



NeuroWell

A guide to brain health
and living well with mild
cognitive impairment
(MCI) and dementia

NeuroWell

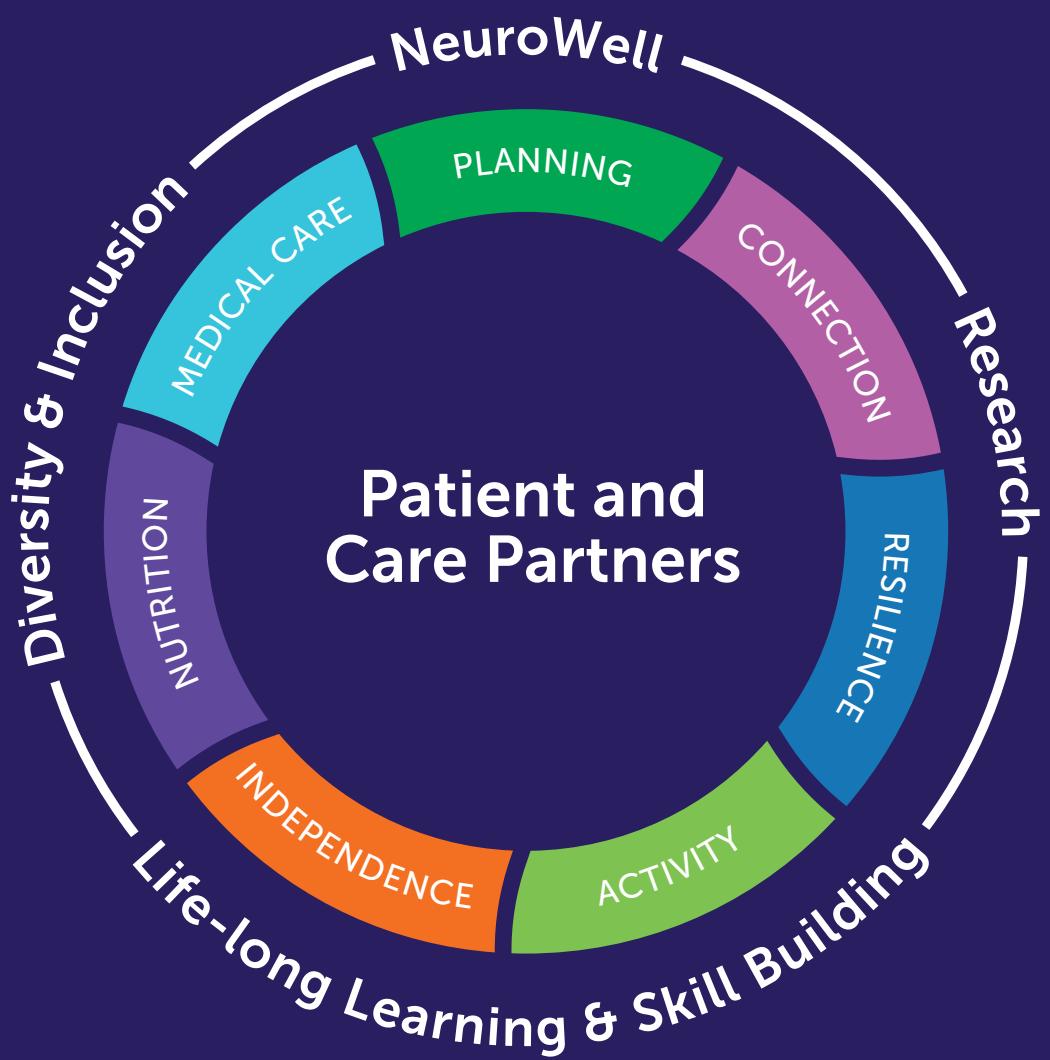


Table of contents

Acknowledgements.....	3
Foreword	5
Introduction	6
NeuroWell	
Planning and goal setting.....	8
Connection, purpose and joy	22
Resilience and emotional well-being	36
Activity.....	48
Independence and performance	58
Nutrition	74
Medical care.....	82
My NeuroWell plan	96
Care partner well-being.....	111
Resources and references	112
Notes.....	114

Acknowledgements

Written by

Michelle Barclay, MA¹, Terry R. Barclay, PhD^{1, 2, 3},
Michael Rosenbloom, MD^{2, 3} and Ricky Lopez, MS, ACSM-CEP, CSCS⁴

Edited by

Michelle Barclay, MA¹, Terry R. Barclay, PhD^{1, 2, 3} and Jeanne Mettner⁶

Special thanks to

Jennifer Feeken, MLIS, medical librarian⁵
Brenna Swanson, graphic designer⁷

HealthPartners Center for Memory and Aging developed this guide with support from donations by grateful families.

¹ Barclay Group, LLC

² HealthPartners Center for Memory and Aging

³ HealthPartners Institute for Research and Education

⁴ Regions Hospital Rehabilitation Department

⁵ Regions Hospital

⁶ HealthPartners Clinical and Patient Education

⁷ bmohrcreative, LLC

Click on the HealthPartners logo mark in the footer of each page to jump back to this page.



“

I do not
worry about
yesterday or
tomorrow.
Instead,
I live in
the moment
of each and
every day.

”

Ken Lehmann

Foreword

You're probably reading this guide because you're worried about your memory or have a diagnosis of mild cognitive impairment (MCI), Alzheimer's disease or another form of dementia.

My name is Ken, and I have been in your shoes.

I was seen by seven clinicians before I received my diagnosis. None of them recognized any signs of Alzheimer's disease, focusing instead on depression. A geriatrician fleetingly mentioned the possibility of Alzheimer's and suggested I return in a year.

I learned about the HealthPartners Center for Memory and Aging (CMA) through the Alzheimer's Association. My clinicians at CMA immediately recognized the possibility of Alzheimer's disease. I went through a thorough evaluation which, in my case, included a brain MRI, lab work, and neuropsychological tests. Ultimately, a PET scan revealed I have all the biomarkers of Alzheimer's. I was devastated, in despair, even more depressed and in denial. I visualized myself in a box labeled "Alzheimer's" with a capital "A" on my forehead.

I quickly learned from my clinicians at CMA that there's life after a diagnosis of Alzheimer's.

I learned the importance of brain-healthy foods, regular exercise, socialization and learning something new. I learned the importance of having purpose in my life, as well as joy!

I met others living with Alzheimer's. Together, we share our hopes for living with purpose. We support one another, encourage one another, and have developed close friendships. I have become a speaker for the medical school at our local university, sharing my story about the importance of early detection. I am a mentor for first-year medical students and for people newly diagnosed with MCI or Alzheimer's, assuring them they are not alone.

My wife, Mary Margaret, and I have gone to Washington, D.C. to advocate for funding to support Alzheimer's research and care. We've met with our legislators at their state and federal offices to tell our story, to educate and advocate.

I am here to tell you that I am living my best with Alzheimer's. I focus on what I can do rather than what I cannot do. I have found many opportunities to feel viable, respected and purposeful. I am a participant in several research studies. I express myself creatively through woodworking classes at our senior center. Mary Margaret and I love to go for walks in the beautiful park across the street from our home. I exercise. I enjoy yoga. I maintain a garden on our deck. We have a wonderful, loving, supportive family. Life is good. I do not worry about yesterday or tomorrow. Instead, I live in the moment of each and every day. I hope you will too.



Ken Lehmann
Living with Alzheimer's disease

Introduction

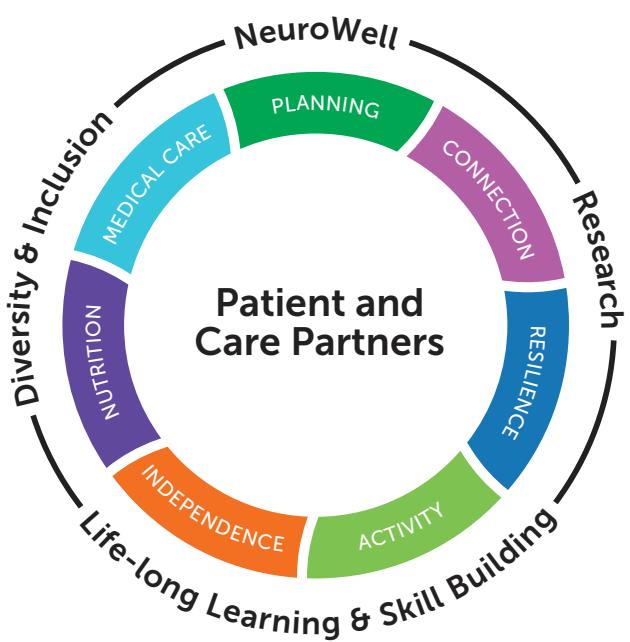
If you've been diagnosed with mild cognitive impairment (MCI), Alzheimer's disease, or another form of dementia, you may be wondering what's next. You may have questions such as, "What can I do to fight this disease?" or "How can I live my best with this diagnosis?"

For many, the first line of defense might be drug treatment. You may already be taking one of the FDA-approved medications for Alzheimer's disease or a related dementia. However, as with most chronic illnesses, drugs are just one part of the big picture. Researchers are also studying how lifestyle changes can reduce the impact of symptoms and improve daily life.

What is NeuroWell?

NeuroWell is a well-being based approach to treatment after a diagnosis of MCI, Alzheimer's disease or another form of dementia and contains seven key components that research suggests are critical to brain health and living your best after a diagnosis.

At the core of the NeuroWell model of care is you and your care partners, surrounded by the seven key components critical to health and well-being, and our ongoing commitment to diversity and inclusion, research, and life-long learning and skill building.



The seven key components critical to brain health and living your best after a diagnosis are:

- Planning
- Connection
- Resilience
- Activity
- Independence
- Nutrition
- Medical care

This guide presents brain health strategies and the evidence supporting them.

While all of these approaches may offer potential benefits, there's currently no therapy or drug that will cure or stop disease progression. However, the lifestyle changes presented here aim to improve overall health and well-being, and are likely to be helpful to anyone who is aging – including friends and family members.

Each chapter highlights a key NeuroWell component, its benefits, perspectives of people living with MCI or dementia, strategies to try, and a place for you to build your own well-being plan.

You may already be doing many activities known to promote brain health.

Take some time to note and feel good about those things as you discover them in this guide. As you read each chapter, you will likely find many new ideas for living your best. Keep in mind you don't have to try them all at once. Start with what is easiest or most interesting to you. You may want to revisit this guide from time to time to celebrate what you've accomplished and to continue trying new strategies.

Congratulations on taking the first step toward living your best life with MCI or dementia.



The interactive version of this guide is available for download.

*Scan this QR code with your phone camera
to view or download a PDF of this guide with
interactive worksheets, checklists and more.*

“ To help our patients maximize their quality of life, we have to think well beyond the traditional medical model. We need to treat the whole person, not just the disease. And we need to treat the whole family, not just the patient. We need proactive care focused on wellness. **”**

Terry Barclay, PhD
Clinical Director, HealthPartners Neuropsychology

Planning and goal setting

Planning and goal setting

After a diagnosis, proactive planning is a critical step toward ensuring overall health and well-being.

A plan for living

Many people with MCI, Alzheimer's disease or other forms of dementia say that living well with the diagnosis means living as freely and independently as possible. Remaining safely at home, connected with friends and loved ones, and participating in activities that bring happiness to life are common goals. In many cases, these goals are achievable with the right education, planning, supports and help from family and friends.

Making a plan early on for how you want to live with your diagnosis can be empowering. It allows you to take care of business now, then let go and focus on truly living and enjoying your life.

Building your team

After a diagnosis, it may be tempting to go home, close the curtains and isolate yourself from friends, family and your community. Often, time alone is needed to grieve the diagnosis. While this time away from the world may be helpful in the short-term, social isolation can have negative consequences in the long-run, increasing risk for depression, greater disability, care partner burnout and early nursing home placement.

It takes a village

Living your best with MCI or dementia takes a village. It's definitely a team sport, more like playing baseball or football than golfing. People who try to do it alone are much less likely to be able to stay at home or remain independent for as long as those who create a wider network of support. You can't win a football game with just a quarterback and a receiver. In fact, it takes 11 players on the field to be successful. The same is true for MCI and dementia. You can't live your best life and achieve your goals by relying only upon yourself or one care partner. You need to build a team. (See page 12 of this guide to list your own 11 players that will make up your support team.)

“
Not everything that is faced can be changed; but nothing can be changed that is not faced.

”

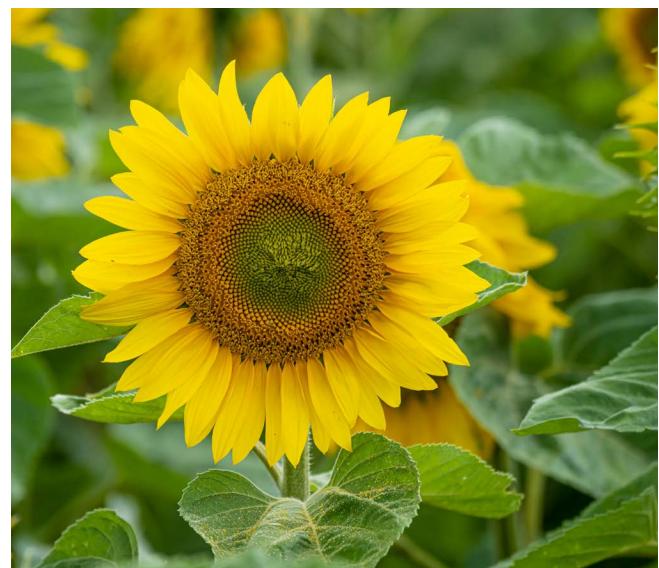
James Baldwin

Telling others about your diagnosis

One of the most important steps in building your team is informing others about your diagnosis. You may be nervous about sharing this information because you're unsure how others might react. Perhaps you're worried people will treat you differently or maybe even stop spending time with you. While everybody copes with this news in their own way, most people with MCI and dementia say telling others is a big relief. It's an opportunity to be open and honest, gives others a chance to ask questions and offer support, and can even lead to closer relationships. Although it might sound stressful to talk about your diagnosis, you'll likely be surprised and touched by the outpouring of love and support you receive after telling your story.

Tips for telling others

- Start by telling people you know well and trust the most, then expand from there.
- Schedule some alone time to have the conversation, or write a heartfelt letter.
- Let those close to you know how important they are in your life.
- Explain the diagnosis and what symptoms they may notice.
- Let people know how they can support you now and in the future.
- Remind others you're still the same person, but may need a bit of extra time or support.
- Talk openly about your hopes for the relationship. For example, "I hope that we'll continue to go golfing together. That's really important to me."
- Invite questions.
- Thank people for their friendship and support and invite them to join your team.
- Take the initiative and reach out again to those with whom you've shared the news, as they may be unsure how or when to talk with you next.



Hidden Disabilities program

Hidden Disabilities is a program that lets others know you have a hidden disability that may not be obvious from the outside. Wearing the Hidden Disabilities sunflower discreetly lets others know you may need extra support, help or more time. Since the program started in 2016, it has been adopted by many airports, including the Minneapolis St. Paul Airport (MSP), rail stations, police and first responder groups, supermarkets and other businesses.

Find out more or order sunflower products at hiddendisabilitiesstore.com.

Connect to resources

Although there are many resources and services that can support you on the road ahead, it's often a challenge to figure out what's available, when you need it, and where to find it. There may be many products or services that could help you stay independent and live your best that you don't even know you need!

It helps to have someone on your team with experience connecting families to resources and supports. This type of expert has many titles, such as a geriatric care manager, care coordinator, social worker or counselor. Ask your clinician for a referral for a consultation with a dementia expert. Or, contact the Alzheimer's Association (**800-272-3900**) and ask to meet with a care consultant.

Care consultation is a service that can help you and your care partners develop a road map for the future and connect you to resources and services that can support you as your needs change.

Get educated

Many people say they heard very little of what their clinician said after they heard the words "Alzheimer's disease" or "dementia." Receiving such a diagnosis can be emotional and even shocking. As a result, it can be a challenge to take in any information, learn about the disease or ask questions during the visit. However, knowledge is power. Learning as much as you can about your diagnosis can help you and your family better understand what's going on, what to expect in the future, how to manage your symptoms, what questions to ask your clinician, and how to get the best care possible.

