MISSION: TO PROVIDE SUPPORT, SERVICES AND EDUCATION TO INDIVIDUALS, FAMILIES AND CAREGIVERS AFFECTED BY ALZHEIMER’S DISEASE AND RELATED DEMENTIAS NATIONWIDE, AND FUND RESEARCH FOR BETTER TREATMENT AND A CURE.

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Staffed entirely by licensed social workers.

“During the Coronavirus pandemic, I often felt alone and invisible. Thank you AFA for helping me give the best care possible to my loved one—while taking care of myself.”
—David J., Caregiver

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Page 1
A MESSAGE FROM
CHARLES J. FUSCHILLO, JR.
AFA PRESIDENT & CEO

This new issue of Alzheimer’s TODAY grew out of the challenging times that we’ve been living in—and still are. The COVID-19 pandemic has forced us to be together in new ways, some of them uncomfortable, maybe even lonely at times. For those who have been unable to visit loved ones, perhaps excruciating.

This entire issue is devoted to sharing what we have learned at AFA during this time, about helping you care for your loved ones and people in your charge, how to make connections and find inspiration virtually (check out our programming on our Facebook page @alzheimersfoundationofamerica), and stay safe physically and emotionally.

We address the basics, many with Spanish-language translations for our Hispanic families:

• An “Ask the AFA Medical Advisory Board” column (p. 4), with Dr. Allison Reiss of NYU Winthrop Hospital, discusses how to stay safe as states begin to reopen; “7 Steps to Preserve Routines” (p. 7), how to handle our disrupted routines; “Caregiver Activities to Fill Your Days” (p. 8), when you are looking for more to do with the person you care for; “Strengthening Family Ties with Care Meetings” (p. 11), because the stress of the pandemic has put additional strain on our family relationships; and “Staying Connected with Loved Ones in Nursing Homes” (p. 24).

We focus on helping caregivers cope better:

• Our “Straight Talk from the Helpline” (p. 12), with an AFA social worker, answers a question about “compassion fatigue,” a unique aspect of caregiver burnout—how to recognize it and address it.

• “Caregiver Self-Compassion” (pp. 13-14) and “Self-Care: A Good Habit That Gives Back” (p. 15) address the truth of being a caregiver. It is extremely rewarding as well as demanding. Dale Atkins, Ph.D., asks our readers to consider how they may have started to change as a result of their caregiver roles and how to find their way back.

We focus on issues that remain constant during the COVID-19 pandemic and beyond:

• “Alzheimer’s and Exercise: The Connection” (p. 18), by Dr. Richard Seibert, lifts up the importance of exercise, when possible, especially for people with Alzheimer’s.

• “Safety Begins at Home” (p. 20) addresses how to create a safe environment for a person living with Alzheimer’s, including dealing with the seen (clutter) and the unseen (lighting) as well as wandering and how to evaluate if it’s safe to leave a person home alone—all recommendations from Gene Saunders, founder and CEO of Project Lifesaver International.

• “The Importance of Power of Attorney” (p. 22), written by Kathie Brown Roberts, Esq., a certified elder law attorney, addresses the plans you should have in place regarding your financial, legal, and healthcare wishes.

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A Year of Overcoming

“Although the world is full of suffering, it is full also of the overcoming of it.”

Those words by Helen Keller weren’t referring to 2020, but they certainly apply to this year which has turned into none like any other.

The global COVID-19 pandemic created unthinkable hardships for families affected by Alzheimer’s disease. Vital community services, such as adult day care and respite care programs, had to shut down. Family caregivers had little to no in-person support. Others were unable to visit their loved ones in nursing homes, who had to shut their doors to outside visitors to protect their residents and staff from the virus.

Many of us got sick. Tragically, some never recovered.

But amid the struggle, pain, and uncertainty that has characterized this year, there is something to be enormously proud: The commitment and resolve to help each other never wavered—in fact, it grew stronger.

Front line workers—health care professionals, police officers, fire fighters and EMTs—put forth a herculean effort to care for those in need. Despite challenging working conditions and exhaustive hours, their commitment to serving all of us remains steadfast.

Nursing homes and care settings used technology and found creative ways to keep residents connected with their loved ones.

Speaking from our own experience, AFA shifted all of its activity and educational programming to a virtual format so that everyone could take advantage of these services while isolated at home. We worked together with our member organizations to reach as many people in need as possible.

Finally, family caregivers themselves, under enormous pressure and facing extraordinary obstacles, did everything they could to make sure their loved ones with Alzheimer’s disease received the best care possible.

As the old saying goes, “Where there is a will, there’s a way.” One of the most important lessons of COVID-19 is to never give up hope because when people come together to help one another, even the longest and darkest tunnels will always have light at the end of them.
I’m very worried about the coronavirus, especially since my elderly mother with Alzheimer’s lives with us. Things are reopening, but I’m still concerned, especially since some health experts are warning about another wave of the virus down the road. What can I do to protect myself and my family?

The coronavirus spreads when someone with COVID-19 sheds infectious droplets from their respiratory system (i.e., coughing or sneezing), which then come into contact with someone else’s mucous membranes: the mouth, nose or eyes.

One of the most effective ways to protect yourself is to continue following protocols provided since the onset of the virus. Wash your hands with soap and water for at least 20 seconds or use an alcohol-based sanitizer; clean and disinfect high-touch surfaces in shared household areas (i.e., door knobs and countertops); avoid rubbing your eyes or touching your face with unwashed hands; practice social distancing by maintaining six feet between yourself and others; limit social interaction; and do not hug or shake hands. Also, wear a mask when out in public; masks have been shown to be extremely effective in reducing the spread of coronavirus.

Since Alzheimer’s impacts memory, your mother may not remember to take these precautions, so it’s important that you continually remind her and show her what to do. For handwashing, use a soothing tone to encourage washing and understand that you may need to explain what to do slowly and step by step. Consider using a fragranced soap, such as lavender, to improve her sensory experience.

