, and yes, Alzheimer's.

Even before birth, research shows that what happens in utero may increase susceptibility to Alzheimer's. And we know that experiences from high school football accidents to domestic violence affect not only the body, but the brain.

Studying Alzheimer's when people are in their sixties, seventies, or eighties is far too late. We need a new approach. If we're serious about preventing this disease, when it comes to brain health, we need to be just as serious about connecting the dots from birth to end-of-life and every stage in between. And, California, no one is better positioned than you to lead that charge, with the help of your world-class universities and research labs.

Focusing on the long-term can be hard when you're in the midst of a crisis. But that's also when it's most important. Over the last several months, the pandemic has upended our day-to-day lives. Californians have lost jobs and loved ones, and watched as any sense of "normal" retreated in the rear-view mirror. This new reality has cast a harsh light on big, systemic challenges like structural racism and disparities in health care and our economy.

The same is true of Alzheimer's – a disease that affects 690,000 Californians and their families, and costs the nation more than \$305 billion annually. Like COVID-19, Alzheimer's takes a disproportionate toll on Black and Latinx Americans. By 2030, they will make up nearly 40 percent of the 8.4 million families in this country whose lives have been touched by this disease. And as with COVID-19, in Maria's words: "No statistic can ever tell the story of what happens when this crisis reaches your own doorstep."

That's why this report and its recommendations are so timely and important. The COVID-19 pandemic has cast a bright light on how crucial it is to prepare for a crisis and understand the vulnerabilities in our public health system – and the toll it can take when we aren't fully prepared.

California, there's a lot we can do to prevent and prepare for the rise in prevalence of this disease, while taking into account our diverse population. Each of us has a crucial role to play – as government leaders, researchers, health care providers, businesses, communities, families, and individuals – in building a healthier California.

By establishing the Alzheimer's Prevention and Preparedness Task Force and the Master Plan for Aging, Governor Newsom has called on all of us to imagine a future where California is the best state in the nation to grow old in. To achieve that end, it's time to recognize that preventing Alzheimer's starts at the very beginning.





## *Conclusion*

# Dear Governor Newsom and State Legislators,



Dear Governor Newsom and State Legislators,

We began this report with a letter to California. Now, we're ending it with a letter to you: some of the people best positioned to take decisive action to confront Alzheimer's and dementia in our state.

You know better than most anyone what this year has done to our great state. The pandemic and subsequent economic fallout have damaged our economy, our healthcare system, and our social safety net. If we've learned anything from this novel coronavirus, it's that when we don't prepare, disaster follows.

So the question is: how do we prepare our families, our caregivers, and our aging population for the Alzheimer's crisis that's already building? The answer is in this set of recommendations. Some are designed to help Californians right now, and

others require more time and resources. But all of them serve as a helping hand to Californians who are looking to their retirement with trepidation, or are feeling more unprepared than ever because of COVID-19.

Families are forever changed by the lives lost to this pandemic. Millions of Californians are without jobs and unable to pay rent, a challenge that has worsened pre-existing problems like homelessness and affordable housing shortages. Our schools are struggling to ensure a generation of students can continue to learn. Local businesses and restaurants have been shuttered forever, while some still cling to survival by holding on long enough to reopen when COVID-19 cases subside.

These devastating consequences are a solemn reminder that we can't afford not to plan, not to invest, and not to protect vulnerable communities from known and unknown challenges.

That's why, even with all the other problems on your plates right now, we cannot afford to wait on tackling Alzheimer's. California needs to do more to take care of our elders, and those who love and support them. Aging Californians deserve respect, security, and dignity. But in the past few months, we've seen all too clearly that our current systems of care are coming up short. Nearly half of California's COVID-19 deaths come from the residents and staff at nursing homes and assisted living communities.



And across the nation, the pandemic is forcing women and people of color into an early retirement faster than white men, a problem exacerbating the pressures on caregiving populations already squeezed by Alzheimer's.

Many of the challenges we face today have been around since long before any of us even heard of the coronavirus. And long after the immediate threat passes, Alzheimer's will still be with us.