There are many sources of information, but you may want to start with these nonprofit organizations:

Alzheimer's Association
(MCI and all types of dementia,
not just Alzheimer's)
alz.org

Lewy Body Dementia Association
lbda.org

The Association for
Frontotemporal Degeneration
theaftd.org

ACTIVITY PAGE

Who can I invite to be part of my team?

You may start by inviting close family members and friends to join your team. As you expand, it may help to think creatively and include neighbors, health care and community service providers, friends, family, volunteers or members of your faith community. Choose people who are helpful, kind and supportive.

My care team		
Name		Contact information (phone or email)
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		
11.		

You may also want to make a list of ways that your team can best support you. This may be simple tasks at first, such as picking you up and having lunch together once a week, or dropping off a few things from the grocery store. Try to be as specific as you can so others know what would be most helpful. Instead of saying, "Thank you, but we're fine right now," try saying, "Thank you. Your support and friendship mean so much to me/us. I could really use a walking partner. Would you be willing to walk in the neighborhood with me once a week this summer? What do you think?"

Most people will want to support you, but probably don't know what would be helpful or how to talk with you about it. Letting others know how important they are and giving them a way to stay close to you is a gift, so give generously!

Ways my team can support me (or my partner)

This might include things you'd like to do with others or things that would make life a little easier for you or your partner. Consider who on your team might support you for each task. Keep in mind that your list will likely change over time.

	Activity	Who?
Example	Help me build my plan	Our social worker, Jennifer
	Walk with me once a week	Yvonne (my sister)
My list		
1.		
2.		
3.		
4.		
5.		
6.		
7.		
8.		
9.		
10.		

“ A goal without a plan is just a wish. **”**

Unknown



Work life and retirement

If you're still working, it's important to know the benefits available to you through your employer and to access those benefits before any decision to leave your job. You may be eligible for many workplace protections and benefits. These options are often complex and can be confusing. You may want to ask an attorney to help you make the best decisions for you and your family.



The Americans with Disabilities Act (ADA)

Alzheimer's and other diseases that cause dementia are covered under the ADA, which prohibits discrimination based on disability, and requires employers to offer reasonable accommodations to employees with disabilities. If your symptoms are affecting your work performance, you can ask your employer to meet with you to discuss what work changes or supports can be put in place so that you can keep working.



Disability insurance

If your symptoms are affecting your work and you already have disability insurance, you may be eligible for short- or long-term disability benefits.



Family and Medical Leave Act (FMLA)

FMLA allows employees working in companies with more than 50 employees to take up to 12 weeks of unpaid leave each year for family and medical reasons – without losing other company benefits, like health insurance. Check with your employer to see if you qualify for this benefit and if there are any return-to-work requirements.



Younger onset dementia

If you're younger than 65 and have a diagnosis of Alzheimer's disease or another form of dementia, you may qualify for Social Security Disability Insurance (SSDI) and/or Supplemental Security Income (SSI) benefits. SSDI pays benefits to people with disabilities who have worked long enough and paid social security taxes. SSI pays benefits to people with disabilities who have financial need.

It's important to apply for SSDI as soon as possible after you stop working because you have to receive SSDI benefits for at least 24 months (two years) to be eligible for Medicare benefits before you turn 65. Consider working with an attorney who specializes in SSDI applications.

Your diagnosis may also allow you to access financial resources from retirement plans, like IRAs, pensions or annuities, before you reach retirement age.

ACTIVITY PAGE

Take care of business

There are many things you can do to make sure that you and those closest to you are prepared for the future. The following tasks may seem overwhelming at first, but putting plans in place now can ease the burden for years to come.

Legal and financial planning

Power of attorney

A power of attorney is a document that allows you to name someone you trust to make financial or health care decisions for you if/when you're unable to do so. You keep the ability to make your own decisions for as long as you maintain legal capacity.

Wills

You may already have a standard will or a living trust. If so, now is a good time to review it and make any changes you'd like. If you don't have a will, now is a good time to create one.

Legal and financial advice

An elder law attorney specializes in legal, financial and other issues that affect seniors. Many have experience helping clients with MCI or dementia and their families complete important documents.

Health care planning

Medical release of information

A medical release of information form gives your clinician permission to share information about your care with friends or family members of your choosing. This can help keep everyone informed and on the same page. Ask your clinician if a medical release of information form is needed.

Advance directives

An advance directive is a written tool to guide health care decisions when a person is unable to do so because of a medical condition.

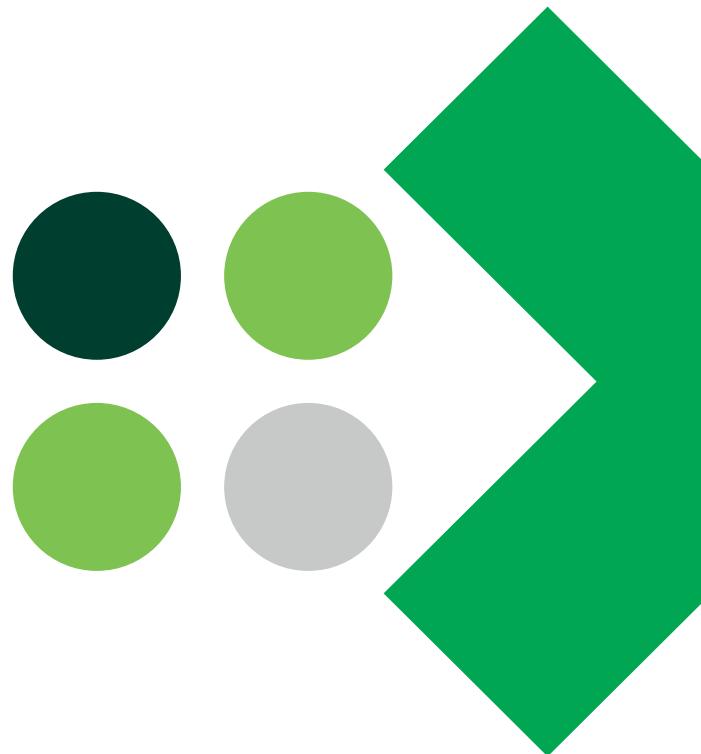
Visit healthpartners.com/acp for more information and to download a blank advance directive form. The final step is to share your advance directive with your clinician and those closest to you.

Making decisions: Ask yourself the following question.

Who do I trust to help me make decisions or to honor my wishes when I am not able to make my own decisions?

Legal and financial decisions:

Health care decisions:



Benefits of planning and goal setting

- Gives you more control over your life now and in the future
- Improves your quality of life
- Helps you get better care
- Gives you access to more resources and services
- Reduces stress and the likelihood of a crisis
- Keeps you out of the emergency room or hospital for mishaps
- Improves your communication and relationships with family and friends
- Helps your care partners feel less depressed or burdened

“If you take the 'I' out of illness, and add 'we', you end up with wellness. **”**

Charles Roppel



Things I can do now:

Check the boxes next to each item you'll try.

-
- Seek out opportunities to learn more about my diagnosis** and the resources available to me (for example, Alzheimer's Association or similar organization's community presentations or conferences).
 - Talk to my friends and family** about my diagnosis.
 - Make a list of everyone on my team.** Include neighbors, members of my faith community, clinicians, friends, family, community volunteers and others.
 - Make a list of specific things others can do to support me or my care partners.**
 - Choose two people I trust** to help me make financial and health care decisions.
 - Meet with an elder law attorney** for legal and financial plans, estate planning and health care directives. Write a list of questions to ask in advance and bring a friend or family member to the appointment.
 - Ask my clinician about free or low-cost opportunities to meet with a social worker or care navigator**, or make an appointment with a care consultant at the Alzheimer's Association or a similar organization to help me develop a plan and access resources.
-



My accomplishments

List the things you already do or have done to make progress in this area.

1.

2.

3.

4.



My action plan

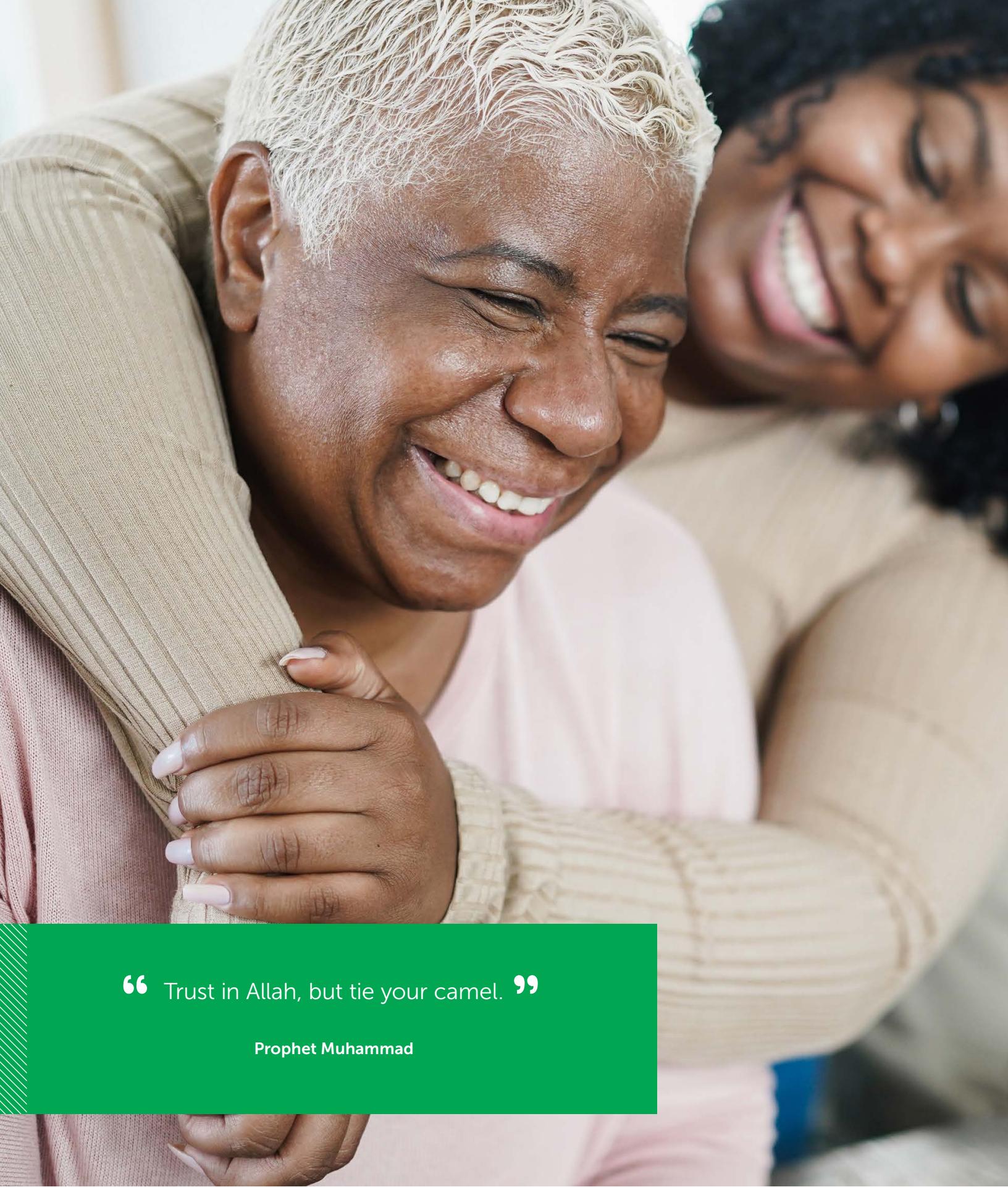
List one to four new things you will do to make progress in this area.

1.

2.

3.

4.



“ Trust in Allah, but tie your camel. **”**

Prophet Muhammad



Voices of experience

"Being proactive allows you to take control of your life, which is a win-win situation. In gaining control, you're in a position to not only improve the quality of your life, but also to live a purposeful life."

Brenda

Living with Alzheimer's disease

"I want to learn more about Alzheimer's. It helps to remove the fear and denial. I want to learn how to stay healthy longer."

Carl

Living with Alzheimer's disease

"For the first six months at least after my diagnosis, I kind of hid under a rock. When you first get a diagnosis like this, right away you think end stage. You don't realize that this is a slow progress – that nobody knows how long it's going to take. Eventually, I realized that I still have a life to live. I still have a voice. I can still enjoy doing the things I like doing, and I can even continue to learn some things."

Mike

Living with Lewy body dementia

"I can't do finances; my husband is my power of attorney, and I have an accountant."

Imani

Living with frontotemporal dementia (FTD)

Connection, purpose and joy

Connection, purpose and joy

We all strive to find connection, purpose and joy in our lives. We know that to be truly well, all people need to feel accepted, useful, needed and engaged in life.

Connection

Did you know that warm, trusted relationships are a vital component of overall health? Strong connections to others provide a sense of security and meaning. Strong family ties, good friendships and involvement in social activities also stimulate the brain, increase self-esteem and provide a buffer against stress, depression and anxiety – all vital to brain health.

Sometimes it can be difficult to stay socially active and connected to those around us. There may be times when you feel frustrated by the changes in memory or thinking you're experiencing. A natural reaction might be to feel embarrassed, to avoid social gatherings or to withdraw from people or activities you used to enjoy. For many people, finding the energy to be social can also be a challenge because symptoms may include a decline in motivation.

The health risks of being alone or isolated are comparable in size to the risks associated with cigarette smoking, high blood pressure and obesity. However, studies have shown that people with the most social interactions experience the slowest rate of memory decline.

Living your best with MCI or dementia means keeping your existing relationships strong and pushing yourself to stay as socially connected, engaged and active as possible.

Benefits of connection

- Increases mental activity
- Promotes a longer, healthier life
- Lowers blood pressure and your body's reaction to stress
- Improves the immune system's ability to fight infection and disease



Did you know?

People aren't the only source of loving relationships. Studies show our relationships with animals are just as good for us. Just like our human friends, animals help us feel loved, useful and needed. You may be surprised at just how many ways a pet can improve your health.



Ways to build connections

Things I can do now: Check the boxes next to each item you'll try.

-
- Schedule a regular lunch date** with a friend.
 - Go to religious services early** or stay late to socialize.
 - Get a pet** or spend quality time with an animal, such as a dog, cat or horse.
 - Find other people who share my hobbies.**
 - Plan a regular walk** with a friend or neighbor.
 - Make plans to visit my children, grandchildren or other relatives.**
 - Join a new group** or social club. Try [meetup.com](https://www.meetup.com) for ideas.
 - Call up old friends.**
 - Connect with others who** have MCI or dementia.
-



“

We can bring positive energy
into our daily lives by
smiling more, talking to
strangers in line, replacing
handshakes with hugs,
and calling our friends just
to tell them we love them.

”

Brandon Jenner

“

Anything is possible
when you have the
right people there
to support you.

”

Unknown

Purpose

Finding purpose is a unique and life-long journey. If you take a moment to reflect, you will probably find that your priorities and sense of purpose have evolved over the years. This is because different stages of life pose new questions and challenges as well as new answers and opportunities.

Transitions, such as advancing age, retirement or a diagnosis of MCI, Alzheimer's disease or other form of dementia can prompt physical, mental, emotional and spiritual chaos as you reorganize your life around new and changing circumstances. However, these same challenges also provide an opportunity to rethink priorities, focus on what's most important and even find new passions in life.

Finding your purpose

Why do you get up in the morning? What things motivate you or give you energy? What activities help you feel needed, happy, peaceful or connected to others?

Dick Leider, author of "The Power of Purpose," asked adults 65 and older, "If you could live your life over again, what would you do differently?" The answers consistently included these three themes:

1. Be more reflective
2. Be more courageous
3. Find purpose sooner

Research supports the power of purpose to improve our lives. For people living with MCI or dementia, studies show that having higher levels of purpose and meaning in life is associated with better memory, fewer limitations on daily activities, lower risk of stroke, better sleep, higher self-ratings of health and greater happiness.

“

The great and glorious masterpiece of humanity is to know how to live with a purpose.

