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FINAL REPORT: 2022 NATIONAL PHILOPTOCHOS CAREGIVER SUPPORT GROUP

Paulette Geanacopoulos, LMSW and Theodora Ziongias, M.A.
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*"I didn't realize how much I needed this group.
I'm so grateful that God guided me to you."*

For eight consecutive Thursday evenings from January 13th to March 3rd, 2022, the Social Services Department of National Philoptochos conducted its third **CAREGIVER SUPPORT GROUP** for Orthodox Christians caring for a loved one who is elderly, chronically ill or disabled. Each time we have held these groups – accessible to members of the Greek Orthodox community nationwide – the response generated has made it clear that caregiving is a topic that broadly resonates throughout our community.

The support group was facilitated by Theodora Ziongias, M.A., and Paulette Geanacopoulos, LMSW, National Philoptochos Director of Social Services. Their strong backgrounds in the field of aging, caregiving and leading support groups created an ideal, safe, and confidential environment for participants to speak freely and willingly.

To acknowledge our status as a ministry of the Greek Orthodox Archdiocese of America, the final session was led by the Rev. Dr. Harry Pappas who is the Pastor at the Church of Archangels, Stamford, CT, and Adjunct Professor at Holy Cross Greek Orthodox School of Theology.

RATIONALE FOR PROGRAM:

Evidence-based research, anecdotal information and practical experiences document that support groups improve caregivers' quality of life by helping them understand they are not alone. They connect participants with others facing similar experiences and provide them the opportunity to speak about and work through their feelings, their hopes, and sorrows in a non-judgmental setting. Support groups enable members to share information about ways to communicate more positively with those around them, including care receivers, family members, neighbors, friends, and fellow parishioners. As importantly, support groups provide accurate information about local and broader resources – many of which vary state-by-state – and referrals for services including managing finances, finding appropriate home health aides, facilities, and programs, as well as counseling options and more.

UNIQUE ASPECT OF THE PHILOPTOCHOS PROGRAM:

While other organizations sponsor support groups, the Philoptochos program is unique in that it highlights the cultural, religious, and spiritual issues distinctive to Greek Orthodox Christians – whether actual or perceived – that inform our lives, influence our caregiving outlook, may impede our willingness to access mainstream services, and that acknowledges our ethnic frames of reference within the context of the American culture.

*"I'm learning to start the day with a prayer.
I'm learning to sit in silence – peaceful silence –
so I can find my own peace.
I'm learning to ask the Holy Spirit to intervene and
give me strength, to help me surrender and let
"Thy Kingdom Come, Thy Will Be Done"."*

GOALS:

- To bring together members of the Orthodox Christian faith who are caring for a loved one who is elderly, disabled or who has a chronic health condition.

*"This group has taught me that we
need to think about what is next
in our own lives – that we need to plan
and prepare for the future."*

- To provide a safe and confidential forum for mutual support, sharing of resources, and comfort.
- To empower participants through knowledge, insight, and faith-based support to help them build resiliency and coping skills as they move forward during their caregiving journey.

OUTREACH:

Through outreach to Metropolis Philoptochos Presidents, Philoptochos and Archdiocesan social media outlets, email blasts to our membership and other interested parties, we notified our community of our program that would be accessible to members of the Greek Orthodox / Orthodox Christian community nationwide.

CAREGIVER SUPPORT GROUP FOR ORTHODOX CHRISTIANS THROUGHOUT THE ARCHDIOCESE



- Are you caring for a loved one who is elderly, has a chronic or life-threatening health condition, or who is disabled?
 - Do you wish you could talk to others facing the same challenges as you?
 - Do you wish you had someone with whom to share your thoughts, concerns, and questions, and who understands our faith, culture and community?
 - Are you so overwhelmed you aren't sure what or who could help or even what questions to ask?