Like me, many of you know the devastating toll of Alzheimer's far too well. Maybe you've lost a parent to this cruel disease, or maybe you're struggling to care for a loved one as we speak. You know how significant it is that, even before the coronavirus

reached our shores, Governor Newsom had the foresight to make Californian's "graying generation" – including their struggle with Alzheimer's – a priority for the state. It's a priority that we must hold onto as we recover and rebuild.

As key components of the state's Master Plan for Aging, California should adopt this Task Force's recommendations for taking on the Alzheimer's crisis. We put together our recommendations with the public health and economic crises in mind, and we strongly believe that the commonsense policies we've put forward will make our economy stronger. They will make our healthcare system stronger. And they will make our communities stronger.

Imagine a future where California pioneers a standard of care and cutting-edge research that can be adopted across the country, across the world even, providing yet another example of our state's capacity for bold leadership. It would be a future where all of our seniors have access to early diagnoses and culturally competent care; where outcomes are not determined by a family's ability to pay ever-growing bills; where young people understand their options for keeping the disease at bay and managing brain health before it's too late; where our research institutions have plenty of funding and are pushing toward a cure; where the populations most impacted by memory loss are well-represented in research; where the government response to this disease is well-coordinated and well-resourced. Together, we could make California the best state in the nation in which to grow old – and the leading voice the rest of the world will want to listen to.

Imagine a future with a statewide Care Corps program, where young people have the opportunity to spend their first working years meeting the caregiving needs of Californians with cognitive impairments. Not only would such a program reduce some of the inequities in our system, but it would also invest more of our future researchers, policymakers, and medical workers in the challenge of finding a cure. It would create many of the intergenerational bonds we've lost, and imbue generations of Californians with a dedication to service.

Imagine a future where California launches a Blue Zone City challenge, incentivizing cities to promote the healthy lifestyles that have led to longer lives around the world and better outcomes in mitigating cognitive decline. Communities would be bonded together, sharing in the knowledge and responsibility of caring for aging Californians well



after retirement; families would be able to afford the nutritious food that fuels brain and physical health; residents would have the outdoor spaces and sidewalks and community centers needed for low-intensity exercise, with grocery stores and churches within walking distance. Both the public and private sectors would be mutually invested in building this better future, because both would realize the potential of a California where everyone is cared for.

You have the power to help make that future a reality. California can be a state where no matter your health, background, or income, everyone has a shot at a long, dignified life. California can be a global model in tackling Alzheimer’s and offering

equitable, effective wraparound healthcare services.

The first job of government is to protect its citizens and that’s what these recommendations will do. Not only will they help ensure anyone can come to California and thrive in their 20s, as I did, but they can also afford to grow old here and live with dignity. We want people to look back and say this is the state that led the way on Alzheimer’s and dementia, just as it has in so many other ways.

This future is within our grasp. Now is the time for California to recommit to our role as a leader for the rest of the nation and courageously take up recovery plans that embrace what this state is capable of.

We’ve seen what California can do. We built the world’s foremost public university and research

system, which now generates an average of five inventions per day. From Hollywood to Silicon Valley, we are telling stories that will touch generations to come and inventing the future as we go. We’ve shown that we are capable of taking on the biggest crises of our time. We addressed climate change even when the federal government abandoned its responsibilities, committing and re-committing to statewide limits on greenhouse gas emissions. And we’ve done it all while building the fifth-largest economy in the world, proving that doing what’s best for business long-term is doing what’s best for the planet.

We are leaders. We don’t turn away from the tough issues, even if others would rather sweep them under the rug. Ours is a story of resilience and strength, of earthquakes and wildfires, adversity and overcoming, and the people who build it all back, better than before. I know there is nothing Californians can’t achieve when we work together.

The next iteration of California’s story will be told in how we handle the crises at hand, including the

Alzheimer’s crisis. We’ve seen what happens when we let a crisis build, and 2021 will be a crucial year for defining our long-term success in addressing this disease. We have a chance to turn despair into hope, and challenges into opportunity. We must learn the lessons of this year and have the courage to invest in the future we want to see for ourselves and all of California.

I urge you to adopt the recommendations respectfully put forward by this Task Force. Thank you for your leadership, and thank you for your believing in California’s ability to lead in the fight against this terrible disease.