Because COVID-19 is spread when individuals are in close proximity with one another, your risk of contracting coronavirus increases as you are around more and more people. Limit the number of outside visitors who come into your home to lessen the chances of exposure. Many doctors are using telemedicine and video visits to see patients. This is another good option to avoid having to travel to in-person care sites. These visits can be done with a family member or proxy present. Avoid taking your mother to grocery stores, restaurants or other large public gatherings.

However, this doesn’t mean you can’t take her outside; walking, exercising or even just sitting in the yard are all good for the body (as long as you practice appropriate social distancing and wear masks when around others). Sunlight is also a great source of vitamin D, which can help strengthen the body’s immune system.

Do what you can to improve her (and your) overall health. Maintain a balanced, nutritious diet with fewer processed, high-salt or high-sugar foods. Good hydration is also important, as is adequate vitamin D and C.

Finally, while it’s important to take this seriously, it’s just as important not to panic. Even in patients over the age of 80, which is one of the highest-risk populations for developing serious complications from COVID-19, the survival rate has far been 85%. Control what’s in your power, follow the guidance from public health officials, and do the best you can.

AFA Medical Advisory Board member Allison Reiss, MD, is Head of the Inflammation Laboratory at NYU Winthrop Hospital Biomedical Research Institute in Mineola, NY, and Associate Professor of Medicine at NYU Long Island School of Medicine. An internal medicine physician and molecular biologist, she studies the causes and treatment of Alzheimer’s disease.

Estoy muy preocupada por el coronavirus, especialmente porque mis padres ancianos con Alzheimer viven con nosotros. Las cosas se están reabriendo, pero todavía estoy preocupado, especialmente porque algunos expertos en salud están advirtiendo sobre otra ola del virus en el futuro. ¿Qué puedo hacer para protegerme y proteger a mi familia?

El coronavirus se propaga cuando alguien con una COVID-19 arroja gotitas infecciosas de su sistema respiratorio (es decir, tos o estornudos), que luego entran en contacto con las membranas mucosas de otra persona: la boca, la nariz o los ojos.

Una de las formas más efectivas de protegerse es continuar siguiendo los protocolos proporcionados desde el inicio del virus. Lávese las manos con agua y jabón durante al menos 20 segundos o use un desinfectante a base de alcohol; limpie y desinfecte superficies de alto contacto en áreas compartidas del hogar (es decir, perillas de puertas y encimeras); evite frotarse los ojos o tocar la cara con las manos sin lavar; practique el distanciamiento social manteniendo seis pies entre usted y los demás; limite la interacción social; y no abrace ni se dé la mano. Además, use una máscara cuando esté en público. Se ha demostrado que las máscaras son extremadamente efectivas para reducir la propagación del coronavirus.

Dado que el Alzheimer afecta la memoria, es posible que su madre no recuerde tomar estas precauciones, por lo que es importante que le recuerde continuamente y le muestre qué hacer. Para lavarse las manos, use un tomo suave para alentar el lavado y comprenda que es posible que deba explicar qué hacer lentamente y paso a paso. Considere usar un jabón perfumado, como la lavanda, para mejorar su experiencia sensorial.

Debido a que COVID-19 se propaga cuando las personas están muy cerca unas de otras, su riesgo de contraer coronavirus aumenta a medida que se encuentra con más y más personas. Limite la cantidad de visitantes externos que ingresan a su hogar para disminuir las posibilidades de exposición. Muchos médicos están utilizando telemedicina y visitas de video para ver pacientes. Esta es otra buena opción para evitar tener que viajar a sitios de atención en persona. Estas visitas se pueden hacer con un familiar o representante presente. Evite llevar a su madre a supermercados, restaurantes o otras grandes reuniones públicas.

Sin embargo, esto no significa que no puedas llevarla afuera. Caminar, hacer ejercicio o incluso simplemente sentarse en el patio son buenos para el cuerpo (siempre que practiques el distanciamiento social apropiado y use mascarillas cuando esté cerca de otros). La luz solar también es una gran fuente de vitamina D, que puede ayudar a fortalecer el sistema inmunológico del cuerpo.

Hago lo que pueda para mejorar su salud (y su salud general). Mantenga una dieta equilibrada y nutritiva con menos alimentos procesados, con alto contenido de sal o azúcar. La buena hidratación también es importante, al igual que la vitamina D y C.

Por último, aunque es importante tomar esto en serio, es igual de importante no entrar en pánico. Incluso en pacientes mayores de 80 años, que es una de las poblaciones de mayor riesgo de desarrollar complicaciones graves por COVID-19, la tasa de supervivencia hasta ahora ha sido del 85%. Controle lo que está en su poder, siga las instrucciones de los funcionarios de salud pública y haga lo mejor que pueda.
7 Pasos para Preservar Rutinas

COVID-19 ha creado interrupciones enormes para muchas partes de la vida diaria para todos, y esos desafíos que se magnifican para alguien que convive con la enfermedad de Alzheimer. Cambios en sus rutinas diarias pueden resultar en ansiedad, confusión, agitación o malestar, especialmente cuando una persona no entiende o no se recuerda porque estos cambios están ocurriendo. En situaciones donde la rutina es interrumpida por varios días a semanas a meses, hay unos pasos que un cuidador puede adaptar en sus rutinas para ayudar a sus queridos mantenerse con calma y cómodos.

1. Mantenga horarios. Si su ser querido está acostumbrado a levantarse, comer y acostarse a horas fijas, mantener las mismas horas tanto como sea posible.

2. Traiga destinos externos adentro. Si la persona regularmente come en sus restaurantes favoritos de mariscos los Domingos, por ejemplo, ordenele su comida de ese restaurante o cocinarla la comida que ellos normalmente ordenan.

