



Position Paper: COVID-19 and Supporting Black Communities at the End of Life

Prepared by the Diversity Advisory Council of
the National Hospice and Palliative Care Organization

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Introduction

There was great excitement and expectation with 2020, new lenses, new visions and new hope for a better and a more enlightened society. These feelings were quickly dashed when COVID-19 took center stage in the global world. As of August 17, 2020 the novel Coronavirus has infected more than 5 million Americans with a death toll of nearly 170,000 of our neighbors, family members and friends.¹ Additionally, the United States is faced with national and international protests over the death of George Floyd, a Black American man killed while in custody of four policemen in Minneapolis on May 25. While most experienced peaceful protests, in some cities and the nation's capital these turned to violence, looting, pepper spray, and arrests. It is against this backdrop that NHPCO's Diversity Advisory Council is putting forth this Position Paper on COVID-19 as it affects hospices with emphasis on the care, treatment and management of diverse populations in the present-day society. In addition, the deaths from COVID-19 to date have impacted the lives of Black people and other diverse groups disproportionately, relative to the general population, nationally and internationally.²

The world is seeing severe devastation from the current pandemic. The Diversity Advisory Council in this Position Paper endeavors to help communities at all levels better understand the situation, with emphasis on building trust with the diverse populations relative to patient care and the pain, misery, grief and sorrow caused by this horrible virus.

We must acknowledge the challenges of dying and death: Work at it, work on it and with the affairs of life and living. The work must be done simultaneously, not separately. A better state of affairs will require addressing barriers and/or removing blocks which hamstringing society in its impetus to move forward in responding appropriately and effectively. We must not let fear of the past, fear of the present or fear of the future impede our efforts.

This Position Paper will help ethnic communities to put forth and foster a better world in which to live well until you die. As we learn from the past and understand the present, we can move forward in the future with a loving, caring, professional patient/family and community atmosphere. To provide for all people in our global community, it is imperative that we develop strategies related to health, mental health, economics, social care and spirituality.

We cannot, we must not, we shall not and will not lose any ground in relation to what we have achieved in the care of diverse populations in the United States of America.

Building Trust

Perhaps it is time for us to look at the barriers within ourselves as providers versus targeting minority communities wondering why we cannot "get in." In the process of compiling research for this Position Paper, this writer could not help but to entertain the question, "If data has continuously revealed disparities in minority enrollment and the issue researched to the extent it has been—why are we not seeing significant improvement in national data?" The institution of hospice and palliative care may in fact need to change itself, its views, its practices, and its mentality.

According to a 2016 Journal of Palliative Medicine article, *Racially Associated Disparities in Hospice and Palliative Care Access: Acknowledging the Facts While Addressing the Opportunities to Improve*, African-American hospice utilization does not correlate with the population's excessive mortality rate from most causes of death—including hospice eligible diagnoses.³ Other researchers

¹ <https://www.cdc.gov/coronavirus/2019-ncov/cases-updates/cases-in-us.html>

² Data source: COVID-19 case-level data reported by state and territorial jurisdictions. Case-level data include about 80% of total reported cases. Numbers are unadjusted rate ratios. <https://www.cdc.gov/coronavirus/2019-ncov/downloads/covid-data/hospitalization-death-by-race-ethnicity.pdf>

³ Payne, Richard. "Racially Associated Disparities in Hospice and Palliative Care Access: Acknowledging the Facts While Addressing the Opportunities to Improve." *Journal of Palliative Medicine*, vol. 19, no. 2, 2016, pp. 131–133. doi:10.1089/jpm.2015.0475.

suggest that social determinants are more likely to change before the more resistant problem of health disparities.⁴ Ultimately, organizations should entertain innovative minority engagement initiatives that add genuine value to communities rather than investing in “Diversity, Inclusion and Equity” solely for capitalization and incentivization. Hospice and palliative care providers would do well to educate themselves on the psyche of Black, Indigenous, and People of Color (BIPOC) that has been shaped by systemic racism, socioeconomic inequities, and disparities in health care education.

“Ought I to trust or not?”

Inclusion is accomplished not by telling communities what they should do, but through establishing trusting relationships. (NHPCO Inclusion and Access Toolkit)

Of all the ingredients of human connection, “trust” is at the core. There are keywords within our vocabulary that have phenomenon elements to them, and “trust” is one of those words. For something to be a phenomenon, it must be an observable fact or event. The sheer nature of “trust” fits into this category every time. *Trust is defined as “a situation characterized by the following aspects: One party (trustor) is willing to rely on the actions of another party (trustee); the situation is directed (in the current position) and the future hopes.”*⁵ The word spreads across multiple subject matters, and health and health care treatment is one that carries an immense weight of responsibility. Trust is the consideration of one person or group of people promising to fulfill a task or duty on behalf of another. Trust is the gateway to a host of emotional feelings that can have both positive and negative outcomes—that challenge the gatekeeper. When you look at the nature of trust you must be willing to investigate the whole and not just the personal adornment of your safety.

One’s space of fragility must become challenged to the point that you are willing to have your privilege broken, damaged, and become vulnerable for the greater cause of all and not some who share cultural genetics and ideology of a select. But many seek to keep their created privilege intact and avoid placing themselves in any state of vulnerability. The title of this writing comes at the hands of the epistemology of trust which asks the question, “Ought I to trust or not?” The epistemology is the study of knowledge, and we must ask what we know about trust and what do we need to know about it.

In the investigation of “trust,” we must seek to bring the focus of it into view with the hopes that it has promise. Annette Baier states the difference between trust and reliance by saying that **trust can be betrayed, whilst reliance can only be disappointed.**⁶ The basis of her statement comes at the heels of Sissela Bok, who said in her writings, “*Whatever matters to human beings, trust is the atmosphere in which it thrives.*”⁷ If the philosophy of trust is a matter of being betrayed and a matter of thriving from the hopes of another being willing to contribute to the needs of the human being’s plight, then what has happened?

The social vantage point of trust is, or at least is supposed to be, that we are all, in some form, in a position to contribute to the social setting of the advancing of each other. But there are barriers that have and continue to hinder this advancement among all people without prejudice and hate. Some of the leading barriers are greed, selfishness, and pride, and it is with just these three that mistrust continues to be cultivated by many lives. Barbara Misztal cites in her book that trust “*makes social life predictable, it creates a sense of community, and it makes it easier for people to work together.*”⁸ And it is by these claims that we have experienced a disconnect around the subject of trust. Can you have trust without truth?

Let us investigate each one of Barbara Misztal’s claims.

- **It makes social life predictable.** Her first statement has a quality of hope which says with trust comes a space of “social life predictability” meaning that one could predict the nature of another on the basis of trust in them or the lack of trust in them. It is difficult to imagine that this level of trust is available, especially in the circumstances of meeting the basic needs of food, clothes, shelter, and health care access and treatment.

⁴ Satcher, David, et al. “What If We Were Equal? A Comparison Of The Black-White Mortality Gap In 1960 And 2000.” *Health Affairs*, 2005, www.healthaffairs.org/doi/full/10.1377/hlthaff.24.2.459.

⁵ Definition of Trust. [https://en.wikipedia.org/wiki/Trust_\(social_science\)](https://en.wikipedia.org/wiki/Trust_(social_science))

⁶ Baier, Annette. “Trust and Antitrust.” *Ethics*, vol. 96, no. 2, 1986, pp. 231–260. *JSTOR*, www.jstor.org/stable/2381376. Accessed 18 Aug. 2020.

⁷ Bok, Sissela. *Lying: Moral Choice in Public and Private Life*. New York: Pantheon, 1978. 326. Print.

⁸ Snijders, Chris, and Barbara A. Misztal. “Book Review.” *American Journal of Sociology*, vol. 102, no. 6, 1997, pp. 1724–1725. *JSTOR*, www.jstor.org/stable/10.1086/231133. Accessed 18 Aug. 2020.

- ***It creates a sense of community.*** The language of this statement has an air of hope in the sense that people have come to trust those within their community on the basis of desired hopes or positive interactions with each other and that a system of correction is in place for mishaps.
- ***It makes it easier for people to work together.*** The nature of trust is also valid in that a community that has come to a place of trustworthiness has desire and a plan to work together.

The unfortunate nature of trust is when the dominant community sets the stage for what and who is to be trusted. This is concerning because the liberty of others is then not valid nor valued. The psychology of trust is the expectation that others will do what they said they would do without or with limited biases. The exclamation of our psychological behavior and how we feel about self and others is often times viewed as a state of discomfort due to many who identify as racial and ethnic minority groups lacking the feelings of hope and security—knowing that our needs have the possibility of being met in fragments, rather than whole. To eliminate all forms of biases is unrealistic; every person has formulated biases throughout their life. What is important is to eliminate the negative impact our biases have on the decisions we make, especially when providing care to others.

To put forth the sheer nature of equitable hope and its ability to offer fair and impartial opportunity is a dream we seek to bring into reality. So how do we add in a connection of trust to end-of-life care in this difficult environment? The most cited concern is maneuvering through or within the health care system before needing palliative and/or hospice care. If the access, treatment, resources, and care is lacking in the beginning, trust is less likely to be there in the moment of end-of-life. The number of cited cases that speak to the mistreatment of minority and underrepresented families is too numerous to just pick one.

The blame for the cause of this mistrust is not one person or one group, but it is the nature of the system that has been created. Insurance rates and coverage, a profit-over-people philosophy, and access depending on geographical location are just a few contributing elements. Not too long ago, doctors made house calls to address sickness and treatment. With the modernization of technology and science, the scope of discovery has gotten more advanced, but fair treatment in health care has not been able to keep the pace.

Some health agencies have felt that returning to the “House Call” model may be the needed answer to supporting sickness and terminal illness. The goal must be to serve and support everyone. One of the great threats to minorities is the inability to receive proper care, in fear of being unheard, misunderstood, judged, misdiagnosed, or worse, feeling that your culture is being targeted for a research study. Patients desire high quality, unbiased health care—that is not dependent on the color of their skin nor their ZIP code.

Though the Affordable Care Act has expanded access to health care to those who are traditionally underserved, opportunities still exist to increase the quality of care. Hospice and palliative care providers must not dismiss the prior journey of treatment along the way. Nancy Krieger, Ph.D., a professor at Harvard School of Public Health, has linked an association between Jim Crow laws as a contributing factor to more lethal breast cancer among U.S. Black women.⁹ Many discriminatory acts were addressed within the laws of government in the 1960s, but we must still address and endure the effects of discrimination in our health care system.

Various examples of mistreatment in the health of minorities and underserved communities continue to impact the decisions made by patients who identify as such when posed with health care decisions. It is important to note that African American men have been the targeted group to test a vaccine to treat syphilis only to be allowed to suffer from another untreated health condition at the hands of science.¹⁰ As we live through a time when the push for a vaccine is a top priority for scientists throughout the world, how many people will die of COVID-19 because they don't trust the vaccine that will ultimately be pushed to prevent it?

How can the health care system and clinicians overcome existing barriers in trust to ensure patients' and families' physical and cultural needs are met? The answer to this question is seemingly simple to answer but difficult to execute. To address this one must reference the statement made at the beginning that **“Inclusion is accomplished not by telling communities what they should do, but through establishing trusting relationships.”** It is from that we must start the dialog.

⁹ Krieger N, Jahn JL, Waterman PD, Chen JT. Breast Cancer Estrogen Receptor Status According to Biological Generation: US Black and White Women Born 1915-1979. *Am J Epidemiol*. 2018;187(5):960-970. doi:10.1093/aje/kwx312

¹⁰ <https://www.cdc.gov/tuskegee/faq.htm>

There are additional factors to consider that affect health and health care, such as the systematic structural racism and the inequalities in access to housing, education, employment, and justice. The health disparities we face challenge us on how we enter this life, maintain a sense of quality of life and how we transition into the eternal place. *Isaiah 26:3-4; You will keep him in perfect peace, whose mind is stayed on You Because he trusts in You. Trust in the Lord forever, For in Yah, the Lord, is everlasting strength.* It is in that trusting of a higher being that we can discover answers to these barriers.

