



Bringing Light to Alzheimer's

2022 Impact Report



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Introduction

HFC aims to support family caregivers throughout their experience of Alzheimer's and related dementias by providing free and tailored services focused on emotional support, respite, skillbuilding, coaching, and brain health education.

The HFC Impact Report reflects the experiences of caregivers participating in one or both of HFC's signature caregiver programs:

1. The In-Home Care Grant Program relieves caregivers, giving them time to rest, recharge, and focus on their personal and professional lives. Delivered with our partner, Home Instead, HFC's Care Grants provide 3-6 months of free, professional, in-home care.
2. HFC's Online Support Groups are free and designed to help people navigate any stage of an Alzheimer's disease diagnosis. Groups are led by credentialed social workers and trained group leaders who have experience supporting Alzheimer's caregivers.

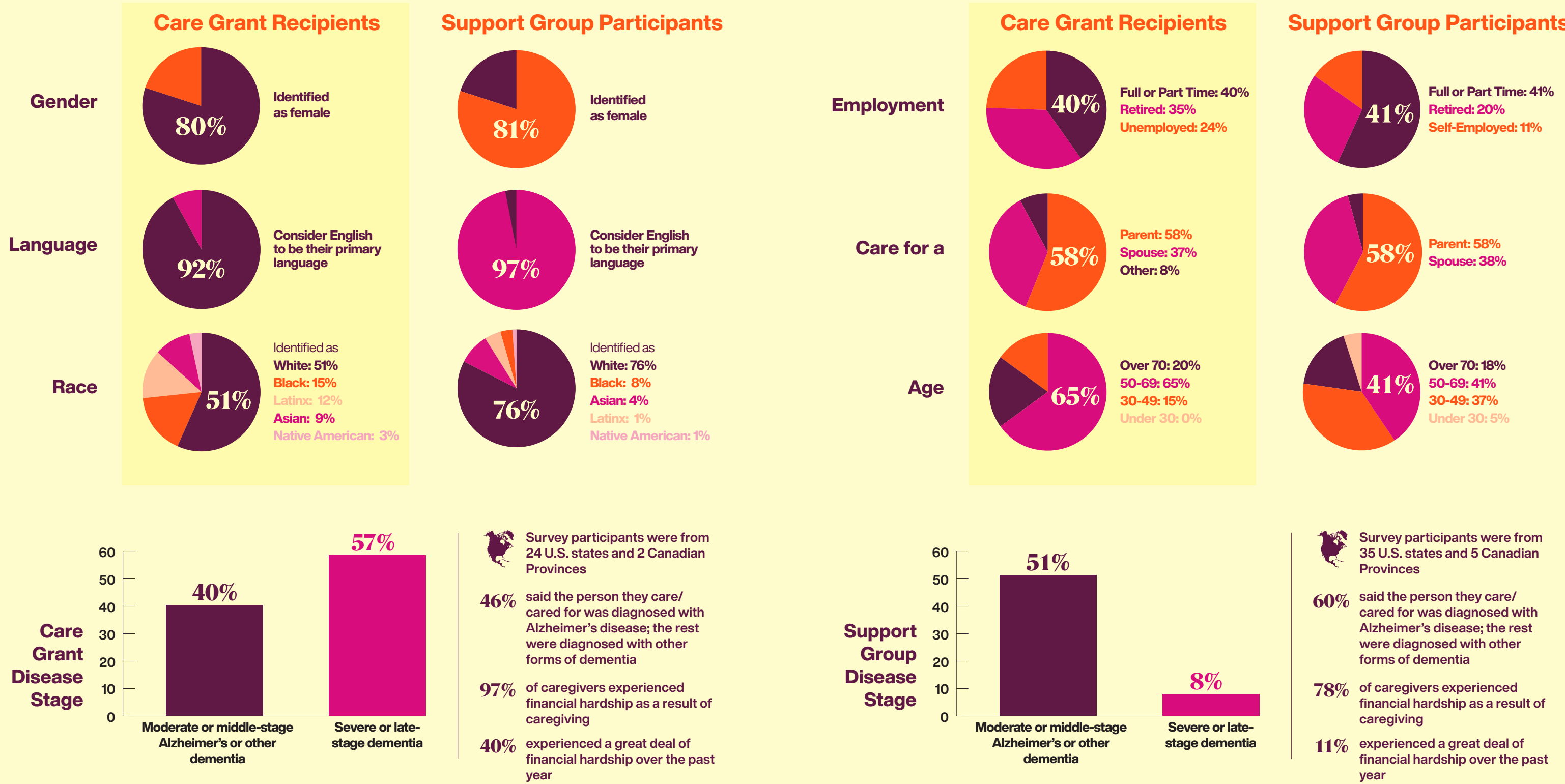


Process

HFC's measurement and evaluation process assesses:

- the caregiver experience and that of the person they care/cared for
- the needs they addressed with grant funding
- the helpfulness of the grant in improving their lives
- the reason for participating in support groups
- their ability to manage their own well-being and provide quality care
- their perceptions about the grant application and overall process
- the marketing of support groups
- their satisfaction with the support group or respite service provider
- the cultural acceptability of services
- their interest in opportunities for brain health education
- their interest in and need for additional programs

Respondent Demographics



Care Grant Disease Stage

Support Group Disease Stage

Moderate or middle-stage Alzheimer's or other dementia

Severe or late-stage dementia

40%

57%

Survey participants were from 24 U.S. states and 2 Canadian Provinces

46% said the person they care/cared for was diagnosed with Alzheimer's disease; the rest were diagnosed with other forms of dementia

97% of caregivers experienced financial hardship as a result of caregiving

40% experienced a great deal of financial hardship over the past year

Moderate or middle-stage Alzheimer's or other dementia

Severe or late-stage dementia

51%

8%

Survey participants were from 35 U.S. states and 5 Canadian Provinces

60% said the person they care/cared for was diagnosed with Alzheimer's disease; the rest were diagnosed with other forms of dementia

78% of caregivers experienced financial hardship as a result of caregiving

11% experienced a great deal of financial hardship over the past year

Learnings from 2021

Feedback from [2021's Impact Report](#) was overwhelmingly positive and confirmed our beliefs that respite and support are critical for family caregivers. We were thankful to receive suggestions from caregivers on how to expand and improve upon the programs, including:

Learnings from 2021	Actions in 2022
Provide additional and improved communications throughout the application and enrollment process for more transparency around program logistics	In 2022, HFC expanded our team by adding a new Senior Manager of Programs to improve the communications journey for caregivers receiving respite care as well as enrolling in support groups. Our goal is to improve the flow of information and provide more clarity and transparency into the application and enrollment processes
Provide additional resources such as coaching, mentoring, and disease education as part of programs	HFC continued to build on our caregiver wellness and education programs throughout 2022 including the addition of a new caregiver-focused event series, Care-ertainment. The educational events bring together special celebrity guests and Alzheimer's caregivers to deliver information, connection, and community in one easy to access event. Additionally, we added a new series, "Dealing With It," alongside our partners at Home Instead, focusing on dementia-related behaviors and strategies to deal with and cope with those behaviors. Each session provided access to two credentialed facilitators and the safe space to ask questions and share experiences



Learnings from 2021	Actions in 2022
Consider geographically-based support groups so participants can more easily engage outside of groups	HFC partnered with El Faro Health and Therapeutics to bring a hybrid support group and caregiver education experience to a clinical trial site in Rio Grande Valley, Texas. This pilot project was carefully designed to serve Latinx family caregivers supporting family members enrolled in the clinical trial. Spanish-speaking, credentialed facilitators provide both disease education and caregiver support in a hybrid in-person/virtual environment
Enable more flexibility for use of care grant hours	In partnership with Home Instead and HFC's Care Advisory Board, HFC is embarking on an in-depth exploration to identify options to bring more flexibility to care grant recipients. Our goal is to make recommendations for expansion in 2023



HFC Co-Founder, Seth Rogen, learns about the human brain (while holding one!) from Andrea Wasserman, Chief Administrative Officer, UC Irvine Institute for Memory Impairments and Neurological Disorders (UCI MIND) at HFC's 10th Birthday Extravaganza in Los Angeles

Key Findings 2022

HFC’s inaugural ratings (2021) were very high. Thus, we expected improvements throughout 2022 to be minimal. As expected, few statistically significant differences were found across key measures. As such, HFC’s programmatic focus in 2023 will be on maintaining these already high levels of helpfulness, impact, and satisfaction (see “Looking Ahead.”)