”

Montaigne

Benefits of finding purpose

- Gives you a reason to get up in the morning and a sense of achievement
- Makes life more interesting, valuable and rewarding
- Improves your self-confidence and self-esteem
- Offers the opportunity to make the world a better place
- Prevents boredom, loneliness and inactivity
- Slows the rate of mental decline and reduces your risk of stroke
- Improves your brain function
- Helps you focus on something positive and productive
- Leads to a happier, healthier and more satisfying life

Take some time to reflect on what gives you meaning and what things you could do differently to find more purpose in life. There are many ways to add more meaning and purpose to your daily life. The key is to seek out activities that help you feel useful, needed and engaged.

What things am I good at? What are my strengths and talents?

What interests have I let go that I could start again? What new interests could I explore?

What things am I passionate about?

What do the people in my family, neighborhood or community need? How could I help?

What activities make me feel good, bring meaning to my life or help me to feel at peace?

What have I always wanted to do but never tried?



Ways to increase purpose in life

Things I can do now: Check the boxes next to each item you'll try.

- Identify, seek out and engage in activities** that bring meaning to my life or help me experience peace.
- Actively set goals.** Start each day by making a list of the two to three things I would like to do.
- Donate time, money or talents** to a charity or nonprofit organization.
- Find a meaningful volunteer opportunity** that fits my schedule (volunteermatch.com).
- Become an advocate** for a cause I believe in, such as the Alzheimer's Association (alz.org), Lewy Body Dementia Association (lbda.org), or the Association for Frontotemporal Degeneration (theaftd.org).
- Help to find a cure** or better treatments for MCI, Alzheimer's or other dementia by participating in research (alz.org/trialmatch).
- Take more time for spiritual activities**, such as prayer or meditation.
- Write a memoir** or jot down pieces of my life story.
- Research my family history** (ancestry.com).

Joy

It's hard to imagine living a purposeful and meaningful life without joy. Luckily, changes in memory and thinking don't impact your ability to feel happiness and joy. Now is a critical time to discover new ways to notice, cultivate and spend more time on the "sunny side of life."



A Cherokee parable: "The Story of Two Wolves"

One evening, a Cherokee elder told his grandson about a battle that goes on inside people.

He said, "My son, the battle is between two 'wolves' inside each of us. One is evil. It's anger, envy, jealousy, sorrow, regret, greed, arrogance, self-pity, guilt, resentment, inferiority, lies, false pride, superiority and ego.

The other is good. It's joy, peace, love, hope, serenity, humility, kindness, benevolence, empathy, generosity, truth, compassion and faith."

The grandson thought about it for a minute and then asked his grandfather, "Which wolf will win?"

The elder Cherokee replied simply, "The one you feed."

This story is an important reminder of the power we have over our experiences and emotions. In each moment you have the power to make the life-changing decision of which wolf you want to feed. There are many ways to find joy and nourish the "good wolf" inside you. Here are a few that experts recommend.

Benefits of cultivating joy

- Joy!
- Gives you a greater sense of peace and well-being.
- Boosts your immune system.
- It's contagious. Your joy helps others to feel happier.

Practice gratitude

One of the best ways to find joy is to find gratitude. Noticing and savoring the good things in your life, no matter how small, can have a powerful and positive impact on your daily life.

Practice random acts of kindness

Doing nice things for others has been scientifically proven to increase happiness. Even just sending wishes of happiness to someone, imagining them smiling and happy, can bring you a "jolt of joy."

Experience beauty and wonder

Taking time to notice the beauty and wonder of our world can bring a sense of peace and connection to life. Studies show that spending time in nature not only increases our happiness, it makes us feel better physically too. Experiencing the arts has also been shown to enhance well-being.

Listen and dance to your favorite music

There's no faster way to tap into joy than to listen to a happy song and move your body to the beat. Music is scientifically proven to increase happiness and well-being. It also stimulates the brain and can act as a memory aid.



ACTIVITY PAGE

Take some time now to reflect on what brings joy to your life.

What are a few things that bring a big smile to my face?

What am I most grateful for?

Where am I when I imagine myself most at peace? Who am I with?

When I am frustrated or in a bad mood, what or who lifts my spirits or helps me relax?

How do I play? What do I do for fun, to be silly? What makes me laugh?

What simple things in life do I most enjoy?



“

Gratitude ... turns what we have into enough, and more. It turns denial into acceptance, chaos to order, confusion to clarity. It can turn a meal into a feast, a house into a home, a stranger into a friend.

”

Melody Beattie

“

Joy does not simply happen to us. We have to choose joy and keep choosing it every day.

”

Henri J.M. Nouwen



Ways to increase joy in life

Things I can do now: Check the boxes next to each item you'll try.

- Savor my first cup of coffee or tea in the morning,** taking in the warm, tasty goodness.
- Keep a daily gratitude journal.**
- Practice my favorite hobby** or start a new one, such as gardening, quilting, woodworking, painting, playing a musical instrument or dancing.
- Stop and notice the beauty** in my surroundings.
- Visit a museum.** Take a guided tour.
- Eat lunch outside.** Sit under a canopy of trees.
- Add plants or pictures of nature** scenes to my home.
- Try natural aromatherapy.** For example, lavender or peppermint oil.
- Listen to a song that makes me happy** – turn it up and dance!
- Join a choir** or sing in the shower.
- Post kind messages to friends on social media.**
- Watch cute or funny animal videos.**



My accomplishments

List the things you already do or have done to make progress in this area.

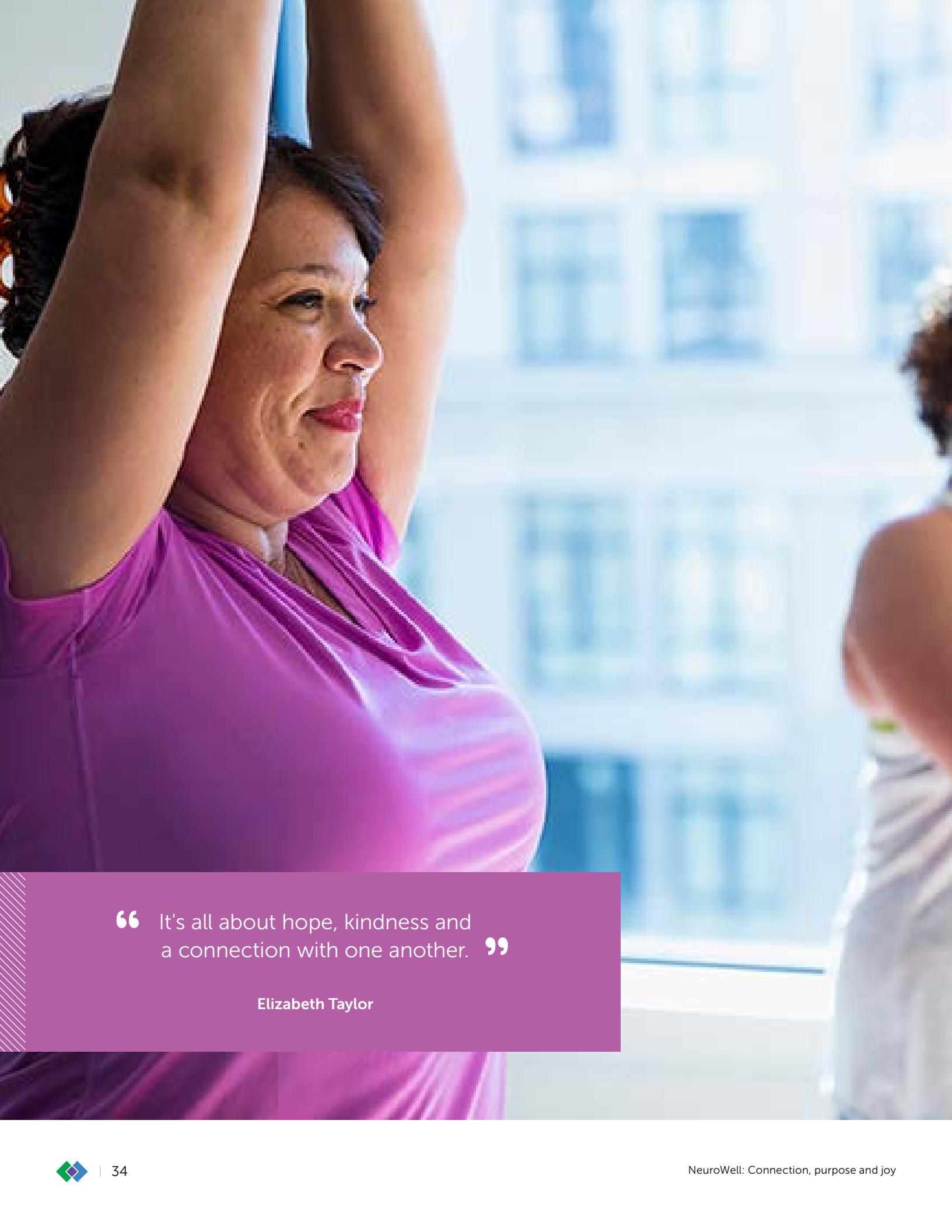
1.	
2.	
3.	
4.	



My action plan

List one to four new things you will do to make progress in this area.

1.	
2.	
3.	
4.	



“ It's all about hope, kindness and a connection with one another. **”**

Elizabeth Taylor



Voices of experience

"It's wonderful knowing my friends are around me and that they can help me."

Jerilynn

Living with Alzheimer's disease

"Muffin doesn't care what kind of mood I'm in – she doesn't care if I remember her name. All she cares about is being my friend."

Jan

Living with Alzheimer's disease

"I work on new friendships and relationships with people who know me for who I am now with dementia. I find these friends offer me the greatest support and spiritual sustenance."

Mike

Living with vascular dementia

"It has really helped to have people to talk to. There are a lot of losses, and many struggles, like giving up driving, but the love that's coming back to me gives me strength."

KEN

Living with Alzheimer's disease

Resilience and emotional well-being

Resilience and emotional well-being

Living with MCI or dementia is usually unanticipated and can be unpredictable, frustrating and stressful at times. Resilience is the ability to recover quickly from life's challenges.

You have probably experienced many different emotions since receiving a diagnosis of MCI, Alzheimer's or other form of dementia. Maybe part of you is relieved to finally have a name and an explanation for your symptoms. However, if you're like most people, the news can also bring sadness, grief, anger and fear. Memory loss, difficulty finding words, trouble focusing, and other thinking challenges may trigger anxiety and stress or cause you to want to withdraw from normal activities, friends and loved ones.

The most important thing to know is that all of these feelings are completely normal and very common reactions to what you're going through. Over the long term, however, chronic depression, anxiety, or apathy can be damaging to your health, thinking abilities, relationships and your quality of life. Your care partners may also have some of the same emotional reactions to the diagnosis.

“

You can't stop
the waves, but you
can learn to surf.

”

Jon Kabat-Zinn

Did you know?

- Depression can accelerate cell death, shrinkage and dysfunction of the memory organs in the brain, called the hippocampi.
- Reducing the occurrence of depression, anxiety and stress can reduce risk of dementia and delay progression to Alzheimer's disease.
- Mood problems make it significantly more difficult to think clearly, concentrate, remember things, and complete everyday tasks successfully.
- Chronic stress and depression can cause insomnia, weight changes, frailty and many other serious health problems.
- Individuals who don't treat their depression, anxiety or behavioral symptoms are at increased risk for earlier placement into nursing homes.

Warning signs

While many of us accept the fact that it's OK to have physical or medical problems, we're often more reluctant to admit when we're struggling with fear, anxiety, sadness, loneliness or other difficult emotions. However, paying close attention to your feelings and, when necessary, taking action to improve your emotions, are two of the most important ways you can stay healthy.

Keep an eye out for these common mood symptoms:

- Angry outbursts or lashing out at others
- Changes in appetite
- Chronic anxiety, worry or fear
- Feeling hopeless or worthless
- Frequent mood swings
- Increased use or abuse of alcohol, tobacco or other drugs
- Irritability
- Loss of interest or pleasure in normal activities
- Neglecting personal responsibilities or self-care
- Persistent sadness or despair
- Sleep problems or significant loss of energy
- Tearfulness
- Thoughts of death or suicide

It's important to talk with your clinician if you have any of these symptoms, especially if they last two weeks or more. There are many options for treating mood problems, including medication and non-medication strategies. Seek medical attention right away if you find yourself thinking about death or making a suicide plan.

Coping and resilience

Resilience is the process of adapting well in the face of adversity, trauma, tragedy, threats or other significant sources of stress, such as a diagnosis of MCI, Alzheimer's disease or a related dementia. Resilience isn't only the ability to recover or "bounce back" quickly from life's challenges; it can also lead to deep personal growth.

While receiving a diagnosis is certainly painful and difficult, it doesn't have to define who you are. There are many aspects of your life that you can control or modify. This is the role of resilience – developing the skills that can get you through difficult and uncertain times and empower you to grow and even improve your sense of well-being along the way. Here are a few ways you can begin to build resilience.

Reduce stress

Stress is a normal part of life. Contrary to popular belief, stress comes from things that you enjoy, as well as from things that are worrisome or threatening.

In the short term, stress can be mentally stimulating, push you to act and grow and provide motivation to get things done. On the other hand, long-term stress can damage your health and have a negative impact on your mood and your relationships.

Identifying sources of stress

Sometimes it's easy to be so absorbed in day-to-day life that we don't stop to notice how much stress and tension we're carrying around with us. To lower the consequences of chronic stress, the first thing to do is to become more aware of what is stressful to you.

To help identify sources of stress and manage stress in your life, ask yourself the following questions.

What are the one or two things in my life right now that are causing me the most anxiety or stress?

How does this stress affect me? What are my stress symptoms or actions? Do I become irritable, argue with others, develop tense shoulders, get headaches or think negative thoughts?

My stress symptoms:

Are my coping techniques helpful or destructive? Am I using healthy strategies, such as exercise, social activities or frequent breaks to control stress? Or, am I overeating, watching too much TV, drinking too much or neglecting things that are important to me?

Ways I cope with stress:

What things can I do now to lower the long-term effects of stress on my body and my brain? Can I work to resolve conflict with others, be better prepared for stressful situations, let go of unrealistic expectations or set aside more time to relax?

One thing I can do now to lower stress:

Research suggests that how you respond to stress matters. It takes practice, but you can change how you react to stress.



“

A calm mind brings inner strength and self-confidence, so that's very important for good health.

”

Dalai Lama

Increase positive emotions

For most people, maintaining or improving emotional health involves a variety of strategies, such as reducing stress, spending time with friends, or being kind to others. Cultivating positive emotions and happiness can take practice. The important thing is to keep at it until you find the activities that work best for you. See the Connection, purpose and joy chapter on page 22 for tips.

Try counseling and support groups

Why cope with stress alone or try to resolve difficult circumstances by yourself when there's so much to learn from talking with others about what challenges you? Trained therapists and counselors teach people how to avoid negative thinking, adjust to a new diagnosis or other life change, improve challenging relationships, heal emotional wounds and live a happier life.

Support groups also present a unique opportunity to meet people who are experiencing similar symptoms or going through the same changes in life and learn from their experiences. At the same time, you get the chance to share your story and any tips and tricks you have found to be beneficial. Many people with MCI and dementia describe counseling and support groups as a real "game changer" on the path to improved emotional well-being and resilience.

Practice yoga, tai chi and qi gong

These three, ancient mind-body well-being practices connect movement and breath and allow you to reach a state of deep focus and relaxation. Movements in these practices also improve balance, stretch and strengthen muscles, and improve flexibility of the body and mind. They are all healthy stress-reduction and resilience-building tools.

“ Worrying is like a rocking chair; it gives you something to do but doesn't get you anywhere. ”

English proverb

Practice mindfulness

Making memories requires us to pay attention. If we're not paying attention to what we'd like to remember, we can't form new memories. Mindfulness is a skill that involves training your brain to pay attention to the present moment with kindhearted awareness, acceptance, openness and curiosity. It typically involves focusing all your attention on a single sensation, like the feeling of your breath moving in and out of your body.

Research has shown that mindfulness meditation leads to better physical health and a greater sense of contentment and well-being. Mindfulness is exercise for your brain. Just like physical exercise, studies show that mindfulness practice improves attention and memory, lowers blood pressure and improves sleep quality. As an added bonus, mindfulness also increases coping skills and builds resilience.