What are some tangible ways to overcome these barriers and build trust?

- Have a health and health care advocate, someone who is in a neutral place but has the influence and authority to see things through.
- Build a framework around treatment and quality of life for elders.
- Identify implicit biases and reflect on the impact they have on decisions made related to patient care.
- Have a clear and precise plan of care and dialog with physician and patient about all options.
- Schedule time for relationship building. If there are patients who are traditionally underserved, plan to spend more time discussing options, providing education, and building trust. Doing this on the front end will prove to be beneficial to both the patient and clinician later.
- Advocate for equitable laws related to health care. The Hospice Action Network and NHPCO advocate annually for policies that impact the Medicare Hospice Benefit and all are welcome to join.

If at any length and hope of achievement, we can get to the place Dr. Bernice C. Harper speaks of which is to *"Go ye, therefore and learn from each patient, each family, each culture, and each community"* to accomplish our dreams of good health and good health care, even at the end of life.

The Impact of Mental Distress on Chronic Disease in the Black Community

In the early days of COVID-19, the White House Task Force announced the importance of coupling humanities with science in desperation to tackle our national health emergency. Several weeks later, the U.S. watched Black America's suffering with its own eyes. "I can't breathe" became the anthem of an oppressed people and Black Lives Matter sparked a national dialogue. Two national emergencies happening simultaneously—with health care and injustice at its center.

An unprecedented pandemic and social unrest made us witnesses to a "New Kind of Grief." This national emergency inspired grief compounded by pre-existing mental stressors sparked by the unceasing emotional tragedy of racism, economic marginalization and poor health in Black communities. An activist in Sacramento told *The Washington Post*, "I'm exhausted. All these things build up, and they make your soul feel such unrest. And then you add that to all the lives that nobody got justice for."¹¹ The correlation between mental distress and chronic illness amongst Blacks begins with the infrastructure of our cities, states, and nation. David R. Williams, Professor of Public Health and African-American studies at Harvard University, writes that Black communities have been living with a pandemic of chronic stress—surviving on low household incomes, living in sub-standard housing compounded by violence and pollution long before COVID-19.¹² **According to Williams, people exceed their ability to cope with stress when it is persistent and routine.** Physical responses include high blood pressure, heart disease, obesity, and diabetes, among other health concerns—illnesses that disproportionately affect Black communities.¹³

Dedication to communal health begs a starting point. Systemically racist and exclusivist institutions are now called to fulfill rhetoric of "Diversity, Inclusion and Equity." The institution of hospice and palliative care has a unique opportunity to assign meaning and action to rhetoric. Beyond medical care, organizations can drive societal health by understanding the psyche of marginalized communities, which requires learning about the plight of a people before asking for their business. For instance, it is imperative for

¹¹Holly Bailey, Annie Gowen. "'It's a Blue-Soaked Anger': Amid Protests, African Americans Feel a Private Grief." *The Washington Post*, WP Company, 31 May 2020, www.washingtonpost.com/national/its-a-blue-soaked-anger-amid-protests-african-americans-feel-a-private-grief/2020/05/31/8a31fe6e-a360-11ea-bb20-ebf0921f3bbd_story.html.

¹²Williams, David R. "Opinion | Stress Was Already Killing Black Americans. Covid-19 is Making It Worse." *The Washington Post*, WP Company, 13 May 2020, www.washingtonpost.com/opinions/2020/05/13/stress-was-already-killing-black-americans-covid-19-is-making-it-worse/.

¹³Ibid.

hospice and palliative care providers to understand the development of Black communities and the impact systemic racism via real estate has on socioeconomic determinants of health.

Redlining

The economics behind redlining was an intentional effort to alienate Black people from the mainstream community. The system of redlining was instituted by mortgage lenders and property owners who outlined specific areas within a city on a color-blocked rating scale. Maps of neighborhoods outlined the highest concentration of blacks in red. Red represents “hazardous” and credit risks—a rating system intentionally designed to set the course for generational poverty, poor education and illness.¹⁴

Hospice and palliative care providers can work towards diversity, inclusion and equity by doing a map analysis of their cities and service areas and pose the following questions:

- Is this organization participating in redlining by not servicing economically disadvantaged neighborhoods?
- Do we identify economically disadvantaged neighborhoods as “unsafe” in order to not serve them?
- How can my organization add value to impoverished communities?
- Which staff have innate cultural competency skills for initiative implementation?

Economics of Redlining, Education and Health Care Segregation

Commitment to addressing racial and socioeconomic health inequities requires overstepping redlines and learning about dynamics beyond research and data gathering—we must ask minority communities what they need from us and be willing to meet these needs. To develop diversity, inclusion and equity strategies, hospice and palliative care organizations need to provide education regarding health system comprehension and navigation, disease processes, and establishing plans to die at home for residents of Black redlined neighborhoods—where access to education has been historically and systematically withheld.

With the suburban community comes the suburban education system. The redlined inner-city/urban community comes with a “hope to become adequately educated” system. For generations, Black, Indigenous, and People of Color (BIPOC) raised children whose education lacked exposure to complicated English language spoken in mainstream society. These children became parents within a perpetual cycle; thus, lacking the ability to be higher education role models.¹⁵ Redlining, inaccessible education, and health disparities have deep systematic, racist connections. Mapped red lines distinguishing Black, “hazardous” and “high credit risk” communities also carved out segregated health systems.

Health care system segregation continues to influence chronic disease susceptibility and mortality rates among Blacks. The economics driving education and health segregation suggests that there are two health systems—one for those who know how the system works and its benefits, and one for those who *decide to trust* and hope to benefit.

Hospice and palliative care providers are encouraged to position themselves in the gap between these redlined delivery systems by addressing disparities in health care education.

Organizations can:

- Conduct an analysis of the education system within redlined communities
- Identify age group(s) that may benefit from early chronic disease education
- Consider investing in a community health education campaign
- Be innovative about multi-generational engagement
- Collaborate with unlikely community health equity stakeholders

¹⁴ Fortson, Jori. “Rating Health After Redlining.” *Public Health Post*, 24 Jan. 2020, www.publichealthpost.org/research/rating-health-after-redlining/.

¹⁵ Commentary • By Richard Rothstein • November 12, Richard Rothstein. “The Racial Achievement Gap, Segregated Schools, and Segregated Neighborhoods – A Constitutional Insult.” *Economic Policy Institute*, Race and Social Problems, 12 Nov. 2014, www.epi.org/publication/the-racial-achievement-gap-segregated-schools-and-segregated-neighborhoods-a-constitutional-insult/.

- Develop sustainable programs
- Normalize hospice and palliative care services by establishing a presence across the health care continuum
- Engage with or including faith leaders in dialogue

While hospice and palliative care organizations cannot single-handedly renew society, there are opportunities to earn and establish trust with a community of persons who have no reason to trust and to educate where education has been withheld. “Black Health” has been a longstanding conversation. Service providers can reinvent what it means to preserve quality of life and develop initiatives to be health system educators and *trusted* service providers.

It is this section’s assertion that hospice and palliative care participation throughout the health care continuum via health education would establish sustainable relationships with BIPOC. Provider initiatives that add value to communities of color in addition to capitalization efforts will have also earned opportunities to become preferred providers by BIPOC for both existing and future generations. Should the hospice and palliative care industry miss opportunities to utilize education as a guide to leading disparate communities out of racial, socioeconomic and health inequities, we will continue to see data that suggests we aren’t trying hard enough to serve the totality of our communities.

A New Kind of Grief: How COVID-19 Has Affected the Grieving Process of Disenfranchised Communities

Grief is defined as a feeling of deep sorrow, and per the Kubler-Ross model, the 5 stages of grief consist of *Denial, Anger, Bargaining, Depression* and *Acceptance*.¹⁶ Since these stages are considered universal and experienced by people across many cultures, and not necessarily in the same order, during this pandemic the experience of grief has become more enhanced. Adjusting to loss of personal freedoms, resources, jobs, schools, social groups, health, and death simultaneously has pushed communities of color that are already dealing with racial and health disparities into finding new ways to cope and mourn.

Grief expert David Kessler provides his perspective about how people can work to process feelings during this pandemic and explains how it relates to the stages of grief.

- Denial: *This virus won't affect us.*
- Anger: *You're making me stay home and taking away my activities.*
- Bargaining: *Okay, if I social distance for two weeks everything will be better, right?*
- Sadness: *I don't know when this will end.*
- Acceptance: *This is happening; I have to figure out how to proceed.*

Acceptance is where the power lies and where we find a sense of control. “*I can wash my hands. I can keep a safe distance. I can learn how to work virtually.*” It’s interesting that David Kessler used this as an example for Acceptance because a disproportionately high share of Black and Hispanic workers cannot telecommute from home, according to a report by the Economic Policy Institute based on federal labor data.¹⁷ People of color often live in urban areas, live in multi-generational homes, and work jobs that are deemed as “essential.” Each of these factors impact how communities of color manage their grief while dealing with the loss due to COVID-19.

Now that we have defined grief, let’s look at the types of grief for a better understanding of how communities are being greatly affected.

- Anticipatory grief: *Feeling of grief for an impending death.*
- Sudden grief: *Unexpected and devastated nature of the experience.*
- Complicated grief: *Grief that is prolonged and dramatically interferes with the ability to function.*

¹⁶ The five stages of grief. <https://www.psycom.net/depression.central.grief.html>

¹⁷ Not everyone can work from home. <https://www.epi.org/blog/black-and-hispanic-workers-are-much-less-likely-to-be-able-to-work-from-home/> (March 19, 2020)

- Ambiguous grief: *Loss that occurs without closure or clear understanding.*
- Disenfranchised grief: *Grief that is not acknowledged by society.*
- Collective grief: *Grief felt by a collective group such as a community.*
- Post-traumatic grief: *A medically defined condition applied to people who are suffering challenging thoughts and reactions following a stressful event.*

At any given time, communities are experiencing these types of grief on both a macro and micro level. From witnessing the tragic deaths and loss of members in the Black community on social media as a nation to seeing how grief is affecting us personally in our own households.

While COVID-19 has disrupted many communal traditions, sudden and ambiguous grief have forced a new norm upon many cultures in traditions regarding death of loved ones, be it a repast, funeral mass, graveside service and/or *shiva*.¹⁸ Now we are seeing how communities that have experienced greater COVID deaths will have to process their grieving and the PTSD that may result after this has concluded. In some Native American communities, many face the challenges of jurisdiction, time and distance when retrieving the body of their loved ones to have them buried on their native soil in keeping tradition to their mortuary customs. The Native American community believes that the whole person should be brought back to their native grounds, be it body part from an amputee, or even the placenta from birthing a baby. There can be resistance when seeking medical service outside of the tribal communities because of the low number of health professionals available to the community, now the patient and/or family is out of that tribe's jurisdiction and the federal government rules are different. These traditions are not always honored outside of the Native American community and so more barriers are present when trying to collect the bodies of their loved ones, especially during these times.