3. Mantenga la persona activa. Si la persona no puede ir a su centro de adulto o a su programa de cuidado de relevo (ejemplos: música, baile, ejercicios), haciendo actividades similares en la casa puede ser beneficioso. Realice estas actividades al mismo tiempo que normalmente lo harían. También pueden ver si hay programas disponibles en la Internet (visitar la página de Facebook de AFA, @AlzheimersFoundationofAmerica, para ver los videos de nuestros programas comunitarios virtuales).

4. Permanecer conectado. Use FaceTime, llamadas telefónicas o mensajes de texto para mantener la persona conectada con sus familiares y amistades que normalmente los visitan en persona. Si alguien los llama por teléfono o por FaceTime regularmente, que viven fuera de su pueblo o ciudad, trata de que mantenga contacto con ellos durante la misma hora rutinaria.

5. Use familiaridad. roulette la persona con artículos positivos como comida, música, y ropa. Esto le puede resultar cómodo y ayuda a reducir la ansiedad y el estrés. Cuanto más familiar, mejor.

6. Apoyarlos. El lenguaje de tu cuerpo y tu actitud puede influir el comportamiento de la persona por la cual cuidas. Mantener calma y poner su atención y demostrarle amor y cuidado puede que les ayude a adaptarse a los cambios.

7. Crear un horario diario con un montón de señales visuales (fotos, pegatinas, dibujos). Un horario regular que puede revisar y hacer referencia a lo que tu persona estará haciendo cada hora, y cada media hora puede ayudarlos y a ti poder pasar estos días que ahora parecen más largos que lo usual.

7 Steps to Preserve Routines

COVID-19 created enormous disruptions for many parts of daily life for everyone, and those challenges get magnified for someone living with Alzheimer’s disease. Changes in daily routines can lead to anxiety, confusion, agitation or discomfort, especially when the person may not understand or remember why these changes are taking place.

1. Maintain schedules. If your loved one is accustomed to getting up, eating meals and going to bed at set times, stick to that schedule as much as possible.

2. Bring outside destinations in. If the person regularly eats at a favorite seafood restaurant every Sunday, for example, order in from that restaurant or cook a favorite dish they like to order.

3. Keep the person active. If the person is unable to attend their regular adult day and respite care programs (i.e., music, dance, exercise), doing similar activities at home can be beneficial. Do these activities at the same time that they normally would. You can also see if programs are available virtually through the Internet (visit AFA’s Facebook page, @AlzheimersFoundationofAmerica, to see videos of our virtual community programs).

4. Remain connected. Use FaceTime, phone calls or text messages to keep the person connected with family and friends who would normally visit them in person. If someone calls or FaceTimes regularly because they live out of town, try to keep the contact during the usual time slot.

5. Use familiarity. Surround the person with familiar and positive items, such as food, music and clothing. This can be comforting and help reduce anxiety and stress. The more familiarity, the better.

6. Be supportive. Your own body language and attitude can influence the behavior of the person for whom you are caring. Remaining calm and attentive and showing the person love and care can help them adapt to changes.

7. Create a daily schedule with lots of visual cues (photos, stickers, drawings). A regular schedule that you can review and refer to detailing what the person will be doing every hour, or every half hour, will help them—and you—get through those days which now may seem longer than usual.
Caregiver Activities to Fill Your Days

When our regular routines were suddenly restricted and we all became more isolated during the COVID-19 pandemic, each of us in our own way had to create a “new normal” to get through our days. Caregivers had to find creative ways to keep their person active while isolated at home. Fortunately, there are ways to do this using many items already in your home.

“Engaging in activities at home is so important during an isolating time. Staying active can be very stimulating, help release tension, and break up the monotony of the day,” says Jackie Gatto, MS, R-DMT, AFA’s Manager of Therapeutic Programming. “Something as simple as singing a few familiar songs on a daily walk or creating a piece of art with watercolor paints can really transform a day of lower energy into a day of feeling grounded and alert.”

15 Activity Tips (for various stages of dementia)

1. Explore old family photo albums together.
2. Listen, sing and dance to favorite songs.
3. Create collages with cutouts from old magazines.
4. Play board games, like The Game of Life, Bananagrams, Scrabble, Connect Four or Jenga.
5. Cut flowers or plants from the garden and arrange them into a bouquet.
6. Have a spa day at home with face masks, manicures, and gentle hand massages with lavender lotion.
7. Explore therapeutic dolls and stuffed animals.
8. Stargaze: Go outside at night and look up at the starlit sky.
9. Play brain games, such as Sudoku, Hangman or simple word association games using categories, such as naming things that begin with the letter “c.”
10. Go for a mindful, meditative walk.
11. Go for a walk with a scavenger hunt list (look for dog, a flower, a stop sign, children playing).
12. Plant a tomato plant or flower from seeds and note its growth every day.
13. Create a reminiscence box full of pictures and favorite trinkets.
14. Fold towels, match socks, sort coins.
15. Explore technology (see below).

Activity Tips Using Technology (a computer, laptop or smartphone)

Virtual tours: Experience field trips and vacations without ever having to leave your home. Go to Google Search and type in “virtual tours” or “virtual field trips.” You’ll be able to access favorite cities, museums, zoos featuring live animal encounters, and national parks. For starters, www.fullscreen360.com will allow you to access 360-degree panoramas of iconic destinations. The National Park Service at www.nps.gov offers a changing monthly virtual tour.

Visit AFA’s Facebook page (@AlzheimersFoundationofAmerica) to view Virtual Community Classes (art, dance/movement, music, performances, meditation, yoga, and fitness); activity tips (e.g., how to set up a Spotify playlist, host a virtual dinner date, experience live music or a Netflix party); caregiver tips (e.g., how to organize a family meeting, “Ask a Social Worker”); and more! All of these are available in the “videos” section of the AFA Facebook page.

Sugerencias de Actividades Uso de la Tecnología (una computadora, computadora portátil o teléfono inteligente)


Conéctese con familiares y amigos: Busque formas de interactuar con sus seres humanos favoritos mediante chats de video (FaceTime, Zoom, Google), mensajes de texto, correo electrónico y llamadas telefónicas. Envíe fotos divertidas electrónicamente. Conéctese a través de las redes sociales.