If you answered yes to some or all of these questions and would like more information, please join the

PHILOPTOCHOS CAREGIVER SUPPORT GROUP

Facilitated by professionals knowledgeable in caregiving and aging services, the support group will “meet” on eight consecutive Thursday evenings from January 13th - March 3rd.

In a confidential and safe environment, we will discuss best practices to help you manage the physical and emotional needs of your loved one; the importance of self-care; dealing with stress, guilt, anger and exhaustion; family dynamics and decision-making; practical and financial resources to help you cope; long-distance caregiving; holiday caregiving; preparing for the future; and spiritual resources to help you find strength and build resilience.

Orthodox Christian caregivers throughout the Archdiocese are welcome to join.

(Information about how to contact us)

NATIONWIDE RESPONSE:

Twenty-nine (29) individuals from throughout the Archdiocese responded to our outreach, with participants hailing from California, Florida, Indiana, Illinois, Maryland, Michigan, Ohio, Virginia, New Jersey, New York, North Carolina, and West Virginia. While the 2022 support group first “met” via a telephone conference call, at the request of the participants, we revised the format and began meeting over Zoom starting with the third session.

SCREENING INTERVIEWS OF APPLICANTS:

All respondents were interviewed over the telephone by Theodora Ziongias to assess their understanding of support groups, their caregiving situation, to obtain a brief summary of their concerns, to compile demographic information i.e., ages of caregivers / care receivers, and, to ensure their understanding of confidentiality. These interviews allowed us to organize discussions to meet the needs of participants to maximize the relevance of the sessions.

DEMOGRAPHICS:

Caregivers ranged in age from 49 to 82, and care receivers ranged in age from 26 to 96, with conditions of mid- to end-stage dementia/ Alzheimer's, Parkinson's, Multiple Sclerosis, cancer, stroke, and mobility issues.

A small number of caregivers worked full- or part-time, while others retired early to care for their loved one.

For the first time, we had participation from a “*husband-and-wife team*” who were caring for the wife's mother, and, a “*sibling-pair*” caring for their mother, one of whom lives with the mom. One caregiver was in the “*sandwich generation*” – caring for her elderly father while raising her teenage son. Another, who cared for her brother, shared caregiving responsibilities with her brother's son and his family, each of whom would “take” him for two weeks at a time. This constant change of venues raised different challenges. Yet another caregiver, whose brother was in a nursing home, lived with her 90+ year old mother who did not want to die before her son.

*“I never foresaw that this would be my life.
I never thought that being a caregiver
would become my identity.”*

TOPICS OF DISCUSSION:

A discussion outline was prepared for each session; nevertheless, we frequently pivoted to enable participants to weigh-in with their own specific concerns. Participants spoke about feeling alone, the sometime loss of control of their own lives, their difficulty asking for help, the effect of needing to be physically present all or most of the time, and their reactions to the reversal of roles with their loved ones. They spoke of isolating themselves from social gatherings so they wouldn't have to answer questions - frequently insensitive ones - about how their loved one was doing ("Did your mother lose her mind?"), and they shared roller-coaster feelings of anger, exhaustion, impatience, and guilt.

COVID-19 continued to cause anxiety during this year's group. We spoke of its impact on caregivers' practical abilities to find home health aides - some of whom needed to be Greek speaking - and to connect with services that continued to limit the number of clients they could accept, or that only offered services remotely or through TeleMedicine.

Some participants raised personal issues related to the pandemic such as invitations to family gatherings with relatives who were neither vaccinated nor wore masks, and, as Churches reopened, their concerns about their loved ones with compromised immune systems receiving the Eucharist with a common spoon.