In communities where places of worship are sanctuaries of emotional and spiritual refuge, these groups have experienced tragic numbers of deaths due to COVID-19. Although there was some resistance regarding social distance recommendations early on, the number of deaths that occurred in faith-based communities has led to increase usage of phone prayers lines and virtual service resources. For all communities, new social distancing guidelines has added heightened distress and complicated grieving processes leading to extended, complicated grief and healing. The inability to complete these rituals and traditions have left many families and friends wondering if they have truly honored the legacy of their loved one, creating feelings of ambiguous grief, guilt, and a lack of closure. These changes have left many with feelings of deprivation because of social distance guidelines and not being able to be comforted, or to be the comforter, without those social interactions of touches and hugs. Since grief looks different for everyone, it is common to experience feelings of extreme sadness, anger and emotional disconnection or numbness.¹⁹ Grief can manifest with physical symptoms such as changes in digestion, forgetfulness, shortness of breath, exhaustion, aches and pains that you didn't notice before and a change in your normal sleeping habits.

This new grief was greatly enhanced with anyone admitted to the hospitals, assisted living facilities, independent living facilities, and nursing home communities. With the Associated Press reporting that one in four deaths in a nursing home were related to COVID-19, visitations with friends and family members were prevented, and often times home care and hospice staff were limited from serving their hospice patients for fear of spreading COVID-19.²⁰ Residents quarantined for up to 14 days experienced various changes in their routine and loss of interaction with their loved ones. This has had a great impact on their physical and mental health, leading to additional feelings of loss and separation.

Face-to-face visits required by Medicare and Medicaid were now done via tablets and phones, and this became the new normal. Electronic devices have become a tether line between patients and families trying to keep some form of normalcy. Many means have been promoted in helping to get grief and mental health help to those who normally would not seek out those services, such as telehealth, tele psych services, Zoom, Facebook apps, and phone calls. Providers such as End of Life Doula's saw an increase in requests for online training from professionals and caregivers alike. It is recommended by the APA and the Mental Health Association of America to continue those practices after the pandemic has passed and restrictions have lifted. Continual follow-up and monitoring will be important because this pandemic will have a long impact on the mental health and grief in the community

¹⁸ A seven day formal mourning period for immediate family, following burial of a Jewish person.

¹⁹ Weir, K. (2020, April 1) Grief and COVID 19: Mourning our bygone lives. Retrieved from <https://www.apa.org/news/apa/2020/04/grief-covid-19>

²⁰ Nursing homes represent more than 1 in 4 COVID-19 deaths. <https://apnews.com/7f79f4e427cf45523d6270f01e5f33ea> (June 18, 2020)

further down the line.

Conclusion

At the onset of the year 2020, many celebrated a year of new vision. At the time, very few anticipated that the world would be challenged with a global pandemic that would greatly impact the economy and education systems and become the cause of death for nearly 170,000 people in the United States. Although 2020 has yet to unfold as many planned and hoped for, the impact of COVID-19 on Black communities has become undeniably clear.

When one becomes a clinician, a commitment is made to respect the basic principles of medical ethics: autonomy, justice, non-maleficence, and beneficence. According to Stanford University, beneficence “demands that health care providers develop and maintain skills and knowledge, continually update training, consider individual circumstances of all patients, and strive for net benefit.”²¹ Building and maintaining trust between a clinician and patient is mutually beneficial and imperative when considering how to best care for the whole person.

NHPCO’s Diversity Advisory Council is a diverse group of hospice and palliative care professionals, dedicated to increasing access to care for those who are traditionally underserved. Like many health care workers, this group sought ways to positively impact change in health care disparities as the data was released related to COVID-19 hospitalizations and deaths. Hospice and palliative care are about peace, respect, honor, and hope. Knowing that so many have died in solitude, away from their families, and at higher rates due to the social determinants of health, contradicts what we represent as hospice professionals.

The existing social determinants of health and inequitable access to high quality care did not develop overnight and will not be resolved immediately. But steps must be taken to ensure that all patient needs are being met. Take time to build trust; invest time and energy into every ZIP code within your service area; be humble enough to know that there’s always more to learn and be open to it; and remember the oath taken when the decision was made to become a clinician. There are always opportunities for personal growth, but we must seek them. Hospice and palliative care were created to provide a personalized plan of care that supports the physical, psychosocial, and spiritual needs of patients and families. In essence, our care is about meeting patients exactly where they are, no matter who they are.

Each person is uniquely created, but we all are born and we all will die. No one’s skin color, religion, income bracket, ZIP code, or any other differing factor should determine the quality of care received at the end of life. In the words of Representative John Lewis,

“If you see something that is not right, not fair, not just, you have a moral obligation to do something about it.”

²¹ Stanford University.

<https://web.stanford.edu/class/siw198g/websites/reprotech/New%20Ways%20of%20Making%20Babies/EthicVoc.htm#:~:text=ideally%2C%20for%20a%20medical%20practice,beneficence%2C%20and%20non%20maleficence>

History of the Diversity Advisory Council

Everything in the world has a beginning, a middle and an end. Thus, the current Diversity Advisory Council of 2020 was appointed by Edo Banach, JD, President and CEO of the National Hospice and Palliative Care Organization (NHPCO).

The Diversity Advisory Council has a historical foundation upon which to build this Position Paper on the Coronavirus (COVID-19). In 1986, the National Hospice Organization (NHO), which later became the National Hospice and Palliative Care Organization (NHPCO), under the Presidency of John Mahoney and the Board of Directors at the time, established the Task Force on Access to Hospice Care by Minority Groups. Dr. Bernice Catherine Harper was appointed Chair, which was tantamount to saying, “No good deed goes unpunished.”

The Task Force on Access to Hospice Care by Minority Groups lasted for 10 years. It set the stage for a variety of programs with the impetus on access and utilization by all minority groups. Activities included town hall meetings, workshops, position papers, reviewing manuals, guidelines and evidenced based practices. These activities gave credence to what became known as the Great Hospice Commission. “Go ye, therefore and learn from each patient, each family, each culture, and each community. Thereby, setting the stage for future generations in the development and utilization of hospice care.”²²

The Task Force also represented an understanding on behalf of NHPCO to assist hospice programs across the country in their outreach plans to serve the entire community. Hospice surveys revealed that more attention needed to be given to the ethnic needs of terminally ill patients and families from all minority backgrounds.

A Regional Conference was held in 1991 entitled “Improving Access to Hospice Care for People of Color.” In 1996 there was a national meeting entitled “Meeting the Needs of the Terminally Ill Persons of Color and Their Families.” An important support document designed to assist hospices in their efforts to improve access by minority groups was the National Hospice Organization’s Resolution on Access passed by the membership in May 1992. The Resolution stated in part: “Resolved that the National Hospice Organization rededicate its efforts to reach the goal of universal access to hospice care for the terminally ill individuals in the United States.” This gave impetus to the fact that NHPCO was taking the necessary steps to make hospice care available to all Americans.

This Position Paper was written by NHPCO’s Diversity and Advisory Council. Members of that Council include:

- Nicole McCann-Davis, *Seasons Hospice & Palliative Care* (DAC Chair)
- Toby Weiss, *MJHS Hospice & Palliative Care Program* (DAC Vice Chair)
- Diane Deese, MCLSS-GB, CACPFI, EMT, *VITAS Healthcare*
- Dr. Bernice Catherine Harper, MSW, LLD
- Ronnie Duncan, *Agape Hospice*
- Brenda Gonzalez, BS, *University of Wisconsin - Madison*
- Marisette B. Hasan, RN, *The Carolinas Center for Hospice and End of Life Care*
- Barbara King, *Center for Hospice Care*
- Arion Lillard-Green, BAJ, M.TS, *Goodwin House Palliative Care and Hospice*
- Sandy Chen Stokes, *Chinese American Coalition for Compassionate Care*

²² Caring for Our Own with Respect, Dignity, and Love: The Hospice Way. Arlington, VA, The National Hospice & Palliative Care Organization, 1994.

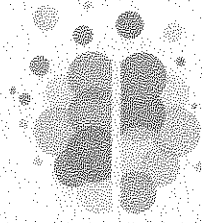


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Coronavirus Anxiety Workbook

**A Tool to Help You
Build Resilience
During Difficult
Times**

This workbook is uncopyrighted. Please feel free to share it on your website with an attribution and a link to our website.

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Introduction

In this unprecedented period of global uncertainty, we felt it was necessary to put together this workbook to provide our community with much needed support.

The first thing to note right now is that it's completely normal to be experiencing a wide range of emotions. Accepting your feelings is an important first step to building resilience. The simple act of naming your emotions has been found to benefit wellbeing. So, take a moment now to tune into your body and notice how you're feeling. Circle the emotions that you identify with:

- Anxious
- Stressed
- Worried
- Fearful
- Low
- Lonely
- Overwhelmed
- Helpless
- Frustrated
- Guilty
- Angry

Remember: It's okay to feel discomfort. Accepting distress is often the quickest way to feel immediately calmer.

What Is Stress and Anxiety?

The terms stress and anxiety are often used interchangeably. To develop a deeper understanding of mental wellbeing, it's helpful to understand how they differ.

Stress

Kelly McGonigal, an expert in the new science of stress, offers us this definition: "Stress is what arises when something we care about is at stake". Many of us are now in positions where things that matter to us feel more uncertain, which understandably gives rise to our stress response.

Stress is best understood as manifesting in the body. It's the racing heart, sweaty palms and funny tummy we're all familiar with. Central to the experience of stress is the amygdala, the area of your brain responsible for generating your body's stress response.

Experts agree that a core component of stress is the perception of threat and danger. You've probably heard of the 'fight-or-flight' stress response as a reaction to perceived danger. In fact, we have various stress responses. For example, there is one response which encourages us to reach out for social support, named the 'tend and befriend' response.

Dr John Arden, author of several books integrating neuroscience and psychotherapy, recently put forward the term *autostress* for describing what happens when our body's stress response goes on for a long time. He explains:

"Like autoimmune disorders that hijack the immune system, attacking the body instead of protecting it, autostress [transforms] the stress response system into something that attacks the self rather than protecting it."



If your body is in autostress mode, you'll experience a wide range of physical stress symptoms on an ongoing basis, regardless of your situation. That's why people often reporting feeling anxious for no apparent reason. If you're suffering from high levels of distress triggered by the pandemic, you might continue to feel this way after the virus has passed.

Signs of autostress include:

- Chest tightness and feeling like you can't breathe
- Muscle tension, aches and pains
- Headaches
- Difficulty sleeping
- Restlessness and an inability to relax
- Heart palpitations
- Digestive issues

Anxiety

Anxiety is commonly described as having both mental and physical symptoms. The distinction between mental and physical anxiety is important because different tools are required for addressing physical symptoms (what we label autostress) and mental symptoms (what we label anxiety).

Anxiety is best described as the unhelpful thinking patterns we experience when our mind fixates on threat, uncertainty and negativity.

Anxiety can occur on its own, as a response to stress, or it can trigger stress. When it occurs as a response to stress, it can intensify the stress, and, in worst cases, lead to panic attacks.

It's important to understand that you cannot control anxiety from occurring – this is your brain's automatic survival mechanism. What matters is learning how to respond to anxiety helpfully, so that you don't get carried away by it.