Programación virtual de AFA: Visite la página de Facebook de AFA (@AlzheimersFoundationofAmerica) para ver las clases de la Comunidad Virtual (arte, danza/movimiento, actuaciones musicales, meditación, yoga y fitness); consejos de actividades (e.g., cómo configurar una lista de reproducción de Spotify, organizar una cena virtual, experimentar música en vivo o una fiesta de Netflix); consejos para cuidadores (e.g., cómo organizar una reunión familiar, “Pregunte a un Trabajador Social”); y más. Todos estos están disponibles en la sección de “vídeos” de la página de Facebook de AFA.

Actividades del Cuidador para Llenar sus Días

Cuando nuestras rutinas regulares se vieron repentinamente restringidas y todos nos quedamos más aislados durante la pandemia de COVID-19, cada uno de nosotros a nuestra manera tuvo que crear una “nueva normalidad” para pasar nuestros días. Los cuidadores tuvieron que encontrar formas creativas para mantener a su persona activa mientras estaba aislada en casa. Afortunadamente, hay formas de hacerlo usando muchos artículos que ya están en su hogar.

15 Consejos de Actividad (para varias etapas de la demencia)

1. Explore viejos álbumes de fotos familiares juntos.
2. Escucha, canta y baila tus canciones favoritas.
3. Crea collages con recortes de revistas viejas.
4. Juega juegos de mesa, como The Game of Life, Bananagrams, Scrabble, Connect Four o Jenga.
5. Corta flores o plantas del jardín y colócalas en un ramo.
6. Disfruta de una pívota de mesa en casa con máscaras faciales, manoplas y suaves masajes de manos con loción de lavanda.
7. Explora muñecas terapéuticas y animales de peluche.
8. Mirada estelar: Salga de noche y admire el cielo iluminado por las estrellas.
9. Juegue juegos mentales, como Sudoku, Hangman o juegos simples de asociación de palabras usando categorías como nombrar cosas que comienzan con la letra “c.”
10. Ve a dar un paseo atento y meditativo.
11. Salga a caminar con una lista de búsquedas del tesoro (busque perro, una flor, una señal de alto, niños jugando).
12. Plante una planta o flor de tomate a partir de semillas y observe su crecimiento todos los días.
13. Crea una caja de recuerdos llena de imágenes y baratijas favoritas.
14. Dobla las toallas, combina los calcetines, ordena las monedas.
15. Explore la tecnología (ver más abajo).

“Participar en actividades en el hogar es muy importante durante un tiempo de aislamiento. Mantenerse activo puede ser muy estimulante, ayudar a liberar la tensión y romper la monotonia del día,” dice Jackie Gatto, MS, R-DMT, Gerente de Programación Terapéutica de AFA. “Algo tan simple como cantar algunas canciones familiares en una caminata diaria o crear una obra de arte con pinturas de acuarela realmente puede transformar un día de menor energía en un día de sentirse conectado y alerta.”
Fortalecer los Lazos Familiares con las Reuniones de Cuidado

Durante los momentos estresantes, como la pandemia de coronavirus, es más importante que nunca mantener saludables los cimientos de su familia. Cuida tus relaciones mutuas. La persona que es el cuidador principal en una familia puede terminar sintiéndose aislada y sola. Mantenga abiertas las líneas de comunicación reuniendo regularmente a todos los miembros de la familia para una reunión de cuidado. Cuando la reunión no puede ser en persona, reúnete a través de una llamada de conferencia, FaceTime o Zoom.

“Las familias son una parte vital de la estructura de apoyo para una reunión de cuidado. Cuando la reunión no reuniendo regularmente a todos los miembros de la familia para una reunión de cuidado. Cuando la reunión no puede ser en persona, reúnete a través de una llamada de conferencia, FaceTime o Zoom.

“Las familias son una parte vital de la estructura de apoyo y atención de una persona que vive con Alzheimer’s,” dice Jennifer Reeder, LCSW, Directora de Servicios Educativos y Sociales de AFA. “Desea tratar de permanecer ‘en la misma página’ sobre la seguridad y el bienestar de su ser querido. Manténgase en contacto sobre cómo van las cosas y divida las responsabilidades, alentándose mutuamente a trabajar juntos en el proceso de toma de decisiones.” Esto puede incluir decisiones financieras y legales además del cuidado personal. Lo más importante es mantener a la persona que vive con Alzheimer’s involucrada en las decisiones durante el mayor tiempo posible. La colaboración y el compromiso son claves para las relaciones familiares efectivas.

Aquí hay algunos consejos para aprovechar al máximo el tiempo de su reunión juntos:

Prepárese para la reunión estableciendo metas realistas. Aliente a los miembros de la familia a contribuir a la reunión y envíe una breve agenda a todos los participantes de antemano. Quizás necesite hablar sobre un nuevo problema de sueño que está experimentando su ser querido o hacer una lluvia de ideas sobre formas de aumentar las actividades sociales. Tenga a mano todos los documentos que pueda necesitar, como las notas de los médicos.

Asignar roles para la reunión: un organizador (la persona que programará y organizará la reunión); un facilitador (la persona que lidera la discusión—a veces puede ser una persona externa, como un trabajador social); y el tomador de notas (la persona que está tomando notas para el seguimiento o para registrar una decisión).

Comience la reunión con una nota positiva. Haga que todos compartan buenos pensamientos o fortalezas observadas sobre la familia. Si su ser querido no puede asistir, reconozca que son la razón por la que se reúne como familia.

Establecer una cultura de respeto y aceptación. Asegúrese de que todos tengan la oportunidad de hablar sobre lo que es importante para ellos. Evite comentarios y juicios negativos. Apéguese a los hechos: las opiniones sobre temas delicados pueden generar emociones acaloradas. Si alguien se siente abrumado por un tema, tómese un descanso y vuelva a él más tarde o la próxima vez.