Discussions comprised 'concrete' issues about dementia and Alzheimer's, i.e., sundowning and sleep issues, complex behaviors of agitation, aggression, paranoia, delusions and wandering; importance of accurate physical and mental health assessments from appropriate providers such as geriatric neurologists and gerontological professionals; medication management; handling of situations where care receivers refused to bathe, change clothes or wouldn't accept help; impact of nutrition on a care receiver's mental status; pros and cons of homecare aides hired privately, through an agency, or provided by a family member paid through Medicaid (*if eligible*); finding (*affordable*) respite care; and resources re: financial and legal issues: public benefit eligibility, wills, estates, trusts; health care proxy, living will, powers of attorney.

Discussions also addressed conceptual issues:

- Need for caregivers to focus on their own self-care and carve out time for themselves - to exercise, socialize, or even spend time alone. We discussed that the opposite of self-care is not self-centeredness - it is self-awareness.
- Family dynamics vis-a-vis decision making; face-to-face family meetings; planning before it is a crisis and when the loved one can participate and make their wishes known.
- Becoming their own and their loved one's advocate.
- Feeling alone - lack of support from family and friends.
- The loss of their previous relationship with their loved one due to dementia, physical disability, depression, etc.
- Finding new ways to "reconnect" with loved ones - taking walks, reading books together, virtually walking down "memory lane," keeping a journal, taking an oral history.
- Impact of caregiving on their relationship with their spouse and other family members.

"There's no 'playbook' to caregiving."

"My friends don't understand and it's difficult to describe to others what it's like to be a caregiver and live with a loved one who needs constant care."

"Sometimes - maybe more than sometimes - I get so angry, and then I feel guilty for getting angry."

*"Am I being ungrateful for what my loved one did for me for so many years?
Am I a horrible person?"*

"I'm getting older myself and I have less energy now than I did when I was younger. And this is happening just when my loved one needs more care and more of my energy."

"There are some personal issues my family has to resolve. I'm using techniques I learned in this group to help us move forward."

"I never thought I would feel such loss and grief now - while my loved one is still alive."

"I know how difficult caregiving is, but oftentimes, I think that after my loved one has passed away, I will appreciate and cherish the time I was able to spend with them."

"The Lord knows we are human and what we are going through - He knows because He was human, too."

"We need fellowship, we need support. We need to share our faith and spirituality. We need to blend our faith and spirituality with the reality of our lives as caregivers."

"I hope you could tell how greatly we all appreciated and benefitted from this group. Like everyone, I hated to see it end. It truly is a ministry. The need is so great."

FINAL SESSION LED BY REV. DR. HARRY PAPPAS:

In recognition of our role as a faith-based organization, we once again invited the **Rev. Dr. Harry Pappas** to be our “closer” to lead the last session. Fr. Harry acknowledged that caregivers want to be good Christians, but sometimes find it hard. Nevertheless, they know what the right thing is to do – and they do it. He stated that support groups are a “community” and a “small group ministry” (*“For where two or three are gathered together in my name, there am I”*) as are prayer groups and retreats, all of which empower participants. He said support groups follow the example of Jesus Christ who believed in community: His community was not just one or two members, but rather, twelve Apostles, and His community included women.

Fr. Harry stated that in a world filled with responsibilities, all *“clamoring for our time and thoughts,”* caregivers benefit from rediscovering self-care – as did Jesus Christ. Fr. Harry said that Jesus Christ recognized His need for self-care, and on occasion, would separate Himself from His Apostles to take care of Himself so that He could take care of others. To further emphasize this point, Fr. Harry suggested that participants *“go inward”* in order to be *“available.”*

Fr. Harry acknowledged that caregivers sometimes feel anger – *“it’s ok to get angry at God, too.”* He equated anger to suffering and said that suffering is inevitable in life, but through Christ, it can be healing and life-giving in the same way the crucifixion led to life-giving. In response to participants stating they feel guilty when they get angry and impatient, Fr. Harry pointed out that in Scripture, guilt is an objective condition that a person feels when they acted to deliberately harm someone, or could have knowingly prevented harm but didn’t, while a caregiver’s “guilt” is subjective, and emotional. He asked that we accept our feelings (*“bare our souls”*) for what they are, whether positive or negative, so that we can work through them.