Here are five examples of what to look out for:

Threat Scanning	<p>When your mind searches the environment for what you fear (consciously or subconsciously). Threat scanning is often associated with your mind assigning meaning to harmless events.</p> <p>Examples</p> <ul style="list-style-type: none">• <i>Frequently checking your body for coronavirus symptoms.</i>• <i>Obsessively checking the news for coronavirus updates.</i>
Catastrophising	<p>When your mind jumps to worst case scenarios, i.e., 'making a mountain out of a molehill'.</p> <p>Examples</p> <ul style="list-style-type: none">• <i>You feel chest tightness and your mind tells you that you have coronavirus and that your life is in danger.</i>• <i>Your mind gives you the mental image of losing all the people you love.</i>



Hypothetical Worry	<p>It's important to note that worry is completely normal. It only becomes unhelpful when you focus excessively on <i>hypothetical worries</i> instead of <i>practical worries</i>.</p> <p>Hypothetical worries include 'what if' thoughts and are typically about things you don't have much control over.</p> <p>Practical worries concern things you do have control over, and they can help you be more proactive.</p> <p>If you're very uncomfortable with uncertainty, you're likely prone to hypothetical worry and spend a lot of time focused on the future instead of the present.</p> <p>Examples</p> <ul style="list-style-type: none"> • "I know I'm following all the guidelines, but what if I spread the virus?" • "What if someone gets too close to me at the supermarket and I catch it?"
Emotional Reasoning	<p>When your mind tells you that your emotions reflect reality. While emotions can act as helpful messengers, they often aren't reliable.</p> <p>Examples</p> <ul style="list-style-type: none"> • "I feel scared, so I must be in danger." • "I feel guilty, so I must've done something wrong."
Fortune Telling	<p>When your mind interprets predictions as facts.</p> <p>Examples</p> <ul style="list-style-type: none"> • "I'm going to be stuck inside for months on end." • "My mental health will keep deteriorating and I'll have to go back on meds."

My Unhelpful Thinking Patterns

Learning how to recognise and reduce anxiety is an extremely helpful life skill.

In Part One of this workbook, we'll introduce you to several tools for dealing with anxiety.

In Part Two, you'll create your *Stress Resilience Action Plan* for preventing and reducing autostress.



PART ONE

*Tools to Help You
Manage Anxiety*

Planning Your Information Diet

The media is fully aware that our brains are built to fixate on threat, uncertainty and negativity – and they capitalize on it. Most news sources are negatively biased, sensationalist and speculative in order to win your attention. Anxiety is easily fuelled by consuming this kind of information. To reduce anxiety, it's important to be aware of and take control over your information diet.

My Current Information Diet

Which information sources are you feeding your mind and how often?



Key Coronavirus Facts

If you're prone to catastrophising, you may find it helpful to redirect your attention to the facts:

- The vast majority of people only experience relatively mild symptoms.
- Coronavirus is fatal in about two to three percent of cases.
- Health advice for the public is as follows:
 - Wash your hands with warm water and soap for at least 20 seconds:
 - After coughing or sneezing
 - Before, during and after you prepare food
 - Before eating
 - After toilet use
 - When you get in from the outdoors
 - When hands are visibly dirty
 - When caring for the elderly or sick
 - After handling animals or animal waste
 - Use alcohol-based hand sanitizers as a substitute for washing your hands, but do so sparingly.
 - Maintain a distance of at least 2 metres (6ft) between yourself and anyone who is coughing or sneezing.
 - Cover your coughs and sneezes and throw your tissue into a closed bin immediately after use.
 - Avoid touching your eyes, nose and mouth.
 - Frequently disinfect surfaces, like your desk, phone, tablet, smartphone, and countertops.

Trusted News Sources

We recommend finding and sticking to a credible source you can trust, such as:

- [GOV.UK](https://www.gov.uk)
- [BBC News](https://www.bbc.com/news)
- [The Economist](https://www.economist.com)
- [CDC.gov](https://www.cdc.gov)
- [WHO.int](https://www.who.int)



Uplifting News Sources

- [Coronavirus chronicles: Here's some good news amid the dire reports](#)
- [Coronavirus: Creativity, kindness and canals offer hope amid outbreak](#)
- [Positive News Amongst Coronavirus Outbreak](#)
- [Italian 101-year-old leaves hospital after recovering from coronavirus](#)
- [98-year-old COVID-19 patient discharged from hospital](#)
- [32 Positive News Stories You May Have Missed During The Coronavirus Outbreak](#)
- [Uplifting stories from New York Times](#)
- [Positive News Magazine](#)
- [Uplifting news stories from BBC News](#)
- [German firm Bosch to cut coronavirus test time 'to 2½ hours'](#)
- [Chinese Company Donates Tens of Thousands of Masks to Coronavirus-Stricken Italy, Says 'We Are Waves of the Same Sea'](#)
- [China's richest man to donate 500,000 coronavirus testing kits, 1 million masks to U.S. to help 'in these difficult times'](#)

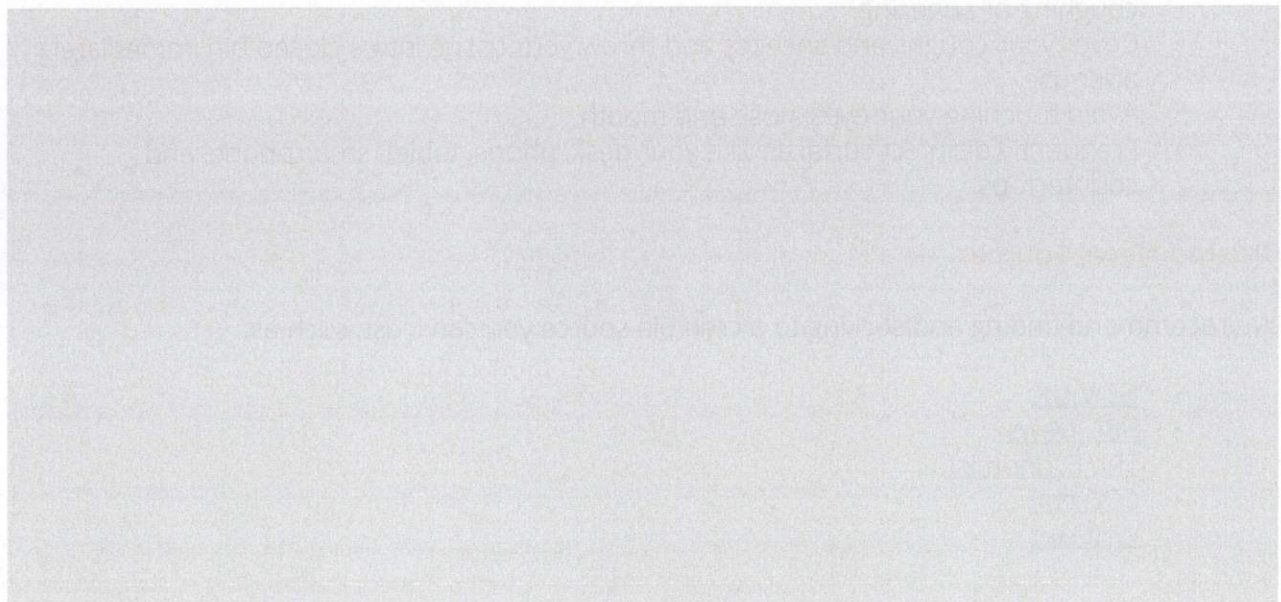
Good News Newsletters

- [The Week](#)
- [The Telegraph](#)
- [CNN](#)
- [Good News Network](#)
- [GoodGoodGood](#)
- [Country and Town House](#)

Planning My Information Diet

To reduce anxiety, we recommend checking your trusted news source once per day. We also recommend balancing out your information diet with uplifting news sources (as listed above).

Which news sources will you use and when will you read them? How else can you limit your exposure to anxiety-provoking news (e.g., by doing one digital detox day per week and limiting time on social media)?



My Spheres of Influence Worksheet

If you're prone to hypothetical worry (i.e., the 'what if?' thoughts), you may find it helpful to practice noticing these thoughts and then redirecting your attention to things within your control.

Research shows that when we shift our focus to what we can control, we see meaningful and lasting differences in our wellbeing, health, and performance. So, write down what you have control over inside the circle below. Then, note the things you cannot control outside of the circle, using the table below as inspiration.

Remember: You cannot stop hypothetical worries from occurring, but you can control your response to them.

Within My Control	Outside My Control
<ul style="list-style-type: none"> • Building resilience • Following the latest information and advice • Focusing on what's important to me • My information diet • My routine • Relaxation • Cultivating connection • Eating well • Exercising • Seeking and offering support • Voting and activism 	<ul style="list-style-type: none"> • Other people's decisions • Other people's health • The news • The government's actions • Schools opening or closing • The state of the healthcare system • Flights and holidays being cancelled • Traffic • Public transport • Aging • The weather

OUTSIDE MY CONTROL

WITHIN MY CONTROL



Practical Wisdom for Tolerating Uncertainty

People who experience anxiety have been shown to have a low tolerance for uncertainty. It's worth reminding ourselves that uncertainty is an inescapable part of life, and the sooner we become more comfortable with it, the sooner we can reduce mental suffering.

Stoic and Buddhist philosophy both emphasise embracing uncertainty and change as the essence of life. Many people find reading about these topics helpful, stating that practical wisdom helped them shift their mindset and reduce anxiety.

Practical Wisdom Resources

Videos

- [The philosophy of Stoicism by TED-Ed](#)
- [Why Stoicism Matters by The School of Life](#)
- [Buddhist Wisdom For Inner Peace by Einzelgänger](#)

Books and Audiobooks

- [Happy by Derren Brown](#) - Listen to this for free on Audible using their [30 day free trial](#)
- [Philosophy for Life](#) by Jules Evans
- [Meditations by Marcus Aurelius](#)
- [Letters from a Stoic by Seneca](#)
- [Buddhism Plain and Simple by Steve Hagen](#)

Quotes

- *"The greatest obstacle to living is expectancy, which hangs upon tomorrow and loses today. The whole future lies in uncertainty: live immediately."* – Seneca
- *"Ask yourself: Does this appearance (of events) concern the things that are within my own control or those that are not? If it concerns anything outside your control, train yourself not to worry about it."* – Epictetus
- *"You have power over your mind, not outside events. Realize this and you will find strength."* – Marcus Aurelius
- *"When I see an anxious person, I ask myself, what do they want? For if a person wasn't wanting something outside of their control, why would they be stricken by anxiety?"* – Epictetus
- *"The universe is change; our life is what our thoughts make it."* – Marcus Aurelius
- *"It's not what happens to you, but how you react to it that matters. When something happens, the only thing in your power is your attitude toward it; you can either accept it or resent it."* – Epictetus
- *"Men are disturbed not by things, but by the view which they take of them."* – Epictetus
- *"Don't demand or expect that events happen as you would wish them to. Accept events as they actually happen. That way, peace is possible."* – Epictetus
- *"Don't let your reflection on the whole sweep of life crush you. Don't fill your mind with all the bad things that might still happen. Stay focused on the present situation and ask yourself why it's so unbearable and can't be survived."* – Marcus Aurelius
- *"Freedom and happiness are won by disregarding things that lie beyond our control."* – Epictetus



Top Tip

Why not research and create a scrapbook of your favourite practical wisdom quotes? When you notice your mind spiralling, try reviewing your scrapbook to reduce your anxiety.



Reducing Anxiety With Thought Challenging

Thought challenging is a simple yet powerful cognitive behavioural therapy (CBT) technique for reducing anxiety.

As mentioned, anxiety is best described as the unhelpful thinking patterns you experience when your mind fixates on threat, uncertainty and negativity. Thought challenging helps by broadening your focus to include the bigger picture.

Below are two thought challenging techniques you can experiment with. Keep practicing and discover what works best for you.

The ABCDE Technique

Attention – When you feel distressed, stop what you're doing and pay attention to your inner dialogue. What is your mind telling you?

Believe? – Do not automatically believe your thoughts!

Challenge – Defuse anxiety by broadening your focus. What's the bigger picture? Is the thought fact or opinion? What might you think if you were feeling calmer?

Discount – Acknowledge that anxiety has been dominating your thinking and let the unhelpful thoughts go.

Explore options – What would be helpful to focus on right now? What options do I have available?

The THINK Technique

True? – Is this thought 100% true? If not, what are the facts, and what is opinion?

Helpful? – Is paying attention to the thought useful to me or others?

Inspiring? – Does the thought inspire me or does it have the opposite effect?

Necessary? – Is it important for me to focus on the thought? Is it necessary to act on it?

Kind? – Is the thought kind? If not, what would be a kinder thought?