Elabore un plan de acción. Identifique las tareas que deben completarse para abordar las inquietudes. Aigne a los miembros de la familia para que sean responsables de cada uno de ellos y establezca una meta para cuándo se debe completar la tarea.

Concluya la reunión acordando una fecha y hora para la próxima. Permite que todos compartan su experiencia de la reunión. El anotador debe enviar por correo electrónico a todos el plan de acción y los resúmenes de cualquier decisión o acuerdo. Use un calendario familiar (por ejemplo, un calendario de Google) para marcar citas médicas, actividades y fechas límite importantes.

Recuerde, no todo se resolverá en una reunión. Las reuniones de cuidado familiar son un compromiso a largo plazo para mantener a su ser querido seguro y bien y sus relaciones familiares fuertes, felices y saludables.

Aliente a los miembros de la familia a contribuir a la reunión y envíe una breve agenda a todos los participantes de antemano. Quizás necesite hablar sobre un nuevo problema de sueño que está experimentando su ser querido o hacer una lluvia de ideas sobre formas de aumentar las actividades sociales. Tenga a mano todos los documentos que pueda necesitar, como las notas de los médicos.

Asignar roles para la reunión: un organizador (la persona que programará y organizará la reunión); un facilitador (la persona que lidera la discusión—a veces puede ser una persona externa, como un trabajador social); y el tomador de notas (la persona que está tomando notas para el seguimiento o para registrar una decisión).

Comience la reunión con una nota positiva. Haga que todos compartan buenos pensamientos o fortalezas observadas sobre la familia. Si su ser querido no puede asistir, reconozca que son la razón por la que se reúne como familia.

Establecer una cultura de respeto y aceptación. Asegúrese de que todos tengan la oportunidad de hablar sobre lo que es importante para ellos. Evite comentarios y juicios negativos. Apéguese a los hechos: las opiniones sobre temas delicados pueden generar emociones acaloradas. Si alguien se siente abrumado por un tema, tómese un descanso y vuelva a él más tarde o la próxima vez.

Elabore un plan de acción. Identifique las tareas que deben completarse para abordar las inquietudes. Aigne a los miembros de la familia para que sean responsables de cada uno de ellos y establezca una meta para cuándo se debe completar la tarea.

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Strengthening Family Ties with Care Meetings

During stressful times, like the coronavirus pandemic, it’s more important than ever to keep your family foundation healthy. Take care of your relationships with each other. The person who is the primary caregiver in a family can end up feeling isolated and alone. Keep the lines of communication open by regularly bringing all family members together for a “care meeting.” When the meeting can’t be in person, meet via conference call, FaceTime or Zoom.

“Families are a vital part of the support and care structure of a person living with Alzheimer’s,” says Jennifer Reeder, LCSW, AFA’s Director of Educational and Social Services. “You want to try to remain ‘on the same page’ about the safety and well-being of your loved one. Stay in touch about how things are going and divide responsibilities, encouraging each other to work together in the decision-making process.” This may include financial and legal decisions in addition to personal care. Most importantly, keep the individual living with Alzheimer’s involved in the decisions for as long as you can. Collaboration and compromise are key to effective family relationships.

Here are some tips to make the most of your meeting time together:

Prepare for the meeting by setting realistic goals. Encourage family members to contribute to the meeting and send a brief agenda to all participants beforehand. Perhaps you need to discuss a new sleeping problem your loved one is experiencing or brainstorm ways to increase social activities. Keep on hand any documents you might need, such as doctors’ notes.

Assign roles for the meeting: an organizer (the person who schedules and organizes the meeting); a facilitator (the person who is leading the discussion—this may sometimes be an outside person, such as a social worker); and the note taker (the person who is taking notes for follow up or to record a decision).

Start the meeting on a positive note. Have everyone share good thoughts or observed strengths about the family. If your loved one cannot attend, acknowledge that they are the reason you are meeting as a family.

Set a culture of respect and acceptance. Make sure everyone has a chance to talk about what is important to them. Avoid negative remarks and judgements. Stick to the facts—opinions on sensitive topics can lead to heated emotions. If anyone is feeling overwhelmed by a topic, take a break and get back to it later or next time.

Draft an action plan. Identify the tasks that need to be completed to address concerns. Assign family members to be responsible for each of them and set a goal for when the task should be completed.

Conclude the meeting by agreeing on a date and time for the next one. Allow everyone to share their experience of the meeting. The notetaker should email everyone the action plan and summaries of any decisions or agreements. Use a family calendar (e.g., a Google calendar) to mark medical appointments, activities, and important deadlines.

Remember, not everything will be resolved at one meeting. Family care meetings are a long-term commitment to keeping your loved one safe and well and your family relationships strong, happy, and healthy.
You’ve taken one of the most important steps you can—paying attention to warning signs and asking for help. That’s vital.

There are three types of “compassion fatigue”: emotional, behavioral, and physical. Caregivers can experience any one of these, or a combination of them.

Some emotional warning signs to look out for include sadness, depression and increased anxiety. You may be feeling guilty that you are not doing a good job in caring for your loved one and you could start doubting yourself.

Behavioral signs can show up when you are increasingly becoming more impatient, defensive with others and socially withdrawn.

Physical symptoms occur when you get sick easier and more frequently, often as a result of not taking proper care of yourself (inadequate sleep, lack of exercise or poor diet).

There are several things you can do to address the caregiver burnout, or compassion fatigue, that you are feeling.

Speaking with someone about your feelings (like you’re doing right now) is important. Whether it’s a professional like me or a trusted loved one or friend, having people you can talk to and vent some of the frustrations you are feeling is important.

Rerframing your thoughts can also be helpful. When getting to your breaking point, ask yourself, “Is this something that will matter in a week? A month? A year?” Is it something that I can ignore? Is it something that I need to react to? Is it really worth my time? As you are thinking about these questions, you are slowing down your thought process, which relaxes and calms your body. Breathe and count to five while you are doing this—it will allow you to process the emotions you are feeling.