HFC Care Grants:

Most caregivers continue to use the respite time to take care of personal daily activities, manage the stress associated with caregiving, and practice self-care.



- “The care grant was the best thing that happened to me in the past two years. It made me feel like I was alive again. It gave me a boost at a time it was really needed. It really felt nice to get the extra care she deserved.”
- “I was almost always exhausted. The care grant allowed me to take a break and breathe normally for a few hours. I usually spent it running errands, but when I was too tired, I would just lie down and rest.”

HFC Support Groups

HFC Support Groups:

Most caregivers had multiple reasons for participating in support groups. The top two reasons were to:

- 1. Connect with others in a similar situation
- 2. Manage the stress associated with caregiving

Enabling Self-Care:

89% report that HFC support groups helped them engage in self-care

HFC Support Group participants reported that the groups helped them:

87% manage the stress of caregiving

82% improve their overall well-being

80% feel more positive about being a caregiver

Support Group participants also reported that the topics discussed were relevant to them as caregivers (87%) and they learned:

87% things that were useful to them as caregivers

84% more about Alzheimer's or other dementias

84% how to provide better care to someone with dementia

“It’s been really nice to just connect with other young caregivers who are caring for their parents. It’s not something I have in my life outside of the support groups.”

“One time I was having an especially bad week. When I talked to my group about what was going on, the outpouring of support and advice from the others really made a huge difference.”

“The connections I’ve made in the group have been invaluable. When my mom collapsed and had to go to the ER, my friend I met in the group was the first person I called. No one can really understand how hateful and horrific this disease is unless you go through it with someone you love.”

HFC Support Group participants reported that the groups helped them:

84% be more present and patient with their care recipient

84% provide the care their care recipient needed

82% improve the quality of care they delivered to their care recipient

87% feel more emotionally prepared to continue caregiving

65% feel more physically prepared to continue caregiving



Brain Health

95%

of care grant recipients and support group participants **worry about developing Alzheimer's or other forms of dementia.**



Survey respondents were least aware that hearing and dental care are supportive of brain health, followed by how diabetes and high cholesterol, a sedentary lifestyle, and lack of sleep all increase one's risk of cognitive impairment. Across the board, there are opportunities for education related to factors that are both detrimental and beneficial to brain health.

2022 Feedback Summary

2022 feedback fell into three general categories:

- 1. Respite Care Grant Flexibility**
 - Improve respite provider scheduling and availability
 - Provide more respite over longer periods of time
- 2. Expanded Caregiver Education**
 - Provide more opportunities for disease education and prevention
- 3. Access to Care Professionals/Tailored Support**
 - Provide opportunities for resource counseling (case management), peer mentoring, and caregiver coaching

Looking Ahead

In 2023, HFC's programmatic efforts will focus on:

- Increasing information/education programs about Alzheimer's Disease and related dementias
- Introducing a support group for Frontotemporal Dementia (FTD) caregivers
- Introducing a support group for male caregivers
- Introducing a support group for Black and African-American caregivers
- Expanding support groups for Latinx caregivers
- Introducing a family wellness support series addressing young-onset Alzheimer's
- Introducing individualized care navigation support & coaching
- Bringing free online therapy to caregivers via a national partnership with BetterHelp
- Exploring care grant expansion strategy to increase flexibility and variety to better meet the needs of family caregivers

About HFC:

Founded in 2012 by Seth Rogen and Lauren Miller Rogen, Hilarity for Charity is a national non-profit on a mission to care for families impacted by Alzheimer's disease, inspire the next generation of Alzheimer's advocates, and be a leader in brain health research and education.



From left to right: HFC Board Member, Jason Zuccari; HFC Board President, Dan Miller; HFC Co-Founders Lauren and Seth Rogen; and HFC Executive Director, Bonnie Wattles



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9301 Wilshire Boulevard, Suite 507
Beverly Hills, CA 90210