Respectfully,  
Maria Shriver







There is a lot that goes into a report like this. A small village of people manage to move a mountain of work in a short amount of time. With that, comes countless people to thank, people who worked diligently from the first ideas to the blossoming of an influential product. It took this small village of experts, practitioners, families living with Alzheimer's, businesses, officials, churches and neighbors to ensure these recommendations not only saw the daylight but also were bold, practical, realistic, and scalable enough to lead a path forward for Californian and the nation.

First things first. Thank you to each and every member of the Task Force, without whom this report would not have been possible. All 31 members contributed to the diverse opinions and expertise that represent all of California. Your voices proved essential for the completion of this report. I want to especially thank Surgeon General Dr. Nadine Burke Harris and Secretary George Shultz for providing their world class leadership and expertise throughout this process.

We could not have finished our work without the generous support of our funding partners. I would like to thank the Ray and Dagmar Dolby Family Fund, [the Sierra Health Foundation](#), [the California Community Foundation](#), [the Silicon Valley Community Foundation](#), [The SCAN Foundation](#), [the IKEA Foundation](#), and [The California Endowment](#). Your belief in us is greatly appreciated.

I am also extremely thankful for the members of the Brain Trust, managed by the phenomenal Dixie Rodgers Noonan who is a veteran of the Shriver Reports and a wicked smart warrior. Our Braintrust offered their time, vital direction, guidance, and advice to the Task Force and the members of our team. Your knowledge and diverse backgrounds contributed immensely to these recommendations, and for that, your efforts are greatly appreciated.

To our key stakeholders, First Partner Jennifer Siebel Newsom, Lieutenant Governor Eleni Kounalakis, State Treasurer Fiona Ma, State Controller Betty Yee, and CA Chief Technology

Officer Amy Tong, thank you for being open to listening to our recommendations and offering thorough insight into ways that we can adapt our work to a changing state. Your knowledge and expertise in your respective areas helped make these recommendations be realistic and proved indispensable for the development of this report.

To the institutions that hosted us pre-COVID: UC Davis Health, the Public Policy Institute of California, UCI Mind and UCSF Fresno Alzheimer's and Memory Center, thank you. It was in your space and environment that these bold, brave and bright recommendations came to life and because of your generosity, these ideas were able to flourish. You gave us the resources needed to listen to the voices of hundreds of Californians from all parts of our great state.

I want to extend my utmost gratitude to all the staff and partners who made this report possible. In the face of adversity and some of the most challenging times our state has experienced, thank you for never stopping, pausing, or wavering from the path forward. Thank you first to the fierce Karen Skelton, who I've worked with closely for many years, and her team at Skelton Strategies. Without her driving force, optimism, and bright strategic brain, this report would not exist. Thank you to my chief of staff as First Lady of California and friend, the amazing Donna Lucas and her team at Lucas Public Affairs, for being the back office and backbone of this effort. Donna's extraordinary leadership, judgment and a great sense of humor are a magic

combination making this big thing happen. These kinds of projects have a way of teaching and raising up the next generation of public servants, and in this case, that was true through the tireless efforts of our excellent project manager from LPA, the talented Daisy Castellon, along with Connor Jang, and Hayley Carbullido. To the team at the Institute for the Future, thank you for guiding us through countless meaningful discussions and navigating this thick material with grace. To Erin Stein and my crew at Women's Alzheimer's Movement, thank you for your commitment to this report and the insight and resources you provide everyday. Thank you to Susan DeMarois - our internal expert on loan from the Alzheimer's Association - and Margaret Lyons - a trusted and seasoned policy and community leader. To Dan Schwerin and Mackenzie Long at Evergreen Strategy Group, thank you for beautifully capturing our story. Lunia Blue and its creative leader Matt Rallens has been my go-to designer-in-residence for years and I appreciate his fresh and cutting-edge talent, and friendship. To another fearless leader, Kim McCoy Wade, who is leading the efforts for the Master Plan for Aging, thank you for your collaboration, patience education, gracious accommodations, and loyal commitment to care for our aging state.