Finally, you can try to adjust your standards or reevaluate your expectations. Many of us try to be perfectionists, but nobody is perfect. We all make mistakes. Just keep reminding yourself that you are doing the best that you can with what you have. Stop saying, “I am trying.” Instead, tell yourself, “I am succeeding!”

By Kara Rogers, LMSW, AFA Social Worker

Contact our social workers seven days a week through AFA’s National Toll-Free Helpline at 866-232-8484 or through our website, www.alzfdn.org.

My father has Alzheimer’s disease and lives with me. Because of the stay-at-home order and being unable to access respite care, I’ve been caring for him by myself, nonstop, for months now. I am trying my best, but I feel like I am at my breaking point and don’t know what to do. Do you have any advice for me?

Truth: Caregiving is a rewarding and demanding responsibility. Whether you are a professional or a family caregiver, you can sometimes be so intensely devoted and focused on your person that you often neglect to take care of yourself. Unfortunately, you cannot sustain a high level of care for another human being without something to sustain you: self-compassion.

What is self-compassion? Being kind and understanding towards yourself.

“Alzheimer’s not only changes the person we are caring for; it changes the caregivers,” says Dale Atkins, PhD, a licensed psychologist, author, and relationship expert. “Consider how you may have started to change as a result of your caregiver role. Do you lose a sense of yourself at times? If you did, how did you gain it back and hold onto the sense of who you are? Recognizing this is helpful in developing self-compassion.”

Dr. Atkins offers the following advice to guide you in enhancing your self-compassion and, ultimately, self-care. Practicing self-compassion requires commitment, time, and attention, but it will fuel your spirit, making you a happier person and a more generous caregiver. Read on:

• Be kind to yourself. Notice how you speak to yourself in your own head. Use words of encouragement, choosing those you would use when talking to a dear friend, beloved family member or child: “Look how well you are managing today.” Try to avoid critical self-talk. And when you notice that you are being harsh, find a gentler, more compassionate way to convey your message.

• Pay attention. Pay attention to everything, most especially the positive. When we don’t take the time to pay attention to what is positive, we humans often end up focusing on the negative—that’s because a survival mechanism we all have is a negativity bias.
• **Explore how you feel through journaling/writing.** Journaling is a practice of writing about how you are feeling over a period of time to notice what is happening (each night or every week). Writing is a briefer practice where you take the time to examine how you might say something better next time or explore how you can talk less critically to yourself over a situation.

• **Eat well.** Do you find yourself eating at the kitchen counter? Eating well means eating healthy foods as well as enjoying the experience of eating. Take time to enjoy the meal and savor the food’s taste, colors, textures, and aroma.

• **Exercise.** Is there a physical activity, like walking, swimming or dancing, that you once enjoyed that you could try today? Physical activity, like walking, particularly in nature, can boost mood, strengthen immunity, and even shorten the lifespan of the common cold. Go for a walk around the block or at a park. You’ll be surprised at how something so simple can make you feel so refreshed.

• **Get quality sleep.** Sleep is not just about quantity of hours but also quality. Ask yourself what you can do that is comforting as you prepare to go to sleep. Use scented candles, enjoy an herbal tea, take a warm bath or listen to calming music before bedtime. These soothers can enhance your sleep quality by helping you relax, making your sleep more restorative.

• **Laugh.** Laughter has both physical and mental benefits. It stimulates the release of pain-reducing endorphins in the brain, brings oxygen into our bodies, increases energy, and provides a sense of well-being. Laughter also protects us from the damaging effects of stress.

• **Develop support networks and nurture positive relationships.** A strong support network is essential. Staying in touch with family and friends, particularly trusted people with whom you can share your feelings and frustrations, can provide a sense of connection and relief. Create and nurture relationships with other caregivers as well. You’ll be able to exchange ideas and provide true compassion to each other.

Adapted from an AFA Alzheimer’s Educational Webinar Series event. To view upcoming webinars and events, visit www.alzfdn.org/events.

### 5 Questions to Foster Self-Compassion

**The 5 “Sanity Savers”™ are SELF, SUPPORT, SURROUNDINGS, STIMULATION, SAVOR**

- How are you caring for yourself—your mind, your body and your spirit? *(self)*
- How do you invite kindness into your relationship with yourself? Do you talk to yourself like a dear friend? *(support)*
- Can you find a place in your environment to create peace? *(surroundings)*
- What do you do to find purpose, meaning and stimulation in your life? *(stimulation)*
- How can you appreciate what is going on in each moment? *(savor)*

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**Use a mantra every morning/evening.** Mantras are sayings, quotes or words that hold meaning for you that can increase motivation or calm and be used as part of a meditation practice. Jackie Gatto, MS, R-DMT, AFA’s Manager of Therapeutic Programming, shared this one:

*Today, I accept what is instead of resenting what isn’t. I am thankful for everything I have. I will release the things out of my control. I am enough. I am doing enough. I am important.*
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INGREDIENTS
(Choose organic ingredients when available.)
• 1/2 cup old-fashioned rolled oats
• 3/4 to 1 cup plain low-fat kefir (depends on how thick you like it)
• 1/4 cup dried cherries
• 2 tsps. tahini or other nut butter*
• pinch salt
• 1/8 tsp. ground cinnamon
• 1 tbsp. pure maple syrup

*You can leave out the nut butter and substitute 1 tsp. of chia seeds.

DIRECTIONS
Combine ingredients in a glass jar. Mix, cover and place in the fridge. For best results, allow the flavors to meld overnight and enjoy the next day! Serves 1. Double the recipe to serve 2!

I have a few secrets that make overnight oats really creamy and even more delicious and nutritious:
• Use plain low-fat kefir (dairy) as the liquid which adds beneficial probiotics for gut health and a smooth consistency. One cup of kefir has about 30% daily value of calcium and 20% daily value of protein.
• A pinch of salt balances out the flavors.
• One teaspoon of chia seeds adds a boost of omega-3 fatty acids and an interesting consistency.
• One-quarter cup of dried fruits, like dried cherries, contain vitamins A, C, and antioxidants.
• Consider adding right before serving (optional): roasted nuts, toasted coconut, and/or fresh fruit.
• If you prefer more sweetener, add an extra tablespoon of pure maple syrup right before serving.