How to get started

1. Find a comfortable position where you can be relaxed, but awake and alert.
2. Soften or close your eyes.
3. Begin to focus on the feeling of your breath moving in and out of your body.
4. When your attention wanders, notice with curiosity the thoughts, sensations or emotions that carried your attention away from your breath. Then with great kindness and a smile, gently invite your attention back to your breath. Begin again.
5. Repeat.

This is the practice. It's simple but absolutely challenging!

Mindfulness tools to help you get started

Video

Meditation 101: A Beginner's Guide (2 minutes)

youtu.be/o-kMJBWk9EO

Apps

Guided meditations can be found at the app store or at these websites:

The Mindfulness App: themindfulnessapp.com

Headspace: headspace.com

Insight Timer: insighttimer.com



Benefits of emotional well-being and resilience

- Strengthens your immune system
- Lowers your blood pressure
- Allows you to have more satisfying relationships
- Gives you stronger coping skills and more resilience
- Helps you sleep better
- Gives you more energy to do the things you want to do
- Improves your attention, concentration and memory

“For there is always light, if only we're brave enough to see it. If only we're brave enough to be it. **”**

Amanda Gorman

Things I can do now: Check the boxes next to each item you'll try.

-
- Give myself credit.** Remind myself about my talents, strengths, things I do well, and what people like about me.
 - Let go of unrealistic expectations.** Allow myself to accept my limitations and say "yes" when help is offered.
 - Slow down.** What's the rush?
 - Express myself.** Be open about my feelings – what I want and don't want.
 - Forgive myself and others.** Anger and resentment are toxic emotions that damage long-term health and well-being. Try my best to set grudges and anger aside as quickly as possible.
 - Offer myself kindness and comfort** when challenges arise. Take care of myself as I would a friend who is having a hard time.
 - Have fun.** Laugh as often as possible. Make more time for enjoyable activities in my weekly schedule.
 - Get outside.** A breath of fresh air or a nature walk can bring peace and relaxation.
 - Exercise.** Physical activity releases endorphins, relieves stress and improves mood.
 - Breathe.** Take five-minute breaks during the day to take a few deep breaths.
 - Practice mindfulness.** Take a mindfulness class, listen to a guided meditation online, or download a mindfulness meditation app.
 - Try yoga, tai chi or qi gong.** Take part in regular classes online or at my local gym or community center.
 - Talk to a counselor or join a support group.** Learn from others how to increase my resilience.
 - Schedule my time carefully.** Leave early and schedule extra time between activities to minimize stress.
-



My accomplishments

List the things you already do or have done to make progress in this area.

1.	
2.	
3.	
4.	



My action plan

List one to four new things you will do to make progress in this area.

1.	
2.	
3.	
4.	



“
Blessed are the flexible, for they are
least likely to get bent out of shape.”

Robert Ludlum



Voices of experience

"The best piece of advice I got from my clinician was to reduce as much stress from my life as possible, and we did that."

Mike

Living with Lewy body dementia

"Since my husband has started daily yoga practice and tai chi three times a week, he's gotten toned and buff – in addition to other benefits. Suddenly at age 67, he's this super-hot guy."

Marnita

Care partner for her husband living with Lewy body dementia

"Stop! Sit or lie comfortably, quiet your mind and focus on something positive."

Julie

Living with Alzheimer's disease

"I think I've got it! It's yoga that has changed my life and impacted my stress level."

Earl

Living with Alzheimer's disease

Activity

Activity

Staying physically and mentally active is vital for maintaining brain health.

You have probably heard the saying "use it or lose it." It turns out that when it comes to keeping your brain and body as healthy as possible, research shows this is indeed true.

Physical activity

Staying physically active is one of the most important things you can do to stay healthy and reduce your risk of health problems, such as type 2 diabetes, high blood pressure, stroke, certain types of cancer, obesity, osteoporosis, falls, anxiety, depression and cardiovascular disease. Physical inactivity is estimated to be the fourth highest risk factor for death, leading to 3.2 million deaths worldwide and the now popular saying, "Sitting is the new smoking."

However, there's good evidence to suggest that people can greatly improve their aerobic fitness, strength, flexibility and balance through exercise well into their 90s. Studies have shown that aerobic exercise can improve the cardiovascular fitness of older adults by 11% to 27%, canceling out the normal loss in fitness we all experience as we get older.

Get your body moving

Exercise is a type of physical activity that's planned, structured and aimed at improving health and fitness. Experts believe exercise can stimulate your body to release neurotrophins, or growth factors for brain cells, which may play a role in how the brain functions and stays healthy. Certain types of neurotrophins are reduced in the brains of people with MCI and dementia. After a diagnosis, staying physically active helps prevent health issues and supports a healthy brain.

There are many different kinds of physical exercise: aerobic, resistance, flexibility and balance. Research suggests all of these types of exercises are helpful and should be included in your weekly routine.

Types of physical activity

- Dancing
- Doing household chores
- Shopping
- Walking and strolling
- Weeding and gardening

“

A man's health
can be judged by
which he takes two
at a time – pills or stairs.

”

John Welsh

Aerobic exercise

Much of the evidence that explores brain health and physical exercise focuses on aerobic activity. Aerobic exercise is aimed at improving the ability of the heart, lungs and blood vessels to deliver blood and oxygen to the body, including your brain. Aerobic exercise has been shown to reduce inflammation, protect brain cells and improve memory and thinking.

Examples of aerobic exercises:

- Aerobic and cardio exercise classes
- Brisk walking
- Cycling
- Gardening activities (such as raking, pushing a lawnmower)
- Jogging
- Moderate to vigorous use of exercise machines (such as treadmill, elliptical, rowing, stair-stepper)
- Shoveling snow
- Swimming and water aerobics
- Zumba, hip hop, Jazzercise and other dance classes

Tip

Experts recommend aerobic exercises that raise your heart rate and make it a little bit harder to breathe for at least:

- 20 to 30 minutes at a time
 - Three to five days a week
 - A total of 150 minutes per week
-

Resistance exercises

Resistance exercises are aimed at increasing the strength of your muscles, improving performance of daily physical activities and reducing your risk of falling. Additionally, there's some research linking resistance exercise to improved ability to think.

Examples of resistance exercises:

- Carrying groceries
- Circuit training
- Lifting milk jugs or cans of food
- Lifting weights at the gym
- Push-ups
- Pilates
- Resistance band exercises
- Tai chi and some types of yoga
- Walking up stairs

Tip

Experts recommend performing resistance exercises two to three times per week or more.



Flexibility

Flexibility exercises help increase range of motion, improve physical movement and reduce your risk of injury.

Examples of flexibility exercises:

- Pilates
- Stretching
- Yoga, tai chi and qi gong

Tip

Experts recommend flexibility exercises at least two to three days per week.

Balance

Balance exercises have been shown to reduce risk of falls and fear of falling by improving coordination and balance.

Examples of balance exercises:

- Bosu ball activities
- Marching in place
- Standing on one leg with or without eyes closed
(Always begin with a hand or finger on a chair for support.)
- Yoga, tai chi and qi gong
- Walking on uneven surfaces like sand, grass and trails

Tip

Experts recommend balance exercises at least two to three days per week.

Exercise tips

- **Warm-up and cool down** for five minutes before and after exercising.
- **Bring a water bottle.** It's important to stay well hydrated when exercising.
- **Consult with your clinician** prior to starting a new exercise program.
- **Work with an exercise specialist** to help you create the right exercise plan for you.
- **Start with a lower amount of activity** and increase slowly over time.
- **Choose physical activities you enjoy,** and have fun!

If you have been inactive, don't worry. Some activity is better than no activity. Talk to your clinician about safe ways to add physical activity or exercise to your routine. It's usually best to start at a comfortable level and add a little more activity each day or week. You can do it!

Exercise your mind

The brain can change and adapt to new challenges. Experts have suggested that keeping your mind actively engaged and participating in new, challenging mental activities can improve brain health by strengthening and creating new connections between brain cells. These improved brain connections may lead to improved thinking and memory.

Examples of brain workout activities:

- Doing something familiar in a new way, such as taking a new route to the grocery store
- Learning a new skill
- Reading, writing and arithmetic
- Solving a problem
- Trying something new, such as a recipe, class or dance

Tip

Experts recommend at least one "brain workout" every day.

Benefits of keeping your brain and body active

- Deepens your sleep
- Gives you a sense of accomplishment
- Helps you feel better and lead a healthier life
- Helps you stay independent and less likely to live in a nursing home
- Improves attention, memory and thinking
- Improves blood flow to your brain and maximizes your brain's use of oxygen
- Improves your mood
- Increases the size of brain areas responsible for memory
- Increases your energy level
- Keeps life interesting
- Lowers your risk of falls
- Strengthens your brain connections and builds new ones



Voices of experience

"Physical exercise is important. It's a lot of stimulation for my brain."

Ron

Living with mild cognitive impairment (MCI)

"Exercise often, even if you only have 20 minutes.
Smile when you finish."

Jerilynn

Living with Alzheimer's disease

"Computer brain games absolutely help me really concentrate.
I do this many times each day, and it's a fantastic
challenge to the brain."

Jim

Living with Lewy body dementia



Things I can do now: Check the boxes next to each item you'll try.

-
- Exercise.** Join a gym or find an indoor or outdoor place to be physically active, or participate in a supervised exercise program. Ask a friend to join me.
 - Get my heart pumping.** Schedule 20 to 30 minutes or more for my favorite aerobic exercise three to four days a week.
 - Do at least one strength-building, balance or stretching exercise** each week.
 - Sign up for a yoga, tai chi or Pilates class.**
 - Walk or ride my bike to a restaurant** to have lunch with a friend.
 - Take a class** or attend a lecture on an unfamiliar topic.
 - Play brain games** on the computer.
 - Teach someone** something I know.
 - Read** a new book and talk about it with friends or family – or join a book club.
 - Write** about my history or life experiences.
 - Join a painting class** or group.
 - Take a dance class.** All dancing is good for you, but dance styles that combine memory (for the steps), exercise and social connection (for example, ballroom, square or line dancing) have been shown to be the best for brain health.
-



My accomplishments

List the things you already do or have done to make progress in this area.

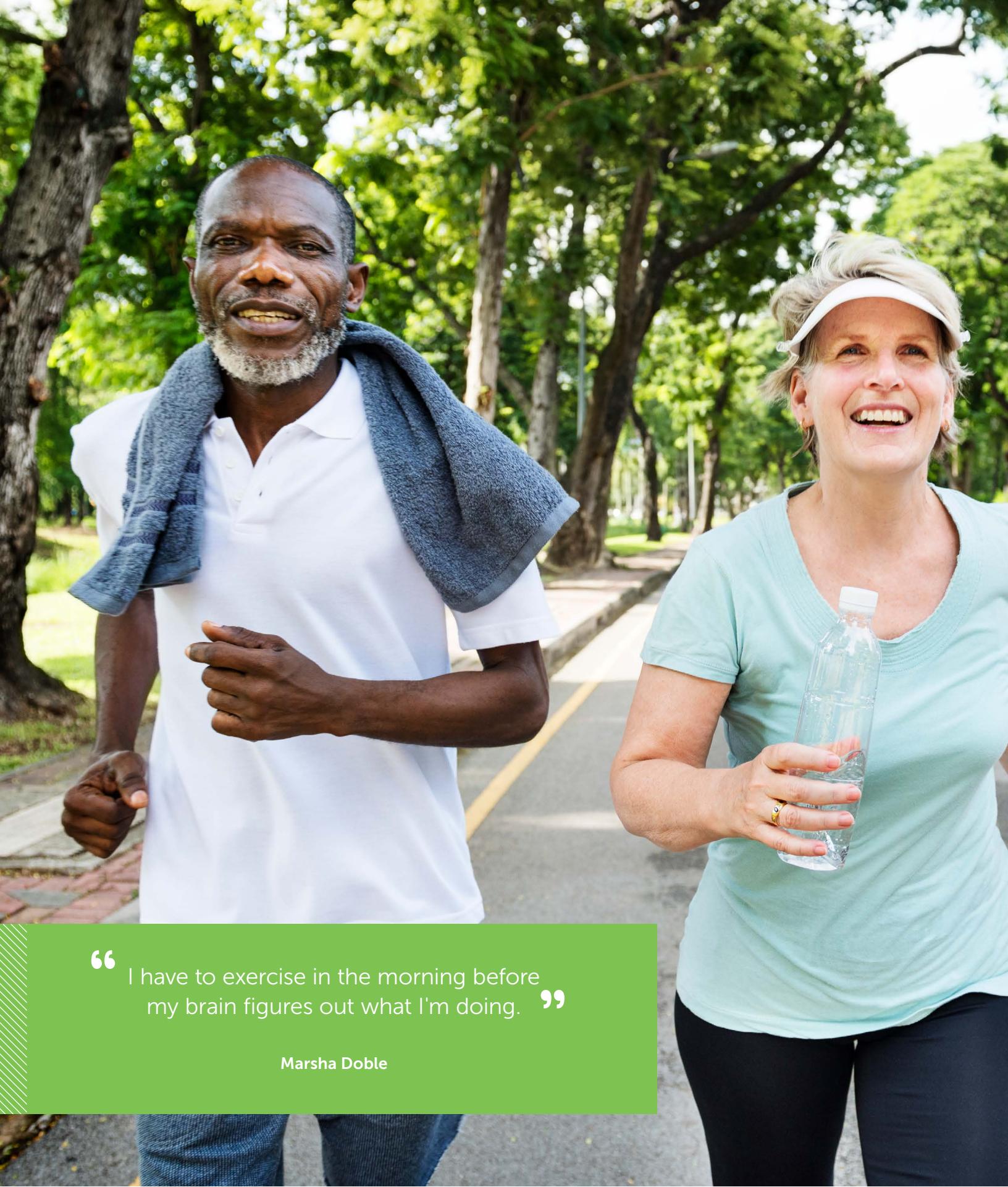
1.	
2.	
3.	
4.	



My action plan

List one to four new things you will do to make progress in this area.

Physical activity	Brain activity
1.	1.
2.	2.
3.	3.
4.	4.



“I have to exercise in the morning before
my brain figures out what I'm doing. **”**

Marsha Doble



Voices of experience

"I have been doing mental exercises as therapy every day since I received my diagnosis. I know this is working for me. If you keep up with this, and you establish it as a routine, it will work. It's like stretching your brain."

Brenda

Living with Alzheimer's disease

"My husband and I have been walking outside for three years. I feel this isn't merely an exercise; it gives him confidence."

Ping

Care partner for her husband living with Alzheimer's disease

"When I exercise, I function better, feel better and I am more cognizant and alert as well as engaged."

Mike

Living with Alzheimer's disease

"We're like the 'Hummingbird Syndrome' where we flit from object to object. Being involved in exercises that help us with our concentration is beneficial and extremely helpful for our day-to-day living."

Norm

Living with Alzheimer's disease

Independence and performance

Independence and performance

Most people want to stay as independent as possible throughout the course of their lives.

The keys to independence and performing your best are keeping active and engaged in life, avoiding accidents and staying safe, maximizing strengths and minimizing the impact of symptoms.

Keeping active and involved

Being active and involved is critical to performing well and maintaining your independence. You may find that activities that you used to enjoy are now harder to do or more frustrating. This is normal. What's important is to adapt to the changes you're experiencing instead of giving up. Making small changes to your activities may help them become easier and more enjoyable.

Benefits of maximizing performance and independence

- Makes it easier to continue doing things that are important to you
- Helps you function at the highest possible level
- Allows you to be more independent and need less assistance
- Gives you greater control and freedom over your life
- Lowers your stress
- Helps you better manage and cope with disease symptoms
- Makes life easier for your care partners
- Lowers your risk of accidents and falls
- Can help limit time in the emergency room and hospital

Tips for minimizing the impact of symptoms

- **Slow down.** Take things at your own pace. Give yourself more time to do things.
- **Keep life simple.**
- **Stop multitasking.** Focus on one thing at a time.
- **Share the fun.** Break up tasks or activities into smaller parts and assign some of the steps to others. Keep the parts you feel most confident about for yourself.
- **Schedule smarter.** Do the things that require the most brain power in the morning or when you feel most rested and alert.
- **Reduce distractions.** Turn off the radio or TV in the background, or find a quiet place when you need to concentrate.
- **Give yourself a break.** Don't push yourself too hard. Schedule rest breaks between activities.
- **Lower the numbers.** It may be helpful to keep social gatherings to a small number of people, when possible, and to have an escape plan (such as a quiet room) for larger or noisier gatherings.
- **Laugh when you can.** Keep your sense of humor when things don't turn out as planned.
- **Be kind to yourself.** Remind yourself that some days are better than others. Tomorrow is a new day.



