



**NHPCO**  
National Hospice and Palliative  
Care Organization



## **Introduction:**

During and following the COVID-19 pandemic, grieving individuals, families, children, and communities need access to timely, informative, bereavement care that is provided by experts who are knowledgeable, experienced, and trained in helping others cope with grief. To fulfill this need, the National Hospice and Palliative Care Organization (NHPCO), the Social Work Hospice and Palliative Care Network (SWHPN), and a consortium of grief experts represented by Hospice Foundation of America (HFA), recommend creating a \$200-400 million grant program that funds a public health campaign to enhance the knowledge of grief literacy and information about where to find available care; the development and dissemination of resources and trainings to enhance grief professionals' ability to provide this necessary care, both to families and to the health care professionals who have been on the frontlines of this crisis the provision of bereavement care itself, the provision of this trauma-informed care; and research focused on complicated and prolonged grief as a result of the pandemic

## **Four-Part Proposal:**

### **1. National Public Information Campaign on Grief Literacy and the Importance and Availability of Bereavement Care**

We advocate for developing a public information campaign that educates Americans about the individual and community-wide consequences of loss when grief is unacknowledged and unsupported. COVID-19 has devastated some communities and has particularly impacted low-income workers and people of color, who are less likely to have access to sufficient mental health care. The psychological toll of the pandemic on these communities is as yet unknown but affected groups must have access to timely and culturally appropriate bereavement services. A National Public Information Campaign will educate the public about grief and loss as well as the availability of resources in communities throughout the United States. As a result, we expect more people will take advantage of these services, thereby minimizing the negative consequences of unsupported and unacknowledged grief, for individuals, families, and communities. As Rabbi Earl Grollman has said, "Grief is not a disorder, a disease, or a sign of weakness. It is an emotional, physical, and spiritual necessity, the price you pay for love. The only cure for grief is to grieve." We advocate for \$40-60 million for this public information campaign over a period of 2 years, based on the cost of two current FDA public education campaigns (This Free Life and Every Try Counts).

### **2. Education and Training for Bereavement Care Providers and Peer Support**

Hospice and palliative care social workers, chaplains, and counselors provide grief and bereavement services to thousands of people each year whose family member died in a

hospital, care facility, or in their own home with hospice care. These professionals have been specifically trained to handle the psycho-social-spiritual aspects of end-of-life care, and have received specialty training, credentials, and certifications in hospice, palliative care, and bereavement.

As a result of the coronavirus pandemic, hundreds of thousands of families are facing grief and loss that is unrelated to a death in a hospice or palliative care setting. Many of these bereaved individuals would benefit greatly from talking with a grief counselor, meeting individually with a bereavement specialist, attending a grief support group, or receiving relevant information from a healthcare provider of their choice. We advocate for \$5 million of funding to specifically expand these services and access to them. The funds would also help create and disseminate resources designed to help social workers, grief counselors, chaplains, and other bereavement care providers train others in understanding the basics of grief, trauma-informed care, and where to locate community grief resources in response to the pandemic.

This funding will provide training for professionals at hospices and palliative care organizations around the country to expand the care they provide in these circumstances. This training would be targeted for qualified professionals, either by requiring that organizations providing this training employ professionals with specific educational backgrounds and professional certifications or have qualified professionals lead the trainings, or by requiring that the trainings be offered only to qualified professionals with certain educational backgrounds or professional certifications. This section of the grant would secondarily provide funding for training for peer-to-peer bereavement support, which would allow a broader range of individuals to support grieving members of their community.

### **3. Grief Counseling for Individuals and Families**

In order for hospice and palliative care specialists to provide grief counseling to individuals affected by COVID-19 deaths, funding should be made widely available to hospitals, hospice facilities, palliative care facilities, and VA facilities. Funds could cover the costs of operating grief support groups, holding memorialization services, software/hardware for operating remote/virtual counseling as needed, and providing other community-based grief and bereavement services. We advocate for a grant program to develop and deploy community-based grief services, including individual counseling, that will be provided by hospitals, hospice facilities, palliative care facilities, and VA facilities.