Recipe and photo by Layne Lieberman, MS, RD, CDN, culinary nutritionist and award-winning author of Beyond the Mediterranean Diet: European Secrets of the Super-Healthy. For more information and recipes, visit www.WorldRD.com.

Recipe for Your Health

Overnight oats are simple to make and satisfying to eat. No cooking required. It’s the perfect breakfast or snack. Just place the ingredients in a glass jar, mix well and set in the fridge for a few hours or overnight, to allow the oats to soak up the liquid. You can use any combination of kefir, yogurt, cow milk or plant-based milk. A daily dose of oats (high in soluble fiber) may be helpful to reduce blood cholesterol and improve blood sugars.
Alzheimer’s patients need to exercise and do so regularly. Aside from the rather obvious and well-documented benefits of exercise, including cardiovascular health, muscular strength, bone density and flexibility, we need to take a look at exercise for the benefit of the Alzheimer’s condition itself.

This would include increased oxygenation of the blood, increased secretion of chemical messengers that transmit signals from one neuron to another, and increased endorphins and beta enkephalins that promote feelings of well-being and a positive attitude. A Scientific American article also reported growing evidence that physical exercise can “clean up” the hostile environments in the brains of mice with Alzheimer’s, allowing new nerve cells to develop in the hippocampus, the brain structure involved in memory and learning.

As with any individual starting on an exercise regimen, clearance should be obtained from each person’s neurologist and/or primary care physician. Exercise should then be guided by a professional, either a physical therapist, chiropractor or certified personal trainer who is comfortable working with special conditions. The movements chosen should be based on the individual’s strength, mobility, and ability to receive instruction and perform the movements without risk of injury.

Common short-term goals could include increased muscular strength, or at least the maintenance of increased flexibility and balance. Goals can also be long-term, such as increased bone density and positive body composition changes. For persons with poor balance, modifications in the exercise routine should include exercises that may be completed while seated.

For cardiovascular and circulatory concerns, a recumbent bike or UBE (upper body ergometer), essentially a seated bicycle for the upper extremity, are excellent choices. If you haven’t tried this, it is indeed a tough workout!

Stretches should be held for 45 seconds to a minute without risk of injury. Common flexibilities work should include stretching on a mat for a minimum of 10 to 15 minutes, with a focus on key areas, including lumbar spine (low back), quadriceps, hamstrings and calves, as well as shoulder girdle and neck stretching. Stretches should be held for 45 seconds to a minute without ballistic or bouncing movements. Stretches should be long, steady and easy with comfortable breathing.

While more research needs to be done to demonstrate the exact mechanisms that result in positive changes in the person living with Alzheimer’s, the efficacy and need for exercise on a regular basis is obvious. Clearly, a varied routine based on an individual’s ability that includes resistance/strength training, flexibility and balance exercises are a must in complete care.

Dr. Richard Seibert (www.seibertdc.com) is a chiropractor specializing in sports injuries and nutrition. He has a private practice in Merrick, NY.

MYTH
“Grandpa really needs to exercise.”
“I know, but he can’t....He has Alzheimer’s!”

A
Safety Begins at Home

Home safety is a critical part of adapting to a family member who has Alzheimer’s. Caregivers need to think about preventing dangerous situations from happening, removing hazards, and adapting the environment so that their loved one can feel secure while being as mobile and independent as possible.

That’s the advice of safety expert Gene Saunders, founder & CEO of Project Lifesaver International, a public safety nonprofit that provides state-of-the-art locating technologies designed to protect, and, when necessary, quickly locate individuals with cognitive disorders who are prone to wandering.

Saunders, who has also served more than 33 years with the Chesapeake Police Department in Virginia and gained his own personal experience as a caregiver for his mother-in-law with cognitive disorders who are prone to wandering.

The following points may help with your decision:

**Basic Home Safety**

- Avoid clutter, it can cause confusion and pose a tripping hazard.
- Install smoke and carbon monoxide detectors throughout the home; ensure proper function and battery life.
- Keep all hazardous substances secured and out of reach: medications, alcohol, cleaning products and chemicals, poisonous plants.
- Display emergency numbers and your current address where your family lives near all telephones and on bulletin boards.
- Check each room for adequate lighting. Use night lights when necessary.
- Avoid use of extension cords and secure any loose electrical cords—they can create a tripping hazard.
- Cover any unused electrical outlets with childproof plugs.
- Remove any scatter and throw rugs—especially in common walking paths.
- Use textured strips or nonskid wax on hardwood and tiled floors to prevent slipping.
- Place red tape around floor vents, radiators, and other heating devices to deter the person from standing on or touching them when hot. Your loved one may recall the color red as a warning after other things are forgotten.
- Install secure locks on all doors and windows leading outside as well as doors to rooms within the home that may pose a safety risk.
- Secure locks should also be placed on cabinets with contents that pose a threat to safety, such as those mentioned earlier, as well as matches and lighters, machinery and tools, firearms and weaponry, and sharp knives and scissors.

**Deal with the Unseen**

We can take many things for granted when we walk around our home, but for a person living with Alzheimer’s who is experiencing physiological changes that may affect their eye sight, hearing and more, you may want to consider the following:

- Paint walls a light color—they reflect more light and will increase visual acuity throughout the house.
- Make sure there’s adequate lighting, while also reducing glare—you may want to remove or cover large mirrors.
- Vary your home environment very little. It will make things comfortable for your person who will be able to more easily move around the house.
- Avoid violent or disturbing TV programs.

**Is it Safe to Leave a Person with Alzheimer’s Alone?**

This issue needs careful and ongoing evaluation by a caregiver, especially as Alzheimer’s disease progresses. The following points may help with your decision:

Does your person...