Thought Challenging Tips

- Writing or typing your thought challenging process is more powerful than trying to do it in your head. We recommend trying out the free CBT Thought Diary app ([Google Play](#), [iTunes](#)).
- If you're not used to paying this much attention to your inner dialogue, thought challenging might feel unnatural at first. That's okay. Over time, it'll start to feel easier.
- This isn't the most appropriate tool if you're feeling very distressed, as it can be hard to think rationally when your emotional brain has taken over. Try defusing your emotions with a distraction activity (see the following page) and returning to thought challenging once you're feeling calmer.

Adapted from Carol Vivyan (2006)



Reducing Anxiety Through Distraction Activities

If your mind continues to spiral with unhelpful thoughts, distraction can be an effective tool for nipping it in the bud. It's important to note that a distraction activity must be very attention absorbing to effectively reduce anxiety. When an activity isn't working well, spend some time reflecting on why this could be and how you could make it more attention grabbing in future.

Distraction activities have the added benefit of helping you feel happier, more motivated and more energised, as well as combatting feelings of boredom.

Low activity and social disconnection are the two most fundamental maintaining factors of low mood, motivation and energy.

To feel better through building up your drive system (see page 8 of our *Understanding Your Mental Wellbeing Guide*), you need to increase your activity levels and ensure you're meeting your social connection needs (which we'll address later).

Here's a checklist of 74 ideas for healthy distraction activities. Tick the ones you like the sound of to add to your distraction activities list alongside your own ideas:

- ☐ 1. Browse mindfulness and meditation resources to try - find lots in [our online guide!](#)
- ☐ 2. Work on personal development through journaling - [here's](#) a list of prompts
- ☐ 3. Browse new [healthy recipes](#)
- ☐ 4. Plan your meals
- ☐ 5. Work your way through this [list of films](#) that have helped people with their mental health
- ☐ 6. Do the [7 Day Happiness Challenge](#) from Action for Happiness
- ☐ 7. Watch [free online documentaries](#)
- ☐ 8. Watch comedy
- ☐ 9. Play on a trivia or [games app](#)
- ☐ 10. Learn some basic yoga poses - we recommend [Yoga with Adriene](#) on YouTube
- ☐ 11. Learn calligraphy or hand-lettering
- ☐ 12. Learn how to play a musical instrument
- ☐ 13. Talk to a volunteer listener (see pages 20-26 of [The Social Connection Planner](#))
- ☐ 14. Read a biography about someone who inspires you
- ☐ 15. Do some mindful colouring - check out our free [mindful colouring sheets](#)
- ☐ 16. Rediscover old music you liked when you were a teenager
- ☐ 17. Watch a live stream theatre show from [The National Theatre](#)
- ☐ 18. Make a list of things to save up for
- ☐ 19. Have a relaxing [DIY foot soak](#)
- ☐ 20. Do a [free online nutrition course](#)
- ☐ 21. [Start a blog](#)
- ☐ 22. Download [Bumble BFF](#) and chat to new people in your area
- ☐ 23. Reorganise or redecorate your living space
- ☐ 24. Do a [jigsaw puzzle](#)
- ☐ 25. Make a list of goals for the year
- ☐ 26. Find a [new podcast](#) to listen to
- ☐ 27. Declutter
- ☐ 28. Update your CV
- ☐ 29. Make a list of books you want to read this year



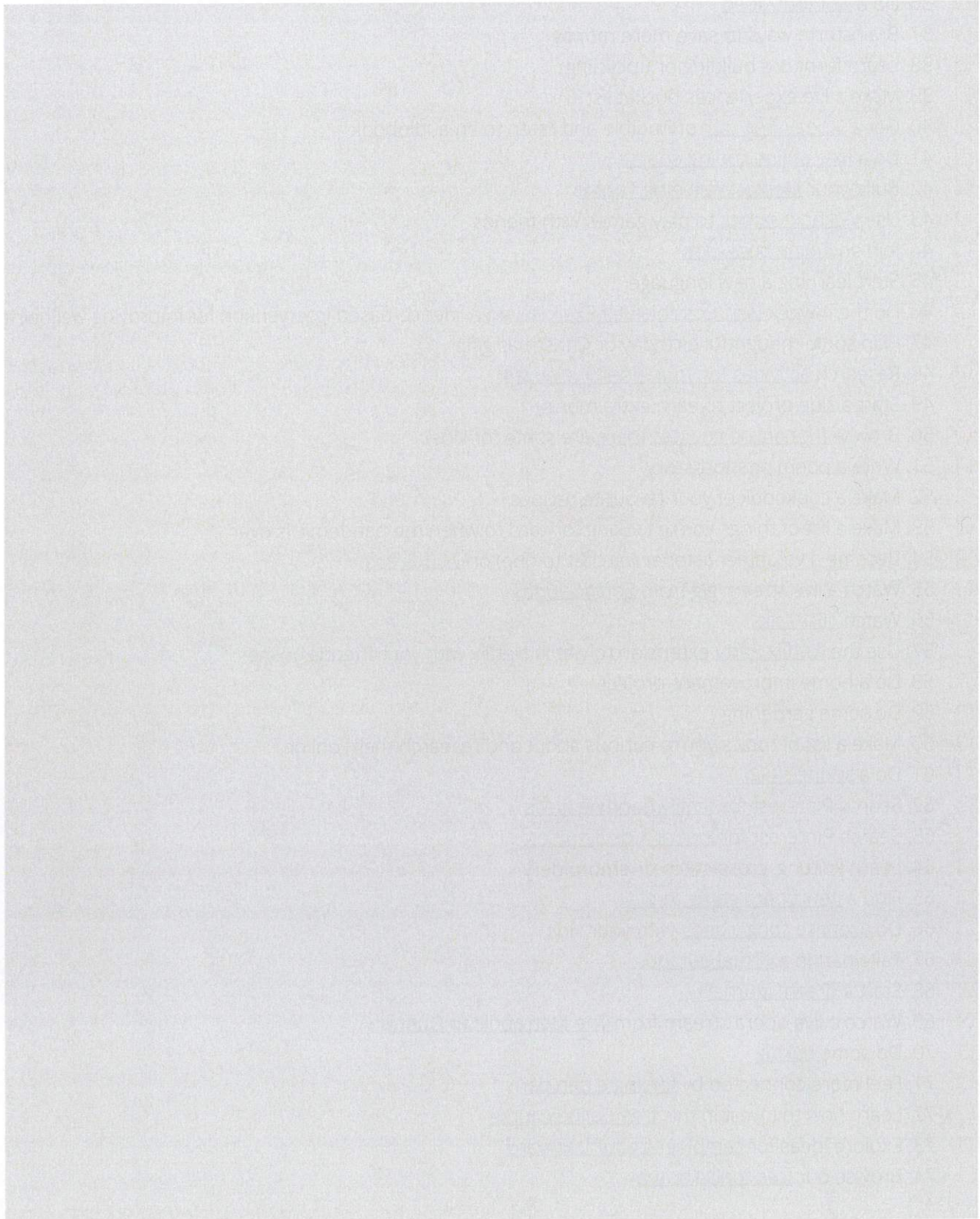
- ☐ 30. Search Pinterest for [craft or DIY project ideas](#)
- ☐ 31. Download Reddit and browse uplifting content such as [r/aww](#) and [r/humansbeingbros](#)
- ☐ 32. Do a [free online drawing class](#)
- ☐ 33. Search Facebook for local groups with volunteering opportunities
- ☐ 34. Arrange to catch up with someone over video chat
- ☐ 35. Explore new music
- ☐ 36. Do a [workout video](#)
- ☐ 37. Brainstorm ways to save more money
- ☐ 38. Learn furniture building or upcycling
- ☐ 39. Make a life experiences bucket list
- ☐ 40. Get a [30 day free trial](#) of Audible and listen to an audiobook
- ☐ 41. Do a [free online coding course](#)
- ☐ 42. Build your [Mental Wellbeing Toolkit](#)
- ☐ 43. Use [Jackbox Games](#) to play games with friends
- ☐ 44. Join an [online book club](#)
- ☐ 45. Start learning a new language
- ☐ 46. Do the 4-week [Best Possible Self Exercise](#), an evidence-based intervention for improving wellbeing
- ☐ 47. Plan some thoughtful birthday or Christmas gifts
- ☐ 48. Research [activities for your elderly relatives](#)
- ☐ 49. Start a side project to earn extra money
- ☐ 50. Browse [free online courses](#) ([here](#) are some for kids)
- ☐ 51. Write a poem or short story
- ☐ 52. Make a cookbook of your favourite recipes
- ☐ 53. Make a list of things you're looking forward to when the pandemic is over
- ☐ 54. Become a volunteer listener (or chat to one) on [7Cups.com](#)
- ☐ 55. Watch a live stream gig from [Sofar Sounds](#)
- ☐ 56. Watch [TED Talks](#)
- ☐ 57. Use the [Netflix Party](#) extension to watch Netflix with your friends online
- ☐ 58. Do a home improvement project
- ☐ 59. Do some gardening
- ☐ 60. Make a list of topics you're curious about and research them online
- ☐ 61. Do a [spring clean](#)
- ☐ 62. Search Pinterest for [family bonding ideas](#)
- ☐ 63. Search Pinterest for [indoor kids activities](#)
- ☐ 64. Learn knitting, cross-stitch or embroidery
- ☐ 65. Find a [new board game to play](#)
- ☐ 66. Do [exercise song videos](#) with your kids
- ☐ 67. Take part in a [virtual pub quiz](#)
- ☐ 68. Start a [dream journal](#)
- ☐ 69. Watch a live opera stream from [The Metropolitan Opera](#)
- ☐ 70. Do some [baking](#)
- ☐ 71. Feel more connected by [finding a pen pal](#)
- ☐ 72. Learn how to invest in this [free online course](#)
- ☐ 73. Explore ideas for [camping in your backyard](#)
- ☐ 74. Browse our [free tools library!](#)



My Distraction Activities

Write the activities you ticked in the box below.

Another idea is to make an "I Get To List". Write: *"Now that I have more free time, I get to..."* and brainstorm your ideas. What opportunities does having more free time bring for you?



MOTIVATION FOLLOWS ACTION.

“What assistance can we find in the fight against habit? Try the opposite!” - Epictetus

If you've been inactive and feeling low for a while, you'll likely be experiencing low motivation and energy levels.

You can build up your motivation and energy by increasing your activity.

Don't think – just do.

Motivation will follow!

Check out [this video](#) on the opposite action technique for more guidance.

PART TWO

Creating Your Stress Resilience Action Plan

—

Here are five different methods for preventing and reducing physical anxiety symptoms (i.e., autostress).

Choose the practices that appeal most to you and add them your Stress Resilience Action Plan.

(The more, the better!)

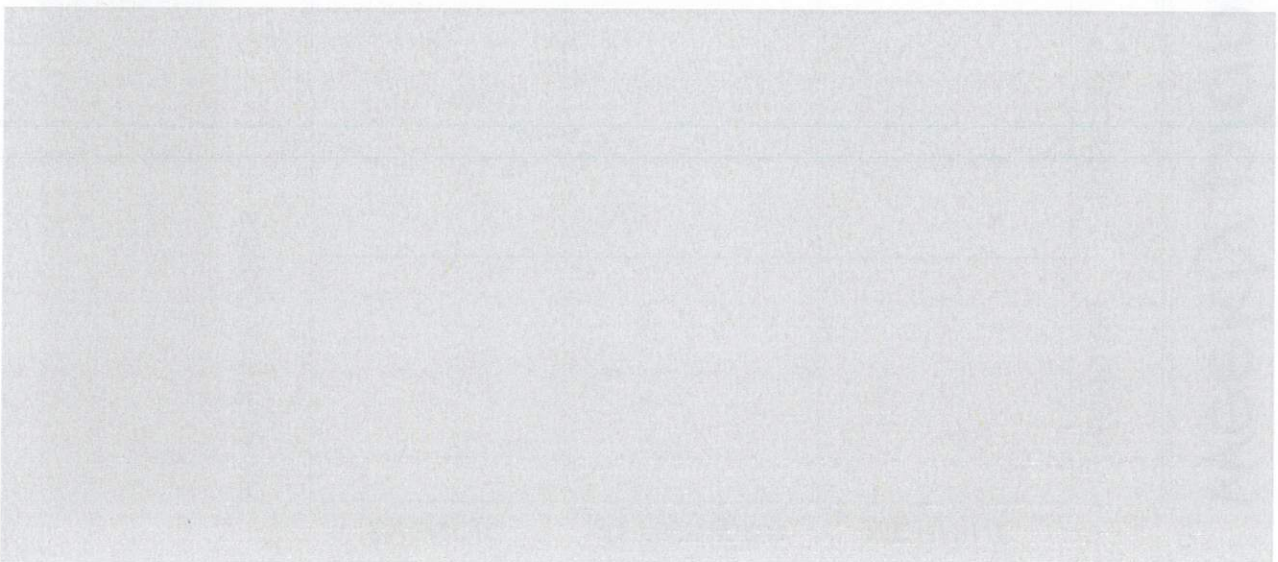
Starting a Planning Practice

Maintaining structure can work wonders for your mental wellbeing. Routines help you increase your sense of control and defuse feelings of overwhelm.

Planning Tips

- **Schedule regular breaks.** Take time to mindfully drink your tea or focus on your breathing – [here's a great website](#) you can bookmark from Calm.
- **Write a weekly goals list.** Identify what you need to do to achieve your weekly goals. Break tasks down into smaller steps and cross them off as you go to maintain a sense of progress throughout the day.
- **Identify 1-3 "Most Important Tasks".** Creating a daily MIT list helps you prioritize your most important and urgent tasks.
- **Review your crossed off items at the end of the day.** Taking stock of your achievements can help boost mental wellbeing.
- **Try a to do list app.** You may prefer a digital format such as [Google Keep](#).
- **Experiment with productivity techniques** such as [The Pomodoro Technique](#) and [Eat The Frog](#).
- **Write your daily to do list the night before.** You might find that being able to start work straight away helps increase your productivity. Also, this practice can help you clear your mind and switch off in the evening.
- **Tidy your workspace at the end of the day.** Research finds that cluttered environments interfere with your ability to focus.
- **Decide on a regular sleep schedule.** When it comes to improving sleep, research suggests that maintaining a regular sleep schedule is of high importance.
- **Create an end of work day ritual.** To enforce work-life boundaries, you might find it helpful to create an end of day ritual such as changing into comfier clothes, switching off work email notifications and putting on some music.
- **Create weekly family traditions.** Strengthen family routines through traditions such as "Board Game Fridays" and "Movie Night Mondays". Find more advice and resources for setting up a family routine [here](#), [here](#) and [here](#).
- **Be kind to yourself.** You might suddenly have a lot more on your plate. Be mindful of your inner critic, and remind yourself that you can only do the best you can.

Notes



weekly planner

WEEK OF:

MONDAY TUESDAY WEDNESDAY THURSDAY FRIDAY SATURDAY SUNDAY

MORNING

AFTERNOON

EVENING

MY WEEKLY GOALS

daily planner

DATE:

6AM

7AM

8AM

9AM

10AM

11AM

12PM

1PM

2PM

3PM

4PM

5PM

6PM

7PM

8PM

9PM

10PM

11PM

3 MOST IMPORTANT TASKS

NOTES

Starting a Daily Gratitude Practice

"Enjoy the little things. For one day you may look back and realize they were the big things." – Robert Brault

Research shows that cultivating gratitude has a plethora of benefits, including:

- Reducing stress and anxiety
- Boosting mood
- Strengthening your immune system
- Improving sleep

A simple way to cultivate gratitude is to keep a gratitude log. Each day at a set time in your daily routine, write down one thing you're grateful for on the following sheet.



GRATITUDE LOG

A circular gratitude log template. At the center is a dark gray circle containing the text "I'm grateful for...". Surrounding this central circle are 24 radial segments, each representing a day or a specific time of day for recording gratitude. The segments are arranged in a circular pattern, with lines radiating from the center to the outer edge of the circle.

Starting a Daily Breathing Practice

Breathing difficulties are associated with autostress. When you have problems with your breathing, you lower the amount of carbon dioxide that's normally in your blood. This leads to a wide range of symptoms, including:

- Shortness of breath
- Chest tightness
- Tingling or numbness in the arms, fingers, toes, or around the mouth
- Feeling dizzy and light-headed
- Weakness
- Heart pounding and racing
- Heart palpitations
- Sweating or hot flushes
- Headaches
- Feeling sick
- Fatigue

These symptoms can appear out of the blue and can also lead to panic attacks.

Your breathing difficulties may be related to:

- *Shallow breathing* (breathing in too quickly)
- *Over-breathing* (breathing in more air as you feel like you're not getting enough, for example through yawning or sighing frequently)

Some people experience both.

So, let's take a moment to test your breathing:

1. Put one hand on your chest, and one on your belly.
2. Breathe for a few seconds. Which hand rises?
3. If it's your chest, you might have developed a habit of shallow breathing.

Although the effects of shallow breathing can be very unpleasant, it won't harm you, and you can reverse the habit with a daily breathing practice. The next time you feel anxious, take a moment to notice your breathing. Focus on breathing through your stomach so that your belly rises when you inhale and drops when you exhale.

Here's a belly breathing exercise you can practice for 5-10 minutes a day:

- Inhale gently, lightly and slowly count to four, expanding your belly as you do so,
- Hold that breath for a count of two,
- Slowly exhale through your mouth for a count of six.

This is referred to as 'belly breathing'. Research shows that practicing regular belly breathing can help people feel calmer within a matter of weeks.



Top Tip

You can use the breathing timer function on the free [Stop, Breathe and Think app](#) to complete your daily breathing practice. They also have a great kids version!



Improving the Quality of Your Social Connections

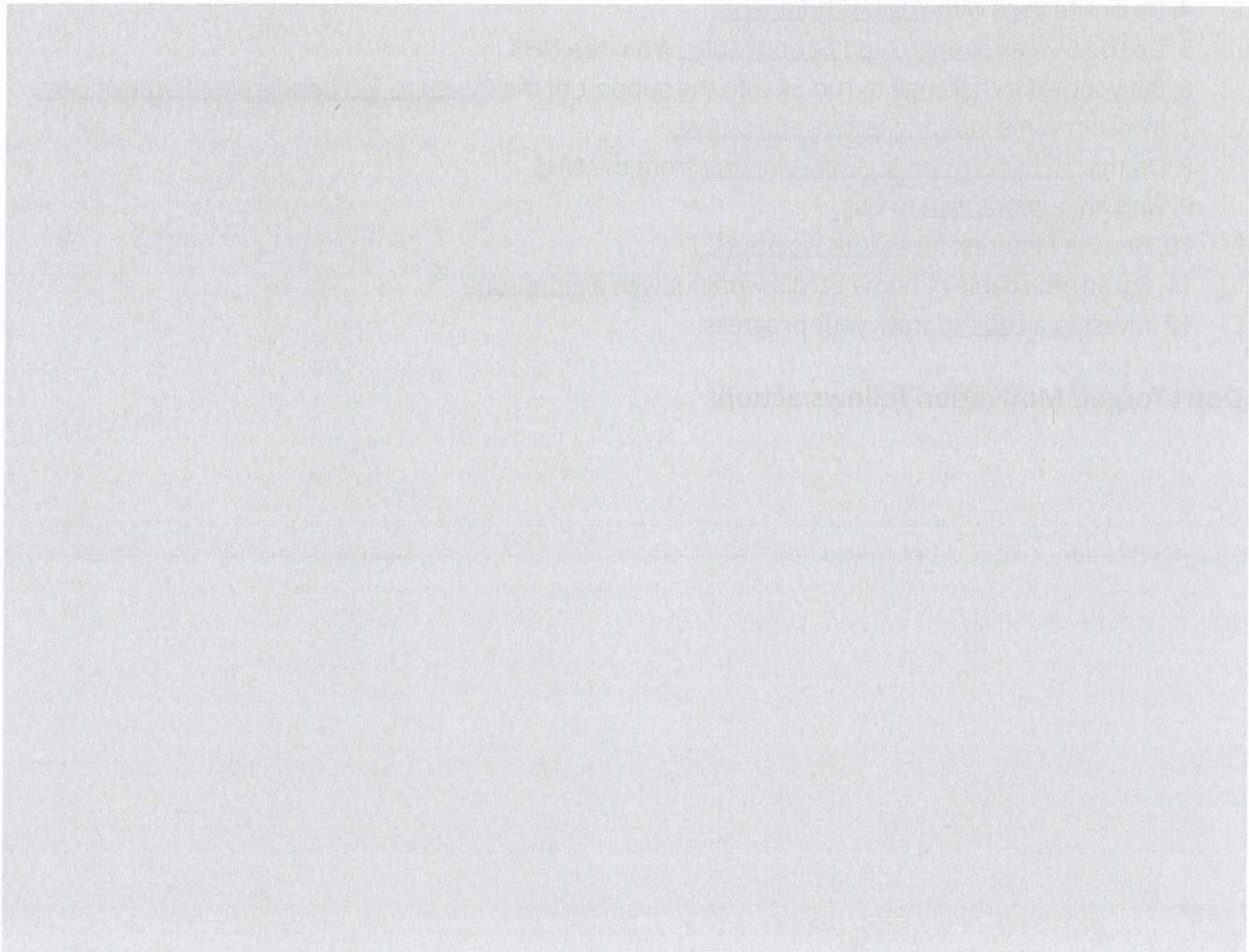
How to cultivate connection in a period of isolation?

Here are some ideas. Tick the ones you're interested in adding to your *Stress Resilience Action Plan*:

- ☐ 1. Use the online support resources listed in page 7 of [The Social Connection Planner](#).
- ☐ 2. Explore improving your communication skills using pages 12-14 of [The Social Connection Planner](#).
- ☐ 3. Talk to volunteer listeners on a helpline (see pages 20-26 of [The Social Connection Planner](#)).
- ☐ 4. Use this time as an opportunity to complete the [Relationship Inventory Exercise](#) (see page 27).
- ☐ 5. Schedule video chat catch ups with friends you haven't spoken to in a while.
- ☐ 6. Use the video chat app [Houseparty](#) to play popular games like trivia and Heads Up! with friends.
- ☐ 7. Have a virtual happy hour over video chat.
- ☐ 8. Browse [Meetup.com](#) for events that have been transferred to online.
- ☐ 9. Organise a weekly lunch date with a friend over video chat.
- ☐ 10. Use the [Netflix Party](#) extension to watch Netflix with your friends online.
- ☐ 11. Send letters to your loved ones using a service like [Postable](#).
- ☐ 12. Play Scrabble and chat to friends using the [Words with Friends](#) app.

[Here's](#) a list of 17 video chat options.

What else could you do? Reflect below.



Developing a Regular Exercise Routine

"Walking is man's best medicine." - Hippocrates

Exercise reduces the overall activation of your amygdala and sympathetic nervous system – the parts of your brain and body that generate your stress response.

Research suggests that aerobic exercise (such as walking, cycling, and jogging) provides the same benefits as non-aerobic exercise (such as yoga and pilates).

Studies also suggest you need around **21 minutes three times a week** to experience the benefits. So, you don't have to spend hours doing it – it's something most of us can fit in to our lives when it becomes a priority.

It's important to find something that you enjoy when it comes to building an exercise habit. Now more people than ever are interested in fitness, you have endless options. These include 'bedroom fitness' resources and tools that make it easy to keep moving indoors.

Here are some ideas. Tick the ones you may be interested in adding to your *Stress Resilience Action Plan*:

- ☐ 1. Schedule a daily walk.
- ☐ 2. Complete [YouTube video workouts](#).
- ☐ 3. Do a free trial of [Les Mills](#) at home workouts.
- ☐ 4. Do online yoga with [Yoga with Adriene](#).
- ☐ 5. Do the 5 week [strength and flexibility plan](#) from the NHS.
- ☐ 6. Set yourself a challenge to run 5k with the support of the [Couch to 5k running plan for beginners](#).
- ☐ 7. Invest in some [indoor exercise equipment](#).
- ☐ 8. Do this [10 minute home cardio workout](#) from the NHS.
- ☐ 9. Find an [outdoor gym](#) to visit.
- ☐ 10. Browse Pinterest for [indoor workouts](#).
- ☐ 11. Do an affordable at home cardio workout with a [jump rope](#).
- ☐ 12. Invest in a [Fitbit](#) to track your progress.

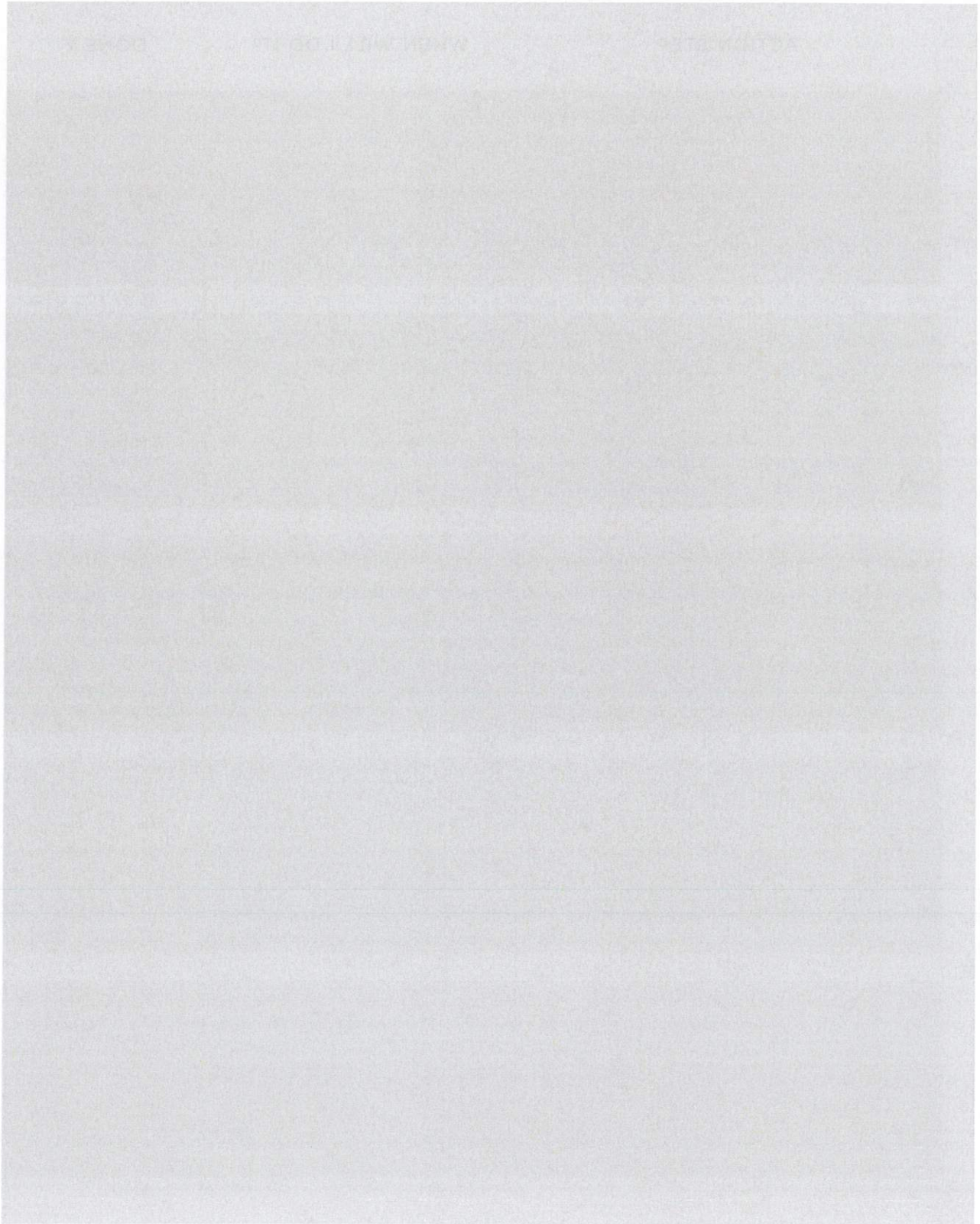
Don't forget: Motivation follows action!



Creating Your Stress-Resilience Action Plan

Review your workbook and make a note of the actions you've considered below.

Then, select up to five actions that feel the most appealing to you to add to your *Stress Resilience Action Plan* on the following page.



My Stress-Resilience Action Plan

ACTION STEP	WHEN WILL I DO IT?	DONE ✓

Further Resources

"Don't be ashamed of needing help. You have a duty to fulfil just like a soldier on the wall of a battle. So what if you are injured and can't climb up without another soldier's help?"
- Marcus Aurelius

There are endless ways to improve your mental wellbeing and an abundance of tools to support you.

This time may represent an excellent and rare opportunity for you to invest in yourself and develop skills that will help you for the rest of your life.

Here are some recommended resources:

- The free online course [Coping during the pandemic](#) from Recovery College Online (click log in as guest)
- [Free Online Meditation Resources for Times of Social Distancing / COVID-19](#) by The Awake Network
- [Coronavirus Anxiety - Helpful Expert Tips and Resources](#) from the ADAA
- The free e-Book [FACE COVID: How to respond effectively to the Corona crisis](#) by Dr Russ Harris
- [Free Guide To Living With Worry And Anxiety Amidst Global Uncertainty](#) from Psychology Tools
- [The Framework](#), our deeper dive into understanding, transforming and reducing stress, autostress and anxiety
- [The Mental Wellbeing Toolkit](#), our comprehensive set of practical tools designed to help you improve your mental health and wellbeing
- [Our online guide to accessing therapy](#). There are many therapists currently working via video chat. If you start to feel too overwhelmed emotionally or physiologically, we strongly encourage you to seek the support of a trained professional

AMMAL International



We love hearing from you.

Thank you to everyone who shared their experiences with us for the development of this workbook.

Collaboration is incredibly important to us, and we really appreciate your help in making our tools the best they can be.

Do you have any feedback on the workbook? Or suggestions for future updates/tools?

Please email us at
hello@thewellnesssociety.org.

We love to hear from you!

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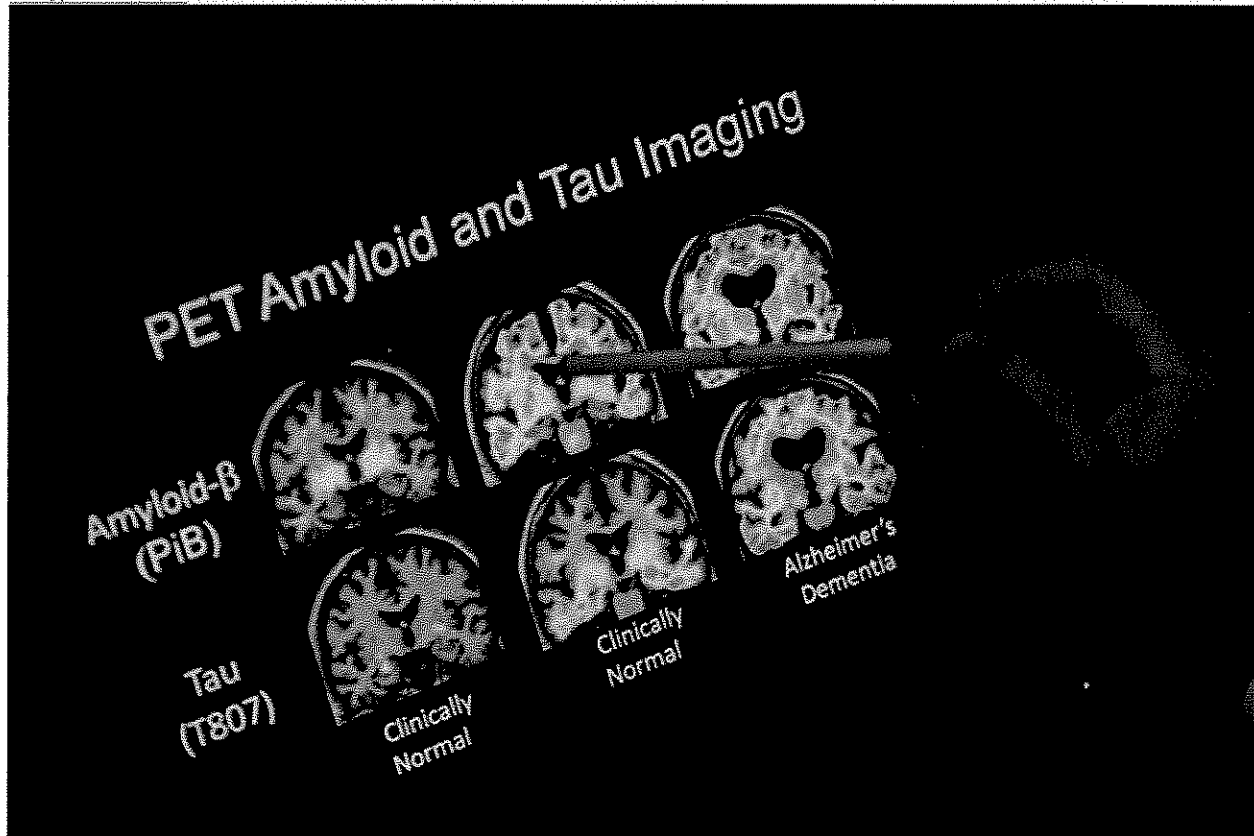
JAMMAInternational.

*A full list of references is available on request
by emailing hello@thewellnesssociety.org*

The FDA Is Reviewing Biogen's 'Breakthrough' Alzheimer's Treatment

August 08, 2020

Angus Chen



After a decade-long process, Cambridge-based biotech company Biogen has shepherded what experts say may be the “first real treatment” for Alzheimer’s disease to the Food and Drug Administration’s door.

It’s called aducanumab. In Biogen’s clinical trials, which had a bumpy road and received some mixed results, participants who got the treatment were able to retain their memory and perform every day tasks for longer than those who got the placebo.

On Friday, Biogen announced that the FDA accepted its application, complete with phase one to three clinical trials, for the treatment's approval. The federal agency will decide whether the new treatment is approved for use in the clinic by March 7, 2021.

"I think there's a reasonable chance that aducanumab, if approved and we don't know that yet, will be the first disease-modifying agent for Alzheimer's, and that will be a huge milestone and patients of mine and others can access the drug," says Dr. Dennis Selkoe, professor of neurologic diseases at Brigham and Women's Hospital and Harvard Medical School. He did not work with Biogen, but some of his patients were involved in aducanumab clinical trials.

Before aducanumab, Selkoe says doctors could only offer Alzheimer's patients drugs that would delay some of the symptoms of the disease, but then would lose efficacy. They could do nothing to slow the progression of the illness itself. But by altering the course of Alzheimer's itself, aducanumab might be able to offer patients something that no other drug candidate has been able to achieve: more time.

"Having cared for hundreds of patients with this disease, this would be a game changer. At least for some of my patients, if aducanumab is approved, [it would be] something that will slow down their deterioration, that will keep them in a better place for a longer time," he says. "This is something patients and their families have been desperately seeking."

I spoke with Selkoe about the drug and how it works. This interview has been edited for length and clarity.

What does aducanumab do?

"Aducanumab is an antibody. It binds to the amyloid beta protein, especially aggregate forms of the amyloid beta protein that we consider to be the principle bad guys in Alzheimer's disease. Alzheimer's begins in many cases, if not most cases, with the build up of this small protein called amyloid beta and the formation of amyloid beta plaques. There's a lot of evidence that people with too much build up of this small protein develop Alzheimer's.

Now aducanumab binds to amyloid beta protein. It mobilizes the body's immune system against the amyloid beta plaques, and seems to clear the plaques themselves.

"The next step in Alzheimer's is the buildup of toxic tangles of a protein called tau, as well as the accumulation of tau in an abnormal form called phospho-tau. In participants in Biogen's clinical trials, amyloid plaque burden went down and tau burden went down.

"Importantly, in the phase three clinical trials, aducanumab helped the rate of decline of cognition in patients — things like memory and other cognitive functions that are lost gradually. There was evidence that aducanumab helped preserve doing household chores, cleaning, preparing a little food and doing other everyday tasks that we expect folks to do relative to the placebo. Aducanumab blunted that decline. It didn't stop the decline, but it slowed it, which is what we're hoping for."

Is the FDA expected to approve aducanumab?

"It cannot yet be concluded that it will be approved. It was a very important step for the FDA to announce that they will review Biogen's application and accelerate that review. An FDA advisory committee will also examine the data and give an opinion — it could be a split opinion. Everything depends on what the experts believe is a sufficient degree of slowing the decline to make this appropriate for approval and therefore [administer] to however many hundreds of thousands or millions of people who present with Alzheimer's disease.

"Some experts may opine that while it shows a clinical benefit and no question removes the abnormalities of Alzheimer's from the brain, the degree of benefit is not that large. It's a small benefit that one sees. Then some will say, even if it's a small benefit, it's one that my loved ones and patients should be offered.

"From my view, it's very impressive that it can actually do that, and it should be approved based on the data. This is a very complex disease, and I don't think anyone believes that aducanumab will solve the patients' problems in

their entirety. It is a very important step in the right direction. You need to walk before you run, and without that first crucial step, we won't get as much progress towards the second and third antibody."

What would the approval of this medicine mean for those with Alzheimer's?

"This is a remarkable development. Time and again, I will tell patients that I see evidence that you have symptoms and signs of Alzheimer's, but I don't have a treatment that will slow that down. We only have symptomatic treatments that can help you for a few weeks or months, then lose effect.

"This is a game changer, even though I and others acknowledge it's not ideal. There's still more work to do. What we need to do is gain experience with how early we should be using aducanumab. It will be a remarkable thing to turn to families and say, 'We do have a drug.' "

I'm Going to Die. I May as Well Be Cheerful About It.

While death is inevitable, our attitude about it is not.

By Mary Pipher

Dr. Pipher is a clinical psychologist.

- March 6, 2020



Credit...Chloe Cushman

Generally, I don't think about death during the day. My schedule is full, and I focus on what is right before my eyes. It's usually only when I go to funerals that I reflect upon deaths past, present and future; most of the time I think about life. Still, about once a month I wake in the night and know with absolute clarity that I will soon be gone.

I have always felt my own finitude. My father had his first stroke at 45 and died at 54. My mother died of diabetes at 74. I am 72. I would like to attend my last grandchild's high school graduation and meet at least one great-grandchild. However, with my family history, that is unlikely. Now, with the news filled with stories of the coronavirus, I am reminded of the many random diseases that can strike suddenly and lethally.

Like almost all my peers, I want to die young as late as possible. I don't want to live beyond my energy level. I don't want to suffer dementia or lie helpless in a hospital. I want to die while I still believe that others love me and that I am useful.

I have done what I can to prepare for my death. I have a will, a health care proxy and medical directives. I've had many conversations with my family and my doctor about end-of-life decisions. My mnemonic device for all of them is, "If in doubt, snuff me out."

While death is inevitable, our attitudes about it are not. We can be sanguine or gloomy, solicitous of others or self-absorbed. We can approach our deaths with fear and resistance or with curiosity and a sense of mission.

Facing death offers us an opportunity to work with everything we have within us and everything we know about the world. If we have been resilient most of our lives, most likely we will cope well with our own dying. It is frightening, of course, but it is our last chance to be a role model, even a hero.

I'd like to face death with the courage of my grandmother. The last time I visited her, she was recently widowed and dying from leukemia. She lay in bed in her small home in eastern Colorado. I could see she was in pain and could barely move, but when I asked about her health, she replied: "Let's talk about you. How is college going this year?"

When I complimented her on her courage, she said simply, "I am going to be in pain and die soon no matter how I behave, so I might as well be cheerful."

By the time we are in our 70s, we are likely to have witnessed many people dying. I've seen my parents and my husband's parents die "bad deaths" with months of suffering and too much medical intervention, and I've witnessed peaceful deaths in rooms filled with love. Most of us boomers know how to behave at a bedside and have a sense of how we want to act when it's our turn to be the one in bed.

We also have had decades of observing the rituals of death — hospitals and hospice, funerals, burials and the communal meals afterward. From these experiences, we have learned what we do and don't want when it's our turn. We may continue some of these traditions, but we will also design our own. Some of my friends with terminal illnesses have hosted goodbye parties in parks or at our local blues bar. Wakes with dancing,

music and storytelling are back in style. Many of us want pine box coffins, green burials or cremations with our ashes tossed in beautiful places.

What happens after death is a popular topic among people I know. Opinions range from, “We turn into dirt,” to “I will see the face of God.” My writer friends want heaven to have a good library. One friend believes we will return to the place we were before we were born.

Jean Nordhaus wrote, “The dead are all around us / feathering the air with their wings.” A therapist who lost her young, cello-playing husband told me she feels his presence and knows they are still deeply connected in spirit. She finds that many people are afraid to die because they have no language for the numinous; however, she is certain that neither life nor relationships end with death.

I feel death may not be as big a change as we suppose. Rather, it might be like crossing a river.

I like to think that my relatives and friends will be waiting for me on the other side. I like to imagine grassy banks and flower-filled pastures shining in the sun. I like to think a lot of things, but I don’t know for sure.

I am not a particularly mystical person, but I have had mystifying experiences. When my Aunt Grace died, I drove to the Ozarks for her funeral. Her little house was surrounded by pink surprise lilies — what my cousins called “naked ladies.” The next spring, even though I had not planted them and they had never come up before, surprise lilies popped up in my garden. The year after that they popped up again but in different places. I concluded that Aunt Grace was greeting me. If I wanted to send a message after death, I would do it with flowers, too.

I love the world but I cannot stay. Death is democratic and we will all participate in its enactment. I will miss the beauty all around me. I have taken so much pleasure in the natural world, in people and books, in music and art, in cups of coffee and lolling cats. If I knew that I had a month left to live, I wouldn’t spend my time much differently than I do now.

All of my life I have loved snow.

When I was a girl in the 1950s, snow fell often in the long winters of western Nebraska. I remember one winter when, after the streets were plowed, mountains of snow 10 feet tall stood in the middle of the streets. As a young mother, my favorite days were snow days when our family could stay home and play board games. I would make soup and popcorn. I relished taking my children outside to do the things that I had done in the snow as a girl. I loved falling asleep with my family safe on a blizzard night when the streets were impassable and a blanket of peace covered our town.

Now, snow has become a profoundly spiritual experience. When it snows, I sit by my window and watch it fall. I go deep into its purity and softness.

Snow falls inside and outside of me. It settles my brain and calms my body.

I hope death feels like watching the snow grow thicker and thicker. Doctors call dying of a morphine overdose being “snowed.” I would not mind that at all. I would like to disappear in a whiteout.

Mary Pipher is a clinical psychologist in Lincoln, Neb., and the author of “Women Rowing North: Navigating Life’s Currents and Flourishing as We Age.”

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A version of this article appears in print on March 8, 2020, Section SR, Page 1 of the New York edition with the headline: *I Love the World, but I Cannot Stay*. [Order Reprints](#) | [Today’s Paper](#) | [Subscribe](#)

Maintaining human connection in time of social distancing



Connection with people is an inherent aspect of our human society. We seek out and lean on human interaction when we are experiencing the stress of life's challenges. This biological programming drives us to gather in groups, usually shielding us from mental and physical harm.

Today, we are faced with a community challenge in the form of the COVID-19 pandemic. This new threat challenges us to be creative in how we maintain our social connections, and manage our mental and physical health. The Centers for Disease Control and Prevention has recommended a policy of social distancing, which is a strategy to slow the infection rate to protect our most vulnerable community members. It preserves the ability of our health care system to provide services without being overwhelmed by extraordinary numbers of patients.

Social distancing strategy asks us to:

- Avoid large crowds.
- Work from home whenever possible.

- Close schools and provide education online.
- Cancel large meetings and conferences.
- Give up our weekly social meetings at coffee shops, restaurants, church groups and even Friday fish fry.
- Stay home.

For extroverts who thrive on social contact, this might seem like some Orwellian control measure designed for torture. For introverts, it may not initially feel much different than a normal day.

However, over time, everyone needs a varying amount of real social contact to maintain his or her mental and physical health. As we adjust to social distancing strategies, we may need to be more creative to meet our need for social connection.

It is important to understand that social distancing does not mean withdrawing from society. It is an invitation to contribute and connect in another way to the communities we live in. We can think about maintaining connection in two ways: internally and externally.

External strategies for maintaining connection

External strategies for maintaining connection can be thought of as creative ways we can safely communicate through our senses of sight, hearing, taste and touch.

Some examples of safe connection using the senses are:

- Use electronics to stay in contact with friends, neighbors and loved ones. This could include using videoconference programs, making voice calls instead of sending texts or talking with a neighbor through windows while maintaining a safe distance.
- Spend quality time with the people you live with, such as playing board games or completing an indoor project.
- Make a family meal or dessert recipe that reminds you of friends or family you are unable to visit, and then call them to tell them about it. This way, you get an experience of internal and external connection.

- Write in a journal about your experiences during this time of social distancing. Not only will this help you sort out what you are thinking and feeling, but also it can be shared going forward as a way for future generations to connect with the past.

Internal strategies for maintaining connection

Internal strategies for maintaining connection can create a sense of shared meaning that connects us to our community through our experiences and shared community values.

Some ways to create shared meaning include:

- Recognize we do not live in isolation. Our interconnectedness and choices affect others in our community, which affects people in neighboring communities, regions and so on.
- Identify friends and loved ones in your life who you are protecting by using a social distancing strategy.
- Recognize how you are protecting others by protecting people close to you.
- Think about what personal and community protection means to you. How does this feel? What value does this represent?
- Spend time sensing and feeling the importance of living your community values in your mind and body.
- Inspire, encourage and recognize others for following protective strategies at work; at home; and through electronic means, such as calls, videoconferences and social media.

Finally, recognize that when we act together to maintain safe distance during this pandemic, we are connecting and bonding. We are acting out the best parts of humanity.

My wish for you, our community, our country and our world is for us to be safe and healthy. Will you join me?

Jennifer Wickham is a licensed professional counselor in Behavioral Health in Eau Claire, Wisconsin.

For the safety of our patients, staff and visitors, Mayo Clinic has strict masking policies in place. Anyone shown without a mask was either recorded prior to COVID-19 or recorded in a non-patient care area where social distancing and other safety protocols were followed.