“

It's not
what they
take away
from you
that counts.
It's what
you do with
what you
have left.

”

Hubert
Humphrey

Playing it safe

Accidents can happen to anyone, but people with memory and thinking changes are at greater risk. To stay independent and keep performing at your best, it's important to know the most common causes of accidents for people with MCI and dementia so you can make changes now to ensure your safety and avoid unnecessary medical problems and hospital stays.



Medications

Medication errors are a common cause of preventable hospitalizations, especially for people with memory and thinking changes. It's easy to forget to take a medication, mistake pills, or take the wrong dose. There are many tools available to make taking medications easier and safer.

Organizers

A pill box can help you organize your medications by day of the week. Ask someone to set it up for you or to double-check your work. Set recurrent alarms to remind you when to take your medications. Automated pill dispensers cost a little more but offer more features, such as built-in alarms, personalized voice reminders, care partner notifications, and the ability to dispense medications for up to a month before refilling.

Mail-order pill packs

Many companies will deliver your medications presorted and packaged by day and time to your home at no additional cost. Search online for mail order pill packs to review options, such as Amazon Pill Pack, CVS Pharmacy, AccuPac and others.



Home safety

Your home is the place where you should feel most safe and secure. Unfortunately, many accidents happen at home, and a diagnosis of MCI or dementia increases risk. The good news is there are many small changes you can make that can help keep you living at home safely. In addition to the tips below, you can also ask your clinician for a referral to an occupational therapist for a complete home safety assessment.

Home safety tips

- Use a smart speaker such as Alexa (Amazon), Google Home, Siri (Apple) for reminders. For instance, you could say to your smart speaker, "Remind me to get ready for my clinician appointment at 9 a.m. tomorrow."
- Program appliances (such as coffee pots and kettles) to shut off after a certain amount of time. You can also plug appliances into auto shut-off safety outlet adapters.
- Set timers when you use the oven, stove/cooktop or other appliances without an automatic shut-off feature.
- Avoid storing cleaning products in the pantry with food items.
- Use labels on cabinets, drawers and closets. It may help to take a picture of what's inside and post that picture on the outside.
- Install grab bars and textured stickers to tubs, showers, stairs or other potentially slippery surfaces.
- Remove tripping hazards, such as throw rugs, extension cords and excessive clutter.
- Install a thermostatic mixing valve on your water heater outlet or shower to prevent accidental burning or scalding.
- Use safety plugs to limit how much water can be filled into the bathtub.
- Add lights to shaded or dark places in the house. It may help to install motion-activated lights that turn on automatically when you enter the room.
- Use plug-in nightlights in the bathroom, bedrooms, hallways, kitchen and living spaces to help you find your way in the dark.
- Apply stickers to glass doors at eye level to ensure doors are visible.
- Keep firearms unloaded and locked, or remove them from your home.
- Install smoke, fire and carbon monoxide detectors, and keep a fire extinguisher in the kitchen.



Driving

Driving isn't a lifelong activity for anyone. We don't start driving until we are teenagers or older and, if we live a long enough, most of us will retire from driving at some point because of changes in vision and hearing or a medical condition.

Your diagnosis alone doesn't mean you have to retire from driving. Many people with MCI and early dementia still drive. However, over time Alzheimer's disease and other dementias will affect the skills you need to drive safely. If you or others are concerned about your driving, it may be time for a driving evaluation. A driving evaluation can help lower your risk of accidents and suggest helpful tips, strategies and supports. Ask your clinician for a referral to an occupational therapy driving evaluation specialist near you.

Retiring from driving doesn't have to limit your freedom. Driving isn't the only way to get where you want to go. Other options include: riding with a friend or family member, using a ride service like Uber, Lyft or taxis, or using other transportation services like public transit, paratransit or shared ride services such as Metro Mobility or volunteer ride programs. You can also save a trip by having groceries and many other items delivered to your door.

Identifying what you want to do and creative ways to make that happen with your support team is the first step in crafting a driving retirement plan.

Driving tips

- Use your phone's GPS or other mapping technology to map your route.
- Minimize distractions, like the radio or noisy passengers.
- Keep to more familiar routes.
- Minimize night-time driving.
- Install a tracking device on your car to give your family peace of mind.

The places I need to go regularly		Driving alternatives
Example	Medical appointments, grocery store	Emily can go with and drive me, I can have groceries delivered
1.		
2.		
3.		
4.		

The places I like to go regularly		Driving alternatives
Example	Poker night at Bill's house, clothes shopping	Walk or have John pick me up on his way, take an Uber
1.		
2.		
3.		
4.		



Getting lost

We all have experienced getting lost and the anxiety and frustration that comes along with the experience. Unfortunately, your diagnosis makes your chances of getting lost a lot more likely. According to the Alzheimer's Association, about 60% of people with Alzheimer's disease and other dementias will become lost or confused about their location at some point, and many will have the experience multiple times.

Of course, we never expect to get lost. It's always an unpleasant surprise, and sometimes can be dangerous. The good news is that there are many things you can do now to be prepared if this happens to you.

- If you're disoriented, it may help to find a place to sit, close or soften your eyes, and take a few deep breaths. You may find that things are clearer when you open your eyes again.
- Let someone know where you're going, and bring your cell phone with you when you go out alone.
- Ask a store clerk, security guard, police officer or bystander to help you connect with a friend or family member.
- Never give your address to strangers. Instead, have those who try to help call a friend or family member for you. Keep the names and phone numbers of trusted contacts in your wallet.

Tools and technology that can help

Tracking devices can help your friends or family locate you if you become lost. Geo-fencing is a technology that alerts you or your team if you leave a certain geographic area that you define. Some options include:

- Project Lifesaver (projectlifesaver.org)
- MedicAlert ID and membership with wandering support (medicalert.org/alz)
- Wearable sensors or smart watches with GPS tracking and alert features (AngelSense, GPS Smart Sole, iTraq, pocketfinder, Trax, Trackimo)
- Car tracking devices that can locate your car should you become disoriented or lost (Track-4, Amcrest, Bouncie, Vyncs, LandAirSea, Spytec)



Emergencies

Accidents and emergencies happen despite our best made plans. There's a very high chance that you will go to the emergency room or be admitted to the hospital at some point in the future. That's just a part of life.

Not many people enjoy being in the hospital. It's especially difficult for people with MCI or dementia. Hospitals can be busy, noisy, confusing and difficult to navigate, especially when you aren't feeling your best. Research suggests that people with dementia are more likely to experience delirium or increased confusion when hospitalized, to be hospitalized more frequently and to stay in the hospital longer than those without dementia.

A trip to the hospital can be very stressful for you and your care partners, but there are things you can do to prepare and lower your stress.

Preparing for a hospital stay

- Pack a "go bag" for emergencies and trips to the hospital. Include your favorite comfort items, like a soft blanket, pajamas, slippers, religious book, pictures, snacks, iPod and earphones for listening to music, as well as practical items, such as a change of clothing, toiletries, hand lotion, personal medications, insurance card, legal papers, list of phone numbers and email addresses of care partners, family and friends. You may want to add items for your care partners too, like a book or deck of cards, as they may be waiting a long time.
- Set up a phone, text or email tree to alert your team. Consider using a program like CaringBridge (caringbridge.org) or another personal health journal to keep everyone informed about your progress (without having to call each person yourself).
- Choose a preferred hospital and practice going there with a care partner.

“

Use strategies until they don't work anymore. Then find new strategies.

”

Dr. Elaine Eshbaugh

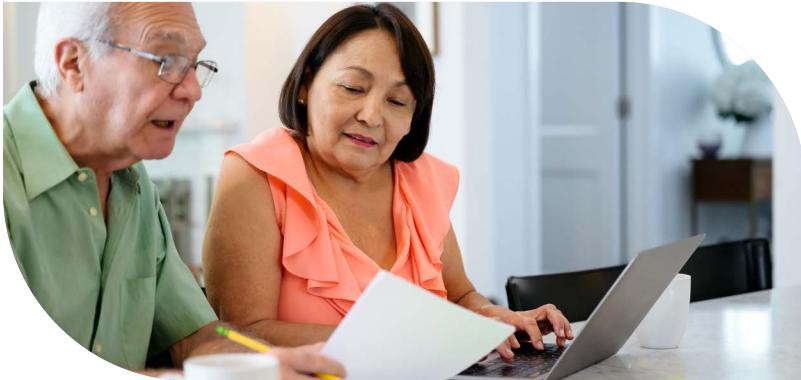


Travel

For some people, travel is the spice of life. For others, it's merely a necessity. Travel can be exciting, but it can also be stressful, frustrating and confusing – especially when you have memory and thinking challenges. Here are some tips that can help you be at your best when traveling.

Travel tips

- Traveling with others is always more fun and is safer after a diagnosis. If you're flying alone, contact your airline or the Transportation Security Administration (TSA) to ask if a pass can be given to a care partner to go with you through security to your gate.
- Consider purchasing travel insurance in case your plans change unexpectedly or you have an emergency.
- Take the most direct route. Limit layovers when flying. If you must stop, leave lots of time for connections, security, checking baggage and traffic.
- Wear a Hidden Disabilities sunflower at the airport, bus station or train station to let staff know you may need a bit more time or patience (hiddendisabilitiesstore.com/us).
- If walking is difficult or you would like a personal escort through security to your gate, consider requesting a wheelchair or motorized cart from the airline at least 48 hours in advance.
- Have a plan for getting lost or separated. For example, wear a tracking watch or MedicAlert bracelet (see page 64), write down a meeting place and keep it in your pocket, or keep your name and a care partner's name in your wallet.
- Take an emergency bag with you for important documents, medications, legal papers, travel plans, clinician's names and contact information.
- Try to maintain your routine when traveling as much as possible (such as your sleep and wake times, mealtimes and exercise times).
- Aim for only one big activity each day when you're most likely to be at your best (for example, in the morning).
- Schedule time for breaks and naps. Don't overschedule.
- Practice going with the flow and delighting in new discoveries. Enjoy!



Finances

You may have already noticed some challenges with balancing the checkbook or remembering to pay bills. Your diagnosis puts you at higher risk for making mistakes and being a target for financial scams. However, there are things you can do now to minimize your risk.

Finance tips

- Add your cell phone number to the National Do Not Call Registry (donotcall.gov) to reduce calls from telemarketers.
- Sign up for direct deposit and automatic bill pay.
- Avoid carrying large amounts of cash. Use a credit card instead of cash, when possible.
- Keep a note on your computer to never give out your bank account number, bank card pin or social security number to anyone requesting this via email.
- Place a "no soliciting" sign in your yard or near your front door.
- If you're having trouble, ask a trusted friend or family member to help you manage your finances. For example, you can have that person write the checks, and you approve and sign them.



“

The secret
of your
future is
hidden in
your daily
routine.

”

Mike
Murdock

Maximizing strengths and abilities

Once you receive a diagnosis of MCI, Alzheimer's disease or another form of dementia, it can feel like the focus is often on what you can't do rather than on the many things you do well. Why not flip that around? Occupational, speech and physical therapists can help you identify and maximize all your many talents and abilities and overcome challenges by leveraging your strengths. Ask your clinician for information about what might be best for you and for a referral.

Occupational therapists help you use your strengths and abilities to cope with symptoms and maintain the skills you need in your daily life. They can offer home and driving safety assessments as well as strategies to improve your ability to cope with memory and thinking challenges.

Physical therapists help you keep your mind and body active, improve your movement and manage pain.

Speech therapists help you with communication challenges and can develop mental exercises to keep your brain stimulated.

The power of routine

Establishing a routine, or a regular schedule, is an important tool to support your memory. Routines make it easier to remember what will happen over the course of a day and can help you develop healthy habits. You may also find that keeping a regular schedule helps you to feel less anxious and ready to face each day with a greater sense of peace and security.

Tips to establish a routine:

- Keep a schedule or calendar in a place where you can see it frequently, like the refrigerator. Cross off activities after you complete them.
- Program your routine into the calendar app on your phone, and set regular reminders for daily activities to keep you on track.
For example, you could ask your smart speaker to remind you to take your medications at a certain time.
- Keep things you need every day in one place. For example, keep your purse or wallet and keys by the door.
- Build brain-healthy activities into your daily life.

Go to My NeuroWell plan on page 106 to create your own routine, including activities from each chapter of this guide.



Things I can do now: Check the boxes next to each item you'll try.

-
- Slow down** – stop multitasking and overscheduling.
 - Schedule home and driving safety evaluations.**
 - Explore alternative transportation options.**
 - Set up autopay for my bills** to reduce hassle and lessen the risk of errors.
 - Use technology** for safety, independence and automated reminders.
 - Establish a daily routine** that includes well-being strategies (see My NeuroWell plan on page 106).
 - Select a place at home to keep important items.**
 - Set up a medication management strategy.**
 - Ask friends and family members for the support I need to do the things I want to do.** Say "yes" when someone offers help.
 - Ask my clinician for a referral** for physical, occupational or speech therapy to maximize my physical and mental performance.
-



My accomplishments

List the things you already do or have done to make progress in this area.

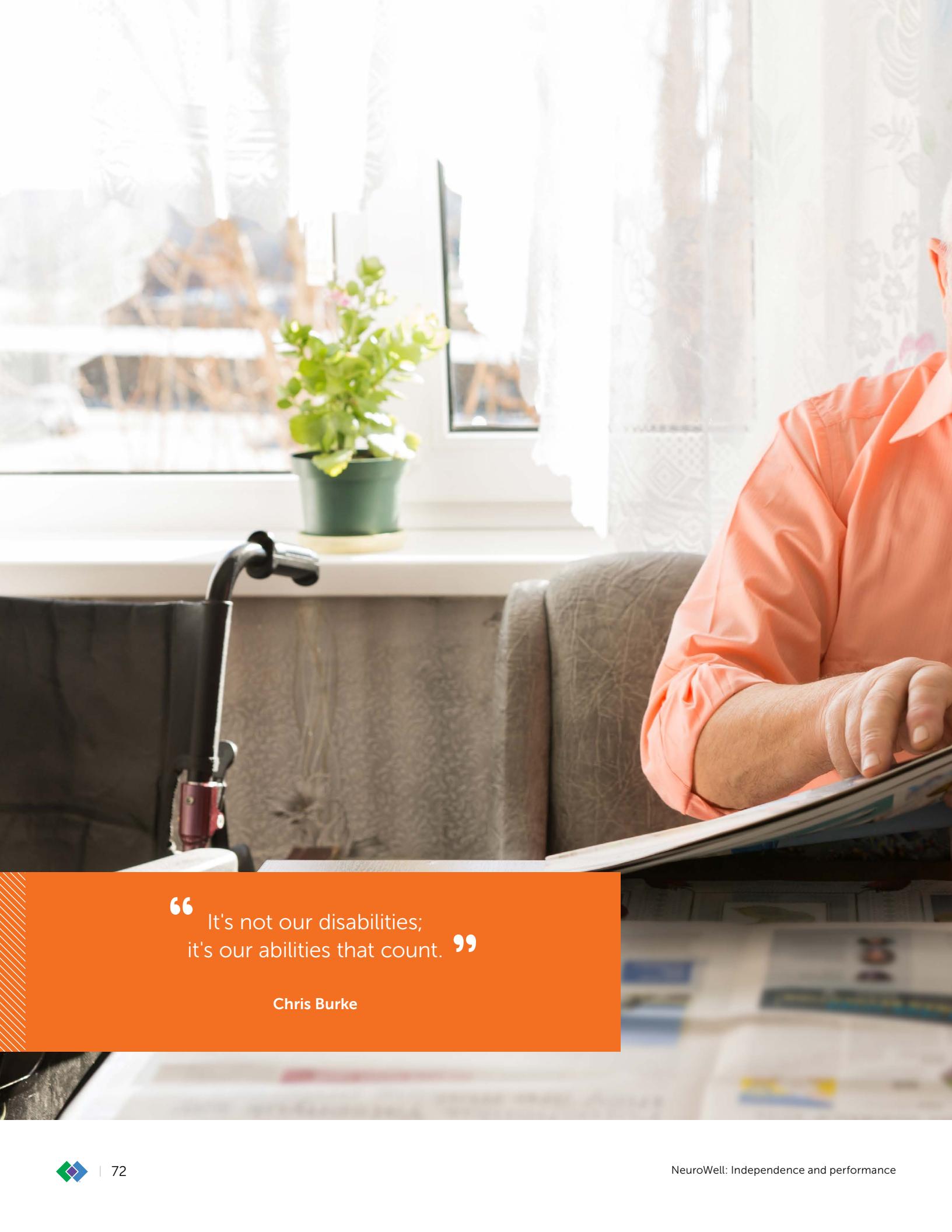
1.	
2.	
3.	
4.	