Fr. Harry spoke of the *“power”* of prayer and finding rhythm rather than balance. While we may control balance, God controls rhythm, and rhythm acknowledges that God *“is.”* Referring to the spiritual resources distributed, Fr. Harry encouraged participants to inform their caregiving through their fellowship, faith, religion, spirituality, and prayer – all of which help us find strength and resilience.

SECULAR AND SPIRITUAL RESOURCES:

- Spiritual resources including articles, books, prayers, and scripture references compiled by Rev. Dr. Harry Pappas were distributed to group participants.
- Secular resources compiled by Paulette Geanacopoulos and Dora Ziongas were distributed to participants.

Please contact the National Philoptochos Department of Social Services at socialwork@philoptochos.org for copies of the resources listed below:

SPIRITUAL RESOURCES:

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| • Books for Caregivers | • Resources for Healing |
| • Recommended Psalms – in Greek | • Spirituality of Eldercare |
| • Recommended Psalms – in English | • The Serenity Prayer |
| • Elderly in Scripture Selections | • Pastoral Responses to Participant Caregiver Concerns & Questions |
| • Why Should the Church Care? | |
| • Church Fathers & Saints: On Life & Suffering | |

SECULAR RESOURCES – each document credits the organization that developed the resource:

ALZHEIMER’S/ DEMENTIA:

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| • 8 Common Myths About Alzheimer’s | • How Dementia Caregivers Can Practice Building Resilience |
| • Alzheimer’s Fact Sheet: Mayo Clinic | • Sleep Issues and Sundowning |
| • Dementia Road Map | • This is What No One Tells You About Losing a Parent to Alzheimer’s |
| • Alzheimer’s and a Full Moon | • Understanding and Minimizing Symptoms of Sundown Syndrome |
| • Choosing a doctor | • When a Senior Refuses to Bathe and Change Their Clothes |
| • Behavioral Triggers | • When Elderly Parents Resist Help |
| • Cognitive Psych Symptoms | |
| • Does the Full Moon Affect Alzheimer’s Patients? | |
| • Guide to Alzheimer’s Caregiving | |

MENTAL HEALTH & WELLNESS:

- Crisis Text Line
- 5 Self-Care Practices for Every Area of Life
- Anxiety Illnesses
- Manage Anxiety and Stress: CDC
- Caregiver Mental Health
- Coping With Stress: Sandwich Generation
- Caregiver Stress Tips for Taking Care of Yourself – Mayo Clinic
- Grieving for a Dying Loved One During the Holidays
- How Forgiveness Can Improve a Caregiver's Life

COVID:

- COVID-19: Homecare for Families and Caregivers
- COVID-19: Tips for Dementia Caregivers
- COVID-19: Emotional Resilience During the Coronavirus Pandemic

HOME HEALTH CARE / HOMECARE / DAY PROGRAMS:

- Signs a Senior Needs Help at Home
- Assessing Home Care Needs of a Loved One
- Guide to Finding an In-Home Caregiver – *assess type of care needed, agency v private v family, interview questions, skills checklist, & more*
- Hiring Home Care – *Family Caregiver Alliance*
- Getting Paid to Care for Mom or Dad: Are You Eligible?
- Choosing a Day Center
- Difference Between Home Health Care and Non-Medical Homecare Services

FAMILY ISSUES:

- Caregiving During the Holidays – Have a Realistic and Positive Approach
- Caregiving With Your Siblings
- Caring for Aging Parents Who Didn't Care for You
- Long Distance Caregiving
- As Caregivers Get Younger, Planning for Long Term Care is Even More Important

LEGAL/ FINANCIAL:

- Advanced Care Directive: Deciding About Treatments that Prolong Life
- Association of Life Care Managers (formerly Geriatric Care Managers)
- Elderlaw: Estate & Disability Planning

WHO WE ARE