This \$15-160 million grant program factors in the magnitude of grief brought on by the COVID-19 pandemic. It includes the average number of people also impacted by grief due to other community tragedies each year, both manmade (such as shootings) and natural disasters such as wildfires, hurricanes, and tornados. A recent study identified an average of nine people who are affected by grief for each COVID-19 death.<sup>1</sup> The number of people impacted by each death of other causes is between one and five.<sup>2</sup> Based on these studies we use a 9x multiplier on the

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<sup>1</sup> Ashton, M., Verdery, E., Margolis, R., & Daw, J. (2020) Tracking the reach of COVID-19 kin loss with a bereavement multiplier applied to the United States. *Proceedings of the National Academy of Sciences of the United States of America*, 117(30), 1769-17701. <https://www.pnas.org/content/117/30/17695>

<sup>2</sup> Antonucci TC., Akiyama H., Takahashi K. Attachment and close relationships across the life span. *Attach Hum Dev.* 2004;6:353–370.

number of deaths from COVID-19,<sup>3</sup> and a 2.5x multiplier by the average or most recent annual number of all other types of death. The number of deaths from overdose and suicide, to cite but two examples, have only increased due to the stressors caused by the pandemic. Basing our estimates on current statistics available from murders and nonnegligent homicides,<sup>4</sup> deaths by suicide,<sup>5</sup> fires,<sup>6</sup> flood, lightening, tornados, hurricanes, heat, winter, cold, wind, and rip currents<sup>7</sup> we estimate an average of 3,933,381.5 people are bereaved due to deaths from these causes annually.

Recent research has shown that over two-thirds of those who have lost someone to COVID-19 experience clinically-significant grief.<sup>8</sup> These risks of grief are not just psychological – they are quantifiable. Grief costs employers \$75 million annually during the average year – it is likely that in 2021, the cost will be much higher, due to the pandemic.<sup>9</sup>

Additional populations which might benefit from bereavement care include the health workers on the frontlines of this pandemic. These workers are experiencing grief for themselves, their families, and their patients.<sup>10</sup> In addition to the personal toll on workers' mental health, their experiences put the workforce more broadly at risk. Recent research shows that as many as 26% of healthcare workers have considered leaving their roles since the beginning of the pandemic, with 14% indicating they have considered leaving find a new profession entirely.<sup>11</sup>

#### **4. Research on COVID-19 and Complicated Grief**

Finally, we advocate for the allocation of \$10 million in funding for research to examine the experience of complicated and prolonged grief, and the efficacy of treatment approaches. This research may consider unique circumstances of complicated and prolonged grief related to the COVID-19 pandemic, and other national emergencies and moments of collective grief, with the goal of identifying unique needs of patients seeking help for grief stemming from these circumstances.

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<sup>3</sup> [https://covid.cdc.gov/covid-data-tracker/#cases\\_casesper100klast7days](https://covid.cdc.gov/covid-data-tracker/#cases_casesper100klast7days) as of 1/26/21

<sup>4</sup> <https://ucr.fbi.gov/crime-in-the-u.s/2018/crime-in-the-u.s.-2018/topic-pages/murder>

<sup>5</sup> <https://afsp.org/suicide-statistics/>

<sup>6</sup> <https://www.usfa.fema.gov/data/statistics/#tab-2>

<sup>7</sup> <https://www.weather.gov/hazstat/>

<sup>8</sup> Doka, K. J. and Tucci, A.S. (Eds.). (2021). *Living With Grief Since COVID-19*. Washington, DC: Hospice Foundation of America

<sup>9</sup> "The cost of grief," by Darlene Gavron Stevens, *Chicago Tribune*, August 20, 2003

<sup>10</sup> Rabow, M. W., Huang, C. S., White-Hammond, G. E., & Tucker, R. O. (2021). Witnesses and Victims Both: Healthcare workers and grief in the time of covid-19. *Journal of Pain and Symptom Management*. doi:10.1016/j.jpainsymman.2021.01.139

<sup>11</sup> <https://morningconsult.com/2021/01/25/about-a-quarter-of-health-care-workers-have-considered-leaving-their-job-since-the-onset-of-the-pandemic/>