My action plan

List one to four new things you will do to make progress in this area.

1.	
2.	
3.	
4.	



“ It's not our disabilities;
it's our abilities that count. **”**

Chris Burke



Voices of experience

"I learned that having memory loss isn't the end of the world. There are still so many things I can do. What I can do, I will do."

Gail

Living with Alzheimer's disease

"Now I am perhaps one of the few men who will ask for directions."

Bill

Living with Alzheimer's disease

"I do well and feel less stress when I organize my medications in a day-by-day container."

Steve

Living with mild cognitive impairment (MCI)

"There are lots of things we can do to live active lives with Alzheimer's. I have lost some cognitive ability, but I have lots of ability left and I can work around the things that I can't do. One learns how to work around a problem, just like learning to avoid a strained muscle."

Jose

Living with Alzheimer's disease

Nutrition

Nutrition

Our brains need a steady stream of nutrients to stay healthy.

The brain is one of the most active parts of the body. It relies upon the nutrients in the foods we eat to perform well. Nutrients, like vitamins, proteins and minerals, fuel the brain and body. If we don't get the right fuel, our health suffers.

Unfortunately, the standard American diet lacks essential nutrients and relies heavily upon processed foods that include artificial colors, additives, flavorings and chemically altered fats and sweeteners. This diet, when combined with low activity, large portion sizes and high stress, is unhealthy for our bodies and our brains.

Many people take vitamins to supplement the foods they eat, but getting nutrients directly from natural food sources is usually best. Although there's no evidence to suggest that any one type of food will improve symptoms associated with MCI or dementia, research shows that foods in the MIND nutrition plan promote overall brain health.

Benefits of brain-healthy nutrition

- Gives you more energy to do the things you want to do
- Helps keep blood pressure and cholesterol at healthy levels
- Helps control or avoid diabetes, heart attack, stroke and other conditions that affect brain health
- Keeps you looking and feeling your best

“ We are what we eat. ”

Ludwig Feuerbach

MIND: a brain-healthy plan

MIND stands for the **M**editerranean-**D**ASH Intervention for **N**eurodegenerative **D**elay. MIND combines the most brain-healthy foods from two popular healthy nutrition plans, Mediterranean and **DASH** (**D**ietary **A**pproaches to **S**top **H**ypertension), which have both been found to lower blood pressure and reduce the risk of heart disease, diabetes and dementia among those who follow them strictly.

There are several possible reasons that the MIND nutrition plan is so good for our brains. Foods that make up this brain and heart-healthy plan have strong antioxidant and anti-inflammatory effects. For example, the antioxidants in berries and the vitamin E in olive oil, green leafy vegetables and nuts promote health by protecting the brain from oxidative stress. The omega-3 fatty acids found in fatty fish lower inflammation in the brain, which helps to slow loss of brain function.

10 MIND brain-healthy foods

Green-leafy vegetables: kale, spinach, cooked greens and other dark, leafy greens

Legumes: beans, peas, lentils, soybeans, chickpeas and peanuts

Berries: strawberries, blueberries, raspberries, blackberries, grapes and cranberries

Poultry: grilled or baked chicken, duck and turkey

Vegetables: all vegetables, including carrots, broccoli, tomatoes, peppers, cauliflower, squash, Brussels sprouts, onions and cucumbers

Whole grains: oatmeal, quinoa, brown rice, whole-wheat bread and pasta

Olive oil: use as your main cooking oil and as a butter and margarine substitute

Red wine: the brain-healthy component in red wine is also found in peanuts, pistachios, grapes, blueberries and cranberries

Fish: salmon, sardines, trout, tuna, mackerel – all rich in brain-healthy omega-3 fatty acids



If you're unable to eat the recommended number of servings of each brain-healthy food every day, don't give up. Research shows that following the MIND nutrition plan even to a moderate degree is associated with better brain health. However, studies do suggest that people who stick to the plan most closely have the greatest benefits, including slower mental decline and a reduced risk of Alzheimer's disease.

5 MIND foods to avoid

To promote brain and heart health, the MIND plan recommends limiting these five foods.

Butter and margarine: Try to eat less than one tablespoon a day. Use olive oil instead.

Cheese: Try to only eat cheese one time a week or less.

Red meat: Try to eat less than three servings a week of beef, pork or lamb.

Fried food: Avoid fried food, especially from fast-food restaurants.

If you can't avoid fried food completely, eat it one time a week or less.

Pastries and sweets: Limit sugary foods, such as ice cream, cookies, brownies, cakes, donuts and candy. Enjoy these treats less than four times a week. Try eating fruit instead.

Other brain and heart-healthy nutrition tips

A little spice

Curcumin or turmeric, an ancient East Indian herb used in curry, is a strong antioxidant and anti-inflammatory agent that supports brain health. Its mild taste allows you to add it to almost any dish.

Fresh and dried herbs and spices, such as garlic, basil, mint, rosemary, sage, nutmeg, cinnamon and pepper are all healthy spices. Garlic, in particular, is packed with important heart-healthy vitamins and nutrients.

Salt or sodium, the most familiar and common of spices, turns out to be bad for your heart and brain in large amounts. The World Health Organization recommends eating less than one teaspoon a day of salt (2,325 mg of sodium). However, almost all restaurants, especially fast-food restaurants, use very high amounts of salt to flavor foods. If you're dining out, consider asking for no salt or very low salt added to your meals. You can always add more at the table, if needed, but you may find that you feel better when you use less. Most pre-packaged and processed foods purchased at the grocery store are also very high in sodium. Cooking with fresh ingredients and using herbs, spices and citrus to flavor food instead of salt is the best way to control your intake.

Sample brain-healthy menu

Breakfast

Greek yogurt with berries, walnuts and pepitas or sunflower seeds, OR
Oatmeal with raisins and walnuts and an apple

Lunch

Spinach salad with tomatoes, olive-oil based dressing, grilled chicken, whole wheat pita, OR Turkey sandwich on whole wheat bread with tomato slice and lettuce with hummus and baby carrots on the side

Dinner

Baked salmon with broccoli and Brussels sprouts (roasted in olive oil) over brown rice or quinoa, and fruit for dessert, OR
Mediterranean pizza with whole wheat or cauliflower crust, topped with feta cheese, vegetables and olives, and fruit for dessert

Mediterranean plan recommendations

In addition to all the MIND foods, the Mediterranean nutrition plan also recommends eating fruits (in addition to berries), seafood (in addition to fatty fish), nuts, seeds and some dairy products. Drinking lots of water is an important part of any nutritional plan.

Fruits: In addition to berries, eat apples, oranges, pears, dates, figs, melons, peaches and bananas.

Seafood: In addition to fatty fish, consider shrimp, oysters, clams, crab and mussels.

Nuts and seeds: Walnuts, almonds, macadamia nuts, hazelnuts, cashews, sunflower seeds and pumpkin seeds (pepitias)

Dairy products: Greek yogurt, parmesan and feta cheeses, and eggs (or egg whites)

Beverages: Water as your go-to beverage; also consider unsweetened coffee and tea





Voices of experience

"I have been eating lots of fruits, vegetables, fish and nuts, and it has made a really big impact."

“

Ron

Living with mild cognitive impairment (MCI)

"I start to think about food for the week and make a plan that will give me the right food for my mind and body."

Came from
a plant,
eat it;
was made
in a plant,
don't.

Jerilynn

Living with Alzheimer's disease

”

"My brain is clearer when I eat right."

Michael Pollan

Julie

Living with Alzheimer's disease



Things I can do now: Check the boxes next to each item you'll try.

-
- Eat less** red meat, saturated fats and sugars/sweets.
 - Eat at least one meal each day that follows the MIND or Mediterranean nutrition plans.**
 - Try a new recipe** that includes brain-healthy ingredients.
 - Limit processed foods.**
 - Try using extra virgin olive oil** rather than butter when cooking.
 - Have salmon, tuna, trout, mackerel or herring** as an entrée once a week.
 - Eat at least five portions of fruits or vegetables** each day.
 - Drink alcohol in moderation.** One or fewer drinks each day, or not at all.
 - Limit salt intake** to no more than one teaspoon a day (2,325 mg of sodium).
 - Spice it up:** add curcumin or turmeric to dishes.
 - Drink lots of water.** Work up to drinking eight cups of water (64 ounces) every day.
 - Watch portion size.** Smaller is usually better.
 - Get brain-healthy nutrients from food** instead of vitamin supplements.
 - Make it fun!** Invite friends over to cook and dine together.
-



My accomplishments

List the things you already do or have done to make progress in this area.

1.	
2.	
3.	
4.	



My action plan

List one to four new things you will do to make progress in this area.

1.	
2.	
3.	
4.	

Medical care



Medical care

Living well with MCI or dementia means actively managing overall health.

A diagnosis of MCI, Alzheimer's disease or a related dementia is a call to action – a call to pay more attention to how you feel and to seek help when you sense that something is wrong. Unfortunately, your diagnosis won't protect you from having other illnesses, many of which can worsen your memory and thinking symptoms. Actively managing your chronic conditions, making wise choices, and doing everything you can to stay well will help keep you the healthiest you can be.

Focus on well-being

It's important to schedule regular visits with your clinician teams, including your primary care clinician and your dentist. This gives you time to focus on well-being and prevention, in addition to treating and managing any health concerns or symptoms that may arise.

Just how often you should see your clinician teams depends upon many factors, such as your age, family history, and the nature and severity of your health conditions. However, the general rule of thumb after a diagnosis of MCI or a form of dementia is to see your primary care clinician and dentist at least once every six months – even when you feel healthy. You may need to make additional appointments when you start new medications or if new problems develop. You may want to ask your clinicians how often you should visit and proactively schedule several appointments in advance.

“ To keep the body in good health
is a duty ... otherwise we shall not be
able to keep our mind strong and clear. **”**

Buddha

Take charge of your health

Regularly seeing your primary care clinician, dentist and other care teams is only the first step toward taking charge of your health. To stay as healthy as possible, it's also important to talk openly and honestly with your clinicians, actively participate in treatment decisions, ask questions until you understand your options, and develop a plan to follow care recommendations.

It's OK to do your own research, ask questions, request more information, express doubt, and seek a second opinion if your goals for care aren't met. It's smart to bring a family member or friend with you to appointments to provide extra support, enhance communication, and keep everyone informed and on the same page.

The people I want to come with me to medical or dental visits are:

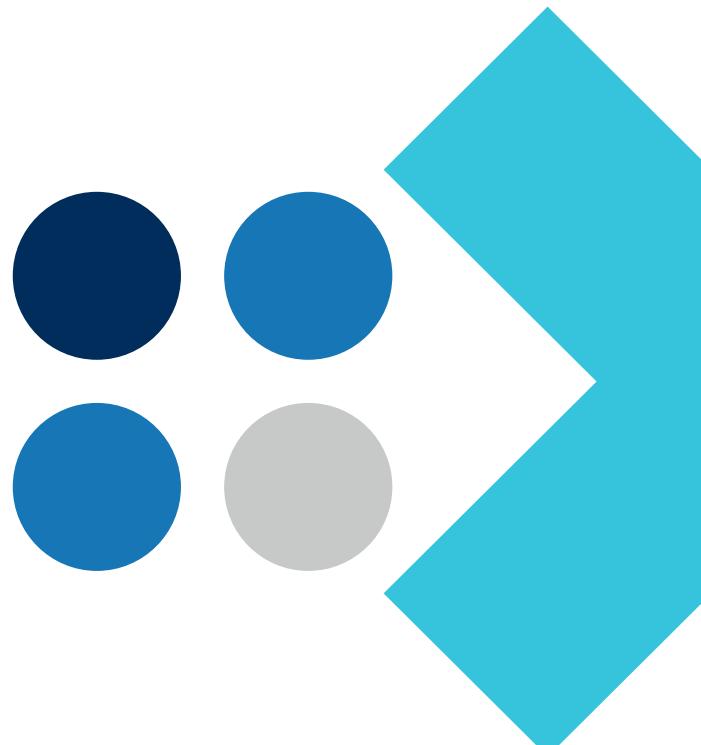
1:

and/or

2:

Tips for medical or dental appointments

- **Bring a family member or friend** with you to all appointments.
- **Plan ahead.** Write down the top three things you want to discuss with the clinician, and bring your list to the visit.
- **Share your symptoms and concerns** honestly – even the embarrassing ones.
- **Ask questions** until you understand.
- **Agree to a treatment plan** that will work for you. If you know you can't follow the plan, it's better to tell your clinicians so they can find other ways to reach your goals.
- **Be proactive.** Schedule appointments in advance, and call your clinician if you develop new symptoms or have new questions.



Mind your medications

Medications are often one part of a person's overall well-being plan. It's common for people to take multiple over-the-counter and prescription medications for a variety of health concerns. Taking your medications correctly is very important to your health. Medication errors can have serious and even deadly consequences.

Symptom treatment

Although there's currently no cure for Alzheimer's disease or other forms of dementia, there are medications that may reduce your symptoms and their impact on your daily life.

Memory, attention and thinking

The most common medications for memory, attention and thinking changes are **cholinesterase inhibitors** and **NMDA receptor agonists**. These drugs work by improving communication between nerve cells in the brain.

Cholinesterase inhibitors are typically prescribed for people with mild, moderate or severe Alzheimer's disease, but may also be effective for people with other dementias, such as Lewy body dementia. However, they may make symptoms worse for people with behavioral variant frontotemporal dementia.

- » **Drug names:** donepezil (Aricept), rivastigmine (Exelon) and galantamine (Razadyne)
- Common side effects:** stomach upset, insomnia and vivid dreams

NMDA-receptor agonists are typically prescribed for people with moderate to severe Alzheimer's disease. There's no evidence these drugs are effective in non-Alzheimer's dementia.

- » **Drug name:** memantine (Namenda)
- Common side effects:** dizziness, headache and confusion

Mood

Many people with MCI and dementia experience depression and anxiety. These symptoms are frequently some of the first to appear because of disease-related brain changes. The World Health Organization recommends trying non-medication treatments first (see Resilience and emotional well-being chapter on page 36), and only adding medications if symptoms continue afterward.

Research shows a combination of counseling or therapy and medication treatment is most effective for ongoing symptoms of anxiety and depression.

Cognitive behavioral therapy (CBT) is a form of non-medication treatment for depression, anxiety and other mood disorders, usually delivered by a psychologist or clinical social worker. CBT has been shown to be as effective or more effective than other forms of counseling or therapy or medication treatment.

Selective serotonin reuptake inhibitors (SSRIs) help relieve symptoms of depression, often with fewer side effects than other medications.

- » **Drug names:** citalopram (Celexa); escitalopram (Lexapro); fluoxetine (Prozac); sertraline (Zoloft)

Serotonin and norepinephrine reuptake inhibitors (SNRIs) help relieve symptoms of depression and anxiety.

- » **Drug names:** devenlafaxine (Pristiq); duloxetine (Cymbalta); levomilnacipran (Fetzima); venlafaxine (Effexor XR)

Talk to your clinician about all of your symptoms and ask which medications or other non-medication treatments may be best for you.

Medication management

After a diagnosis, it's important to review all of the prescription and over-the-counter medications you're taking with your clinician. The goal is to take as few medications at the lowest doses possible to get the maximum benefit. Your clinician may recommend that you stop taking certain medications that could worsen memory and cause confusion. Your clinician may also be able to reduce the number of medications or the number of times you have to take medications each day to make this task simpler and safer.