- Become confused or unpredictable under stress?
- Recognize a dangerous situation, such as fire?
- Know how to use the telephone in an emergency?
- Know how to get help?
- Stay content within the home?
- Wander and become disoriented?
- Show signs of agitation, depression or withdrawal when left alone for any period of time?
- Attempt to pursue former interests or hobbies that may now warrant supervision, such as cooking, appliance repair or woodworking?

**Wandering Preparation & Prevention**

“Wandering is a very common and potentially dangerous behavior for individuals living with Alzheimer’s disease,” says Saunders, who pioneered the search and rescue technologies used internationally under the Project Lifesaver name. Here are his suggestions on how a caregiver can prepare for wandering:

- Notify your neighbors of your family member’s potential to wander and alert them to contact you if they see your loved one out alone.
- Give a profile of your person to the local police department—information will already be at their disposal if your loved one wanders.
- Use identification tools. Obtain a medical ID bracelet with the words “memory loss” and an emergency phone number inscribed. Place name and phone number labels in garments to aid in identification in case your loved one doesn’t always wear the bracelet.
- Consider using Project Lifesaver, an electronic tracking bracelet. Visit www.projectlifesaver.org or call toll-free 1-877-580-LIFE to get more information as well as determine if there’s a local agency in your area that can provide this valuable service.

**Project Lifesaver state-of-the-art technology.**

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The Importance of Having a Power of Attorney

By Kathie Brown Roberts, Esq.

The COVID-19 pandemic reinforced that life can change very quickly, which is why it’s important to have plans in place regarding your financial, legal and healthcare wishes.

A power of attorney is a legal document authorizing someone to step in and legally help with financial and healthcare decisions without having to go to court. Everyone with a family history of Alzheimer’s, or who may have learned recently that they or someone close to them has the disease, should create a power of attorney to protect their future.

Having a power of attorney in place can help ensure your wishes are carried out when you can no longer voice them. It is important to remember that these documents, when put in place, dictate what can or cannot be done on your behalf. It’s critical to appoint an agent that you can absolutely trust to make financial and/or healthcare decisions for you. Additionally, these documents have to be created before you lose the legal ability to sign them.

You can change your mind about who can make decisions for you as long as you have capacity, the ability to use and understand information to make a decision, and communicate any decision made. All power of attorney documents are generally revocable (can be changed) by the principal, assuming that the principal has the capacity to revoke the document. Similarly, all power of attorney documents are ineffective upon the death of the principal.

Decisions about finances and healthcare are significant, and you should play a leading role in making them. Detailing them ahead of time through a power of attorney makes sure your voice is always heard.

Whether or not an agent (the person or persons you designate to be in charge) is able to perform a power or direct an action on your behalf also depends on state law and the provisions document itself. State laws on how to protect power of attorney may vary so your state’s law needs to be reviewed when creating this legal document.

It is important to remember that these documents, when put in place, dictate what can or cannot be done on your behalf. It’s critical to appoint an agent that you can absolutely trust to make financial and/or health care decisions for you. Additionally, these documents have to be created before you lose the legal ability to sign them.

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Decisions about finances and health care are significant, and you should play a leading role in making them. Detailing them ahead of time through a power of attorney makes sure your voice is always heard.

Kathie Brown Roberts, Esq., is a certified elder law attorney (CELA) and member of the National Elder Law Foundation.

A Certified Elder Law Attorney (CELA) must have years of work in the discipline and pass a rigorous examination to prove their knowledge of tax, public benefits, trust and other disciplines comprising elder law. CEAs are required to update their skills and knowledge throughout their careers and are subject to peer review. You can find a CELA near you at www.nelf.org or by calling 520-881-1076.
Nursing homes across the country closed their doors to outside visitors to protect the health and safety of their residents and staff during the COVID-19 pandemic. The restrictions were necessary (senior citizens with underlying health conditions are among the most vulnerable to the coronavirus), but nevertheless hard for family members who had to go months without visiting their loved ones.

Whether it’s a situation like COVID-19, where guests are prohibited, or simply that you live too far away to visit regularly, geographical and physical distance do not have to stand in the way of keeping regular contact with a family member in a nursing home. Here are ways to stay connected if face-to-face visits are impossible or limited:

**Use technology.** Video chat platforms such as Zoom, Skype, and FaceTime allow you to see and speak with your loved one in real time from anywhere. If that’s not an option for you, phone calls, email or writing letters are all viable alternatives. Most nursing homes will be happy to assist you with this; care settings across the country facilitated regular interactions between residents and their families throughout the COVID-19 pandemic.

**Send favorite items.** Care packages with favorite trinkets, snacks and/or other fun items that have special meaning to your loved one can help provide them comfort, improve their mood and reduce stress and anxiety (as well as reminding them you are thinking about them). Before sending a care package, check with the nursing home first to find out if any items are prohibited for health reasons.

**Have a dialogue through photographs.** Care settings often assist families in sending photos back and forth. In some cases, they encourage “themed” pictures (i.e., wearing a funny outfit) to spark a fun, engaging, ongoing dialogue. Photos can also be a form of reminiscence therapy, having the added benefit of eliciting memories.

**Get updates from the care setting.** In a situation like COVID-19, where there are prolonged disruptions in programming and possibly some services, find out how the facility will deliver special care needs that your loved one may have, such as physical or occupational therapy. If they need personal care services, like getting toenails or fingernails cut, inquire about how those services will be delivered or what alternatives are in place. Ask about what steps the care setting is taking to deliver activity programming (i.e., music, art, dance/movement, crafts, exercise) that can help keep your loved one engaged and active.
A RESOURCE FOR FAMILIES
WHEN THEY NEED IT THE MOST.

For caregiving support every day, go to www.alzfdn.org

Helpline
7 Days a Week
866-232-8484

Educational Programs & Webinars

Online activity programs & tips

Informational factsheets (in English & Spanish)

National Memory Screening Program