We are indebted to the first class state agencies and leaders whose collaboration and brain-smarts we depended on throughout this project, starting at the top with Secretary Dr. Mark Ghaly and his entire professional staff at the California Health

and Human Services Agency (CHHS), the California Department of Public Health, and the Alzheimer's Disease and Related Disorders Advisory Committee led by Dr. Howard Rosen. Within these agencies are hundreds of MVPs, and among them, much appreciated shout-outs go to Marko Mijic and Janne Olson-Morgan, and their teams. We couldn't have received more support from the hard working, dedicated, and razor sharp operation working with Governor Gavin Newsom, including his fearless Chief of Staff Ann O'Leary and his entire team who helped us at every turn, including Ana Matosantos, Richard Figueroa, Kathleen Kelly Janus, Vivek Viswanathan, Maricela Rodriguez and Anastasia Carney.

And finally, to the leader of our state, Governor Gavin Newsom, thank you for asking me to take on this assignment and giving me the chance to serve you and the people of California. Thank you for making this a priority for our state and being the leaders that the rest of our Nation can look to for a bold path forward for an aging Nation.

Last but not least, thank you to my family and friends for the continuous support. Your love and friendship drive me to work harder each day, and for that, I am eternally grateful.



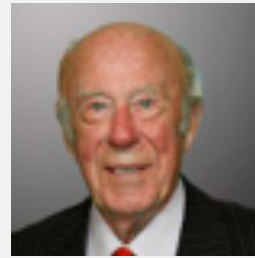
# Task Force Members



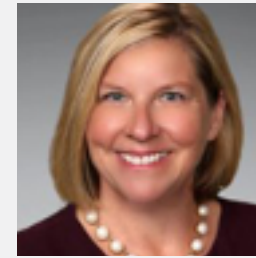
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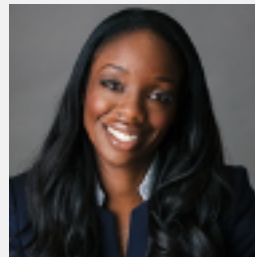
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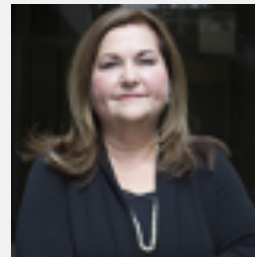
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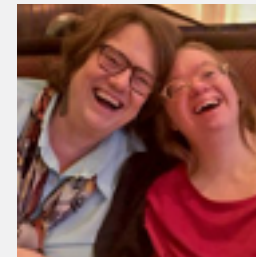
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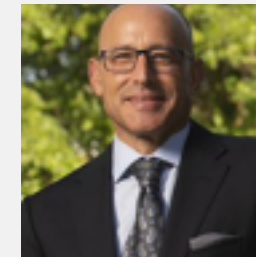
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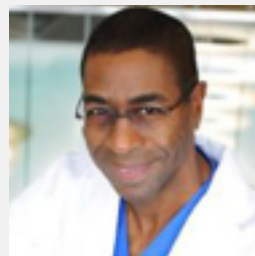
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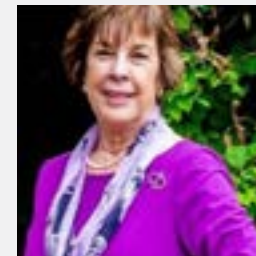
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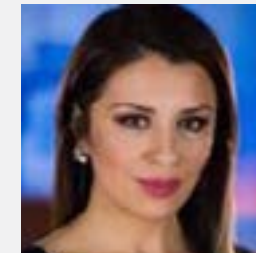
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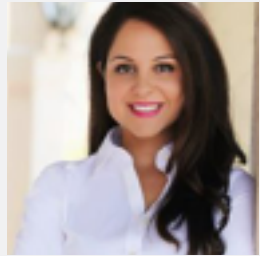
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The Task Force consults with a “brain trust” of high-level experts and practitioners who have strengthened the recommendations. Members include:

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[CAAlzTaskForce.org](http://CAAlzTaskForce.org)

For families seeking resources related to Alzheimer's Disease,  
please visit the Women Alzheimer's Movement at  
[thewomensalzheimersmovement.org](http://thewomensalzheimersmovement.org)

- or -

the Alzheimer's Association at  
[alz.org](http://alz.org)