Medications can be helpful, but they can also be very dangerous if not taken properly. It's easy to make a mistake and take too much medication, forget to take medication or to take medications that don't mix well together. One small error can land you in the emergency room or hospital. For this reason, it's important to develop a plan for how you will take your medications each day.

See Independence and performance on page 58 for tips.



Medications to avoid

These medications can increase risk of confusion and may make your memory and thinking changes worse.

- Anticholinergics, such as oxybutynin (Ditropan), commonly prescribed for overactive bladder
- Antihistamines, such as diphenhydramine (Benadryl), often used for allergies
- Benzodiazepines, such as diazepam (Valium), commonly prescribed for anxiety
- Barbituates, such as phenobarbital (Solfoton), often prescribed for seizures
- Hypnotics, such as zolpidem (Ambien), commonly prescribed for insomnia
- Narcotics, such as oxycodone (OxyContin), oxycodone and acetaminophen (Percocet), often prescribed for pain



“

All the things that
we know are bad
for your heart
turn out to be bad
for your brain.

”

Marilyn S. Alpert, PhD
The Healthy Brain Initiative

Manage chronic medical conditions

As we age, the risk of chronic conditions such as hypertension (high blood pressure), hyperlipidemia (high cholesterol), coronary artery disease and diabetes increases. Unfortunately, these conditions increase your risk of heart attack and stroke, both of which can lead to early disability or death. Stroke, in particular, can cause memory and thinking changes and even dementia.

The good news is that you can protect your brain from these changes by regularly visiting your primary care clinician and addressing the following risk factors for vascular disease, heart attack and stroke.

Blood pressure

High blood pressure affects the heart. If left untreated for long enough, high blood pressure can also affect the brain. The goal for systolic blood pressure (first or top number) should be less than 130 mmHg. Blood pressure monitors are sold in most pharmacies and can help you keep track of your blood pressure at home.

Cholesterol control

Studies suggest very high cholesterol levels increase the risk of heart attack, stroke, Alzheimer's disease and vascular dementia. To reduce your risk, your total cholesterol should be below 220 and your lipoprotein (LDL) or "bad cholesterol" should be below 100. The first line of treatment is a combination of nutrition and exercise and, if needed, statins or cholesterol-lowering medications may be prescribed. The current evidence for use of statins in people at risk for or diagnosed with Alzheimer's suggests the benefits outweigh the risks of these medications.

Diabetes

Many studies have shown that diabetes could as much as double a person's risk of developing MCI and Alzheimer's disease. Poorly controlled blood sugar is associated with a high risk of memory and thinking changes. If you have diabetes or prediabetes, regularly monitor your blood sugar to help protect your brain. In general, it's recommended that people with diabetes maintain an HbA1c (3-month average of blood sugars) at less than 7%. This is the level that should reduce the risk for stroke.

Get enough sleep

Getting a good night's sleep gets harder as we get older, and sleep problems are common with MCI, Alzheimer's disease, Lewy body, and other types of dementia. Paying close attention to your sleep is important because studies have linked poor sleep with many health problems. For example, waking up often at night and being sleepy during the day contribute to poor concentration and faster decline in memory and thinking. If you've ever suffered through sleepless nights, you're probably quite familiar with the "brain fog" that often happens the next day. Sleep problems are also associated with:

- Depression, irritability and other mood symptoms
- Decreased ability to perform daily activities
- Increased likelihood of nursing home placement

Experts recommend that adults get seven to nine hours of sleep each night. A brief daily nap can be refreshing, but sleeping more than an hour during the day can disrupt the sleep-wake cycle.

Sleep disorders

Rapid eye movement (REM) sleep behavioral disorder is a condition in which people act out their dreams while asleep. This is a common symptom of Lewy body dementia and can be treated with over-the-counter medications, such as melatonin.

Obstructive sleep apnea is a condition in which breathing stops involuntarily for brief periods of time during sleep. Treatment of this disorder with a continuous positive airway pressure (CPAP) machine has been shown to improve brain function and slow down mental decline.

If you have sleep problems or a sleep disorder, it may be helpful for you to schedule an appointment with a cognitive-behavioral therapist who specializes in insomnia or a clinician who specializes in sleep medicine.

Manage pain

Unfortunately, pain is a common experience for everyone. As we get older, we're more likely to have pain associated with arthritis, illness, surgeries, muscle strains and chronic back issues. Pain can affect our ability to think clearly during the day and to sleep well at night, both of which can make symptoms of MCI or dementia a lot worse.

The best medication to use in the treatment of pain is acetaminophen (Tylenol), which has the least effect on memory and thinking abilities. There are also complimentary interventions for pain, including acupuncture, massage, mindfulness-based stress reduction and others. Be sure to let your clinician know if you're having frequent pain that's affecting your daily life.

Correct hearing and vision

We rely on our hearing and vision to interact with the world around us – to engage in conversations, to follow the plot of a television show, to safely navigate our way to the grocery store. As we get older, most of us can't hear or see as well as we could when we were young. If left untreated, hearing and vision loss can negatively impact memory and thinking abilities. Recent studies show that hearing loss can even increase the risk of dementia. It's important to get regular vision and hearing exams and treat any problems as they arise. Regularly wearing glasses or contacts or hearing aids, or both, will lower the effect that sensory changes have on your brain health and overall well-being.



“

No time
for your
health today
will result in
no health
for your time
tomorrow

”

Irish
proverb

Kick unhealthy habits

We all have habits. Some of them support brain health, like exercise and routine, while others are bad for our bodies and brains and can make disease symptoms worse. Taking an active approach to your health means adopting lifestyle habits that promote long-term well-being.

Tobacco

The use of tobacco products has been known for years to increase the risk of various cancers as well as heart disease and stroke. Smoking increases the risk of dementia by 1.6 times. However, studies show that not smoking for more than four years may reduce this risk. Stopping smoking is one of the best things you can do for your physical and brain health.

Alcohol

Alcohol is a sedative and slows down your brain's ability to coordinate movement, process information and produce speech. While some studies suggest there may be some health benefits from moderate alcohol use (one or two drinks per day), heavy drinking is linked with many negative effects. Experts recommend people with MCI or dementia drink as little alcohol as possible. If you do drink, limit your intake to fewer than 14 alcoholic servings per week. Drinking wine and beer is preferable to drinking hard liquor or spirits, such as whiskey.

Changing habits takes strength, courage and support. Taking even little steps toward your well-being goals is a big accomplishment.

Benefits of proactive medical care

- Allows you to be more independent
- Helps you feel better and lead a healthier life
- Increases your energy level
- Keeps you out of the emergency room or hospital
- Keeps your memory and thinking abilities as strong as possible
- Lowers your chances of needing nursing home care
- Makes life easier for your care partners



Things I can do now: Check the boxes next to each item you'll try.

- Schedule regular visits** (every three to six months) with my primary care clinician and dentist. Invite a friend or family member to join me during medical appointments.
- Review my medications** (both prescribed and over-the-counter) with my primary care clinician or pharmacist to maximize my brain health and independence.
- Stay on top of chronic conditions** that affect brain health, like high blood pressure, cholesterol, heart disease and diabetes.
- Treat depression and anxiety.** Medications can help regulate chemicals in the brain that support mood.
- Try to get between seven to nine hours of sleep every night.** Schedule an appointment with a sleep specialist or a sleep cognitive-behavioral therapist if I'm having sleep problems.
- Limit daytime naps** to less than 60 minutes a day.
- Avoid over-the-counter medications** that may make my symptoms worse, like Benadryl or Tylenol PM.
- Reduce or quit smoking and drinking alcohol.**



My accomplishments

List the things you already do or have done to make progress in this area.

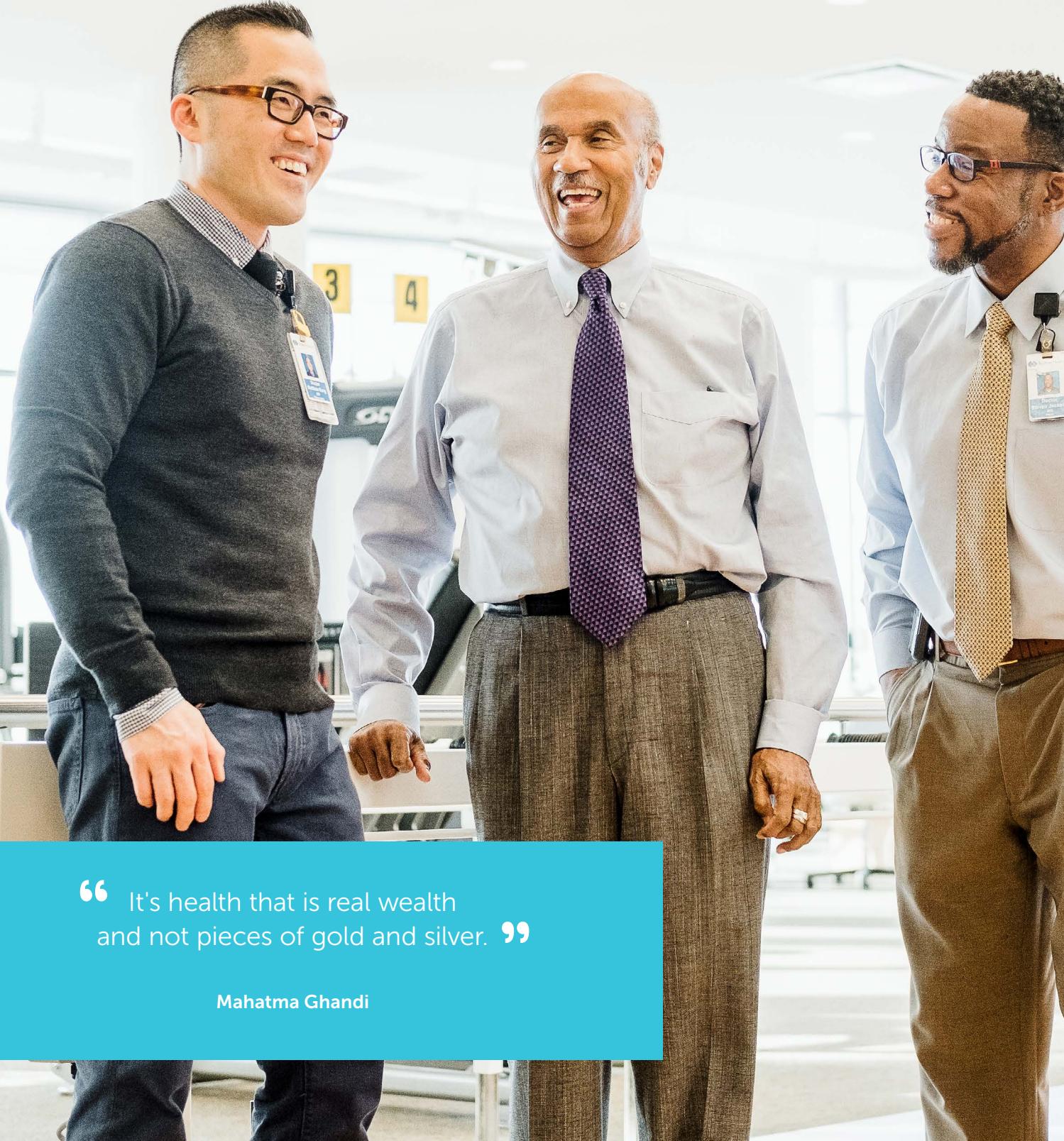
1.	
2.	
3.	
4.	



My action plan

List one to four new things you will do to make progress in this area.

1.	
2.	
3.	
4.	



“ It's health that is real wealth
and not pieces of gold and silver. ”

Mahatma Ghandi



Voices of experience

"One thing that makes a difference is assuring a good night's sleep."

Julie

Living with Alzheimer's disease

"When I got the diagnosis, I was pretty upset and didn't know what to do. My doctor suggested that I see a counselor, so I did. It was one of the best decisions I made."

Darius

Living with Lewy body dementia

"The last thing I want is a stroke, so I watch my blood pressure and my diabetes."

Bilan

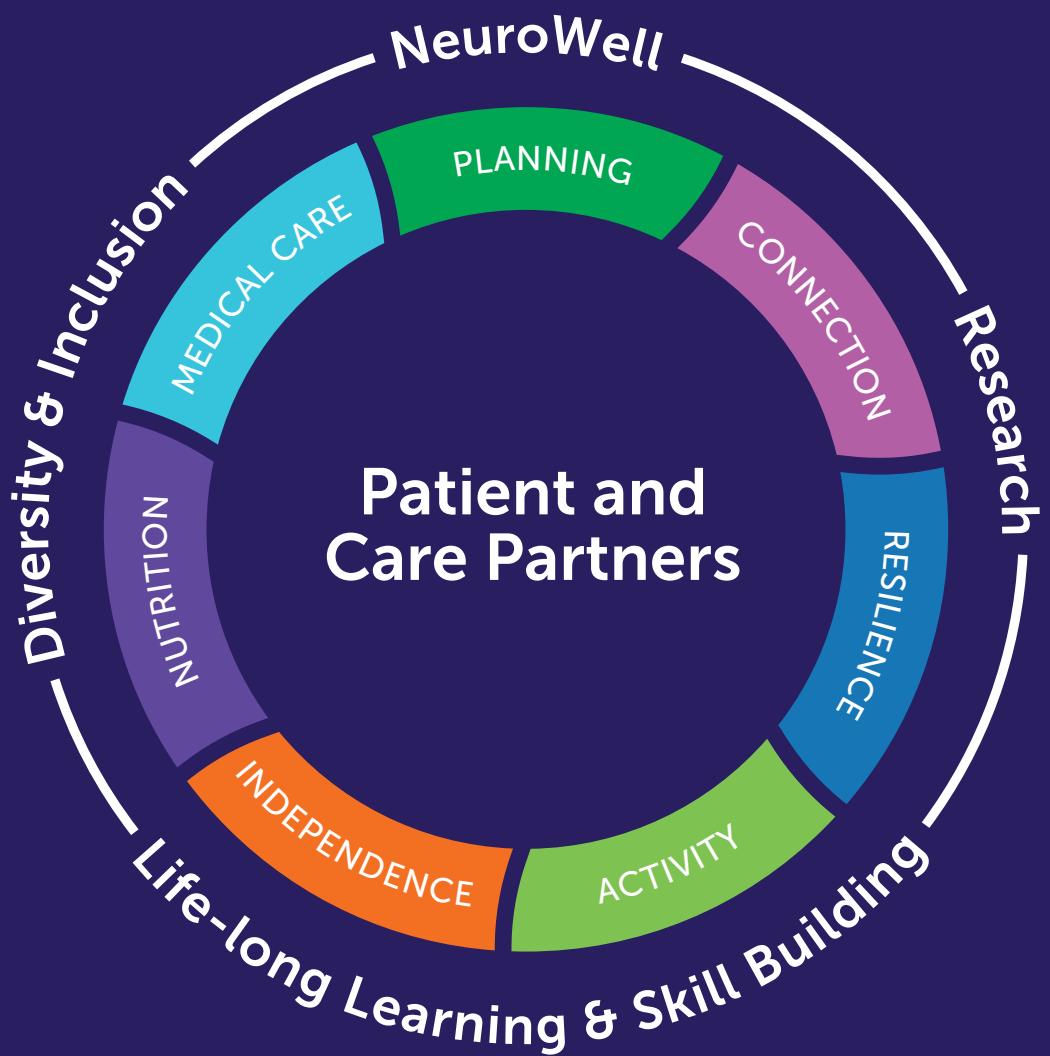
Living with vascular dementia

"Communicate! Communicate! This is what makes my relationship with my clinician a good one."

Jim

Living with Alzheimer's disease

My NeuroWell plan



My NeuroWell plan

After a diagnosis of MCI, Alzheimer's disease or other form of dementia, proactive and ongoing planning is a critical step toward ensuring overall health and well-being.

Getting started

At this point, you have learned a lot about different strategies to live your best after diagnosis. Hopefully, you've written down things in each chapter of this guide that you're already doing to keep your brain and body healthy, along with some new things you're planning to try.

Living your best with MCI or dementia doesn't happen by accident. Making sure your brain and body are working at the top of their potential takes planning and effort. This effort will pay off in the long run for you and the people who care about you.

As you learned in the Independence and performance chapter on page 58 of this guide, building a routine or a regular schedule is the key to making sure you're successful now and over time. Routines support memory and help us develop habits. We usually think of habits as bad things, like smoking or biting your fingernails, but it's also possible to develop healthy habits, like exercising every day. A habit is hard to break – even for people with MCI and early dementia. Creating a routine that includes well-being strategies can help to provide structure to your days and keep you engaged and active in your life.

Follow three simple steps to get started:



1. Make a plan
2. Schedule it
3. Try it out

Step 1: Make a plan

If you've gotten this far, you have already done the work for this step. Congratulations! Review your accomplishments and action plan from each chapter of this guide. On the following pages, review your accomplishments and action plan from each chapter of this guide, making any changes you'd like as you go along.

Planning and goal setting

Things I already do or have done

1.

2.

3.

4.

Things I will try

1.

2.

3.

4.

Connection, purpose and joy

Things I already do or have done

1.

2.

3.

4.

Things I will try

1.

2.

3.

4.

Resilience and emotional well-being

Things I already do or have done

1.

2.

3.

4.

Things I will try

1.

2.

3.

4.

Activity

Things I already do or have done

1.

2.

3.

4.

Things I will try (physical activity)

1.

2.

3.

4.

Things I will try (brain activity)

1.

2.

3.

4.

Independence and performance

Things I already do or have done

1.

2.

3.

4.

Things I will try

1.

2.

3.

4.

Nutrition

Things I already do or have done

1.

2.

3.

4.

Things I will try

1.

2.

3.

4.

Medical care

Things I already do or have done

1.

2.

3.

4.

Things I will try

1.

2.

3.

4.



Voices of experience

"What I realized is you cannot dwell too long on what you can't do anymore. It's a new life – how do I begin to take my new life on?"

“

Zeb

Living with Alzheimer's disease

"I look at what my goal is, lay out what I will do, and get into a routine."

Ron

Living with mild cognitive impairment (MCI)

The first step towards getting somewhere is to decide you're not going to stay where you are.

”

"We've made my life more of a habit. When we walk, we walk the same path; we eat dinner at the same time, and that helps make things a lot simpler."

J.P. Morgan

Jan

Living with Alzheimer's disease

Step 2: Schedule it

Create a weekly calendar that includes your well-being action plan activities. Here are some tips that can help you build a brain-healthy routine:

- Set regular times** for waking up, going to bed, taking medication and eating meals.
- Make sure to move your body** as much as possible every day.

- Schedule regular visits** with friends and family.
- Build in breaks** and time to relax. Leave lots of time between activities.
- Keep it simple.** It's OK to take it easy and not pack in too much. You may only want to schedule one activity or outing that requires a lot of effort or attention each day.
- Have fun!** Try new things. Do something you love every day. Enjoy your life.

Sample weekly calendar		AUGUST					
MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY	
MORNING							
8 a.m.	Wake up						
8:30 a.m.	Meditation						
9 a.m.	Brain-healthy breakfast						
10 a.m. Gardening	10 a.m. Golf with Judy and Jim	10 a.m. Water aerobics	10 a.m. Brain gym	10 a.m. Dental visit	10 a.m. Water aerobics	10 a.m. Religious services	
AFTERNOON							
12 p.m. Brain-healthy lunch at home		12 p.m. Lunch at the gym	12 p.m. Brain gym group lunch	12 p.m. Brain-healthy lunch at home	12 p.m. Lunch at the gym	12 p.m. Family brunch	
1 p.m. Rest break/nap	1 p.m. Lunch with Judy and Jim at golf club	1 p.m. Rest break/nap		1 p.m. Rest break/nap	1 p.m. Rest break/nap		
2:30 p.m. Neighborhood walk	2:30 p.m. Rest break/nap		2:30 p.m. Rest break/nap	2:30 p.m. Volunteer		2:00 p.m. Rest break/nap	
EVENING							
5 p.m. Card club		5 p.m. Babysit grandkids	5 p.m. Walk with neighbors	5 p.m. Ballroom dance class		5 p.m. Yoga class	
7 p.m. Card club dinner	7 p.m. Brain-healthy dinner	7 p.m. Brain-healthy dinner	7 p.m. Dinner with neighbors	7 p.m. Brain-healthy dinner	7 p.m. Date night	7 p.m. Brain-healthy dinner	
11 p.m.	Bedtime						

My weekly calendar

Schedule well-being activities from each chapter into your weekly routine.

MONTH:						
MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
MORNING						
Every day:						
AFTERNOON						
Every day:						
EVENING						
Every day:						

Step 3: Try it out

Once you have put your plan and routine in place, try it out.

After a month, ask yourself these questions:

How is my plan working overall?

Did I plan too much or plan too little?

What do I like most about my new routine?

What have I accomplished? What am I most proud of or excited about?

What isn't working well? Why not?



Once you have things down, stick to your new routine as much as possible. Getting into a routine helps you build healthy habits that support your memory and allow you to stay independent.

What keeps me from doing things on my plan?

What could I do instead?

What will I change? What will I add? What will I take away? What will I try next?

Things I can do now: Check the boxes next to each item you'll try.

-
- Post it.** Put the weekly calendar with my new schedule on the refrigerator or in another location that I see every day.
 - Refine it.** Try my plan and new schedule for the next month. Make changes to things that don't work or that I don't like.
 - Just do it.** Once my plan and schedule are set, do my best to follow the calendar each day until it becomes a habit.
 - Celebrate accomplishments.** Notice all that I'm able to do and celebrate my successes.
 - Keep it up!** I'm committed to living my best.
-

Congratulations!

Living your best happens one decision, one activity, one moment, one day at a time. Today is the day that you take your first step toward living your best with MCI or dementia.

“ A journey of a thousand miles begins with a single step. **”**

Lau Tzu

Care partner well-being

If you're a care partner for a person with memory loss or dementia, you may be experiencing a range of feelings about your new role.

Providing support to someone else can bring moments of joy and increase meaning and purpose. After all, providing care and support is one of the biggest gifts you can offer another person. At the same time, being a care partner can be stressful and frustrating at times, can put strain on close relationships and may increase risk of depression, anxiety and other mental health problems.

Self-Check Tool for a Caregiver



We all have good days and bad days. This tool can help you decide when to reach out to family members, trusted friends and experts for more help or information.

EXCELLENT – KEEP UP THE GOOD WORK!



Staying active



Eating a balanced diet



Staying socially connected



Sleeping well



Having time to yourself

Continue: Learning about the disease, preparing for the future, making legal and financial plans, facing changes with courage and creativity, having regular follow-up visits with your doctor

PAY ATTENTION – USE CAUTION...



Losing your temper frequently



Feeling unsupported or resentful



Trouble sleeping



Weight loss/gain



Feeling overwhelmed



Feeling lonely or isolated



Neglecting your own health

Check in: Talk to someone, practice asking for help and delegating tasks, join a support group, try short-term respite or hiring in-home help, re-evaluate priorities and expectations, and tell your doctor about your challenges

WARNING ALERT – SEEK HELP!



Feeling hopeless or despair about the future



Thoughts of hurting yourself or others



Not sleeping or sleeping all the time



Acting aggressively towards or restraining patient

Contact a back-up caregiver, consult with therapist or case manager, seek emergency help if needed, call 24/7 Alzheimer's Association hotline (1.800.272.3900), make an appointment with your doctor as soon as possible

Research on caregiving

- Seeking help and support as a care partner improves emotional well-being and quality of life.
- Denial and refusing help contribute to emotional problems, increased burden and poor physical health.
- Care partners who communicate openly and transparently with family members, trusted friends, and experts respond better to stress and are more resilient.

Used with permission from the Care Ecosystem, memory.ucsf.edu/care-ecosystem.

Resources and references

Resources

- » HealthPartners Neuroscience Center
NeuroWell
myneurosciencecenter.com

Books

- » "Living Your Best with Early-Stage Alzheimer's" by Lisa Snyder, MSW, LCSW
- » "The Alzheimer's Action Plan: What You Need to Know – and What You Can Do – About Memory Problems, from Prevention to Early Intervention and Care" by P. Murali Doraiswamy, MD and Lisa P. Gwyther, MSW
- » "The Spectrum of Hope: An Optimistic and New Approach to Alzheimer's Disease and other Dementias" by Gayatri Devi, MD
- » "Travel Well with Dementia: Essential Tips to Enjoy the Journey" by Jan Dougherty, MS, RN, FAAN

For care partners

- » "Alzheimer's A to Z: Secrets to Successful Caregiving" by Jytte Jokvig, BA, MA
- » "Caring for a Loved One with Dementia: A Mindfulness-Based Guide for Reducing Stress and Making the Best of Your Journey Together" by Marguerite Manteau-Rau, LCSW

Guides

- » By Us for Us Guides
the-ria.ca/resources/by-us-for-us-guides
- » BrainGuide
mybrainguide.org
- » Living With Dementia – My Life, My Goals
dementiaallianceinternational.org/wp-content/uploads/2021/10/my-life-my-goals-workbook-AlzSocUK.pdf

Information and support organizations

- » Alzheimer's Association (MCI and all types of dementia, not just Alzheimer's)
alz.org
800-272-3900
- » Lewy Body Dementia Association
lbda.org
- » The Association for Frontotemporal Degeneration
theaftd.org
- » Senior LinkAge Line
minnesotahelp.info
800-333-2433

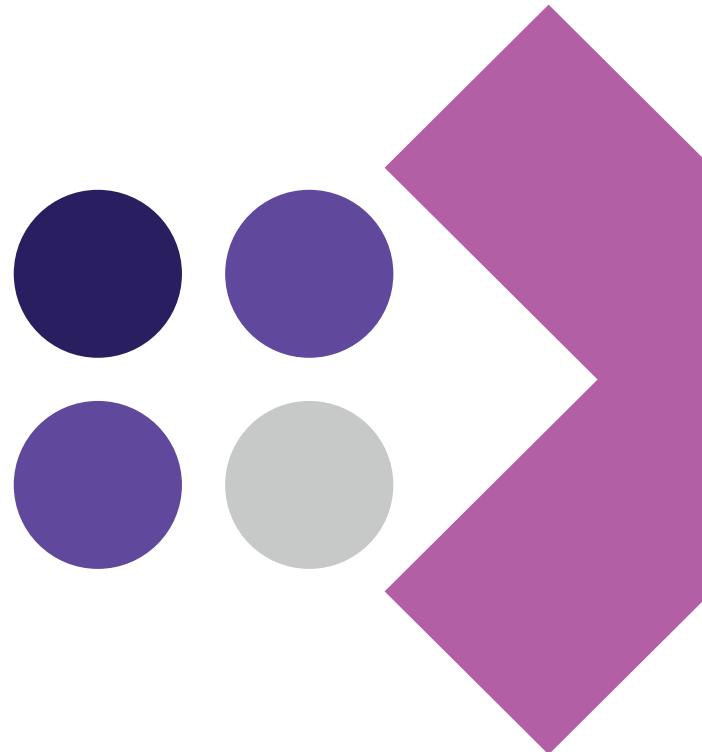
Other resources

- » Hidden Disabilities Sunflower
hiddendisabilitiesstore.com/us
- » Presence Care Meditations
presencecareproject.com/podcasts

References

- » [myneurosciencecenter.com/
MyNeuroscienceCenter/neurowell/10000](http://myneurosciencecenter.com/MyNeuroscienceCenter/neurowell/10000)





Find joy in helping people just like you – donate today!

HealthPartners Center for Memory and Aging developed this guide with support from donations by grateful families.

Special thanks to John and Yvonne Huizinga who provided funding so we can provide printed copies of this guide to patients and their families.

If you found this guide valuable, please consider making a donation so that we can continue to offer these types of resources to the community.

How to donate:

1. Visit healthpartners.com/hp/doctors-clinics/specialties/cdac/donate-memory-aging or scan the QR code on this page.
2. **Select your desired donation amount.** A gift of any amount is greatly appreciated.
3. Under the designation drop down box, select the following from the list:
Memory Clinic Programs fund - supports patient & family programs.
4. Please write **NeuroWell Guide** in the additional comments box.
5. Enter your contact information and payment details. Find joy in knowing that you're helping get this valuable resource into the hands of people just like you!

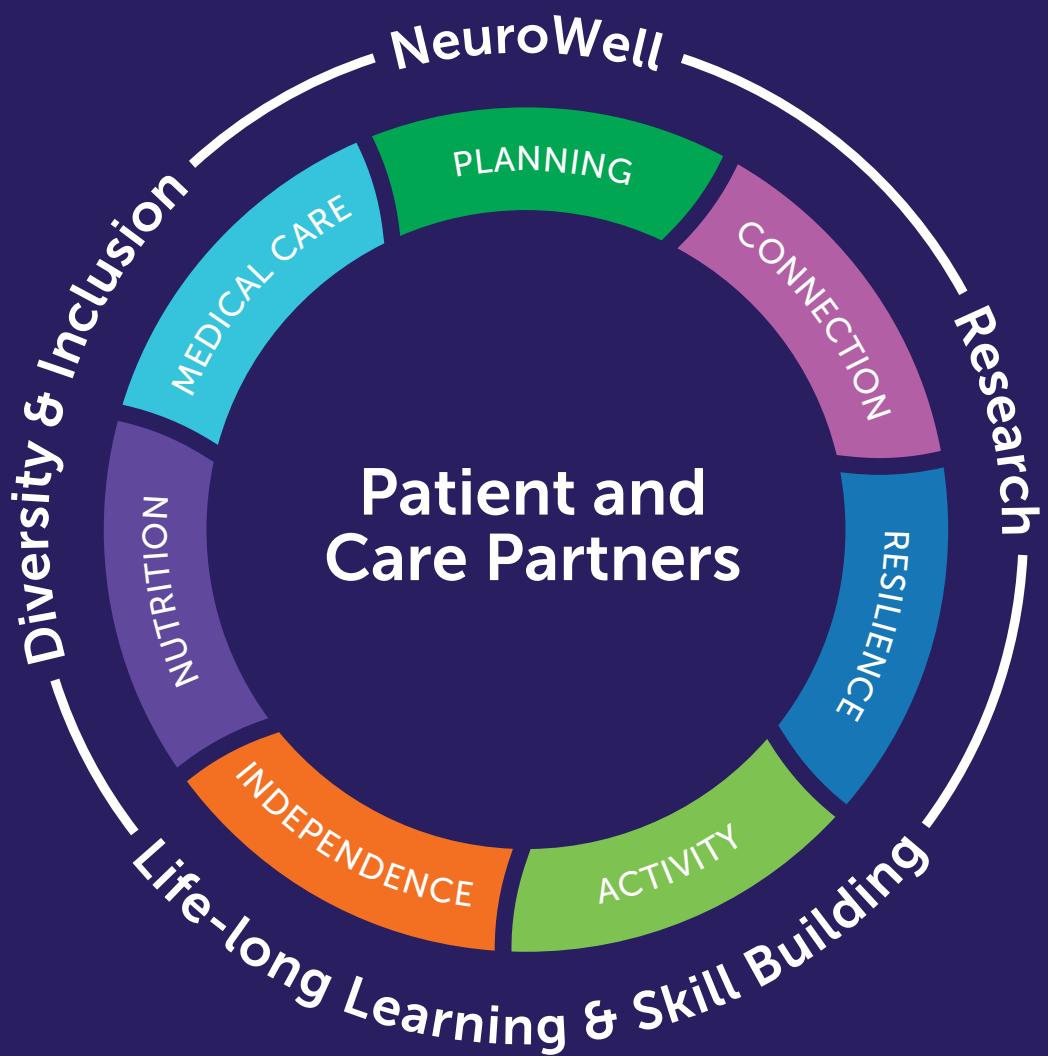


Scan this QR code with your phone camera to donate to HealthPartners Center for Memory and Aging.



Notes





HealthPartners Neuroscience Center
Center for Memory & Aging
295 Phalen Blvd.
St. Paul, MN 55130
651-495-6300 (phone)
952-883-9676 (fax)
healthpartners.com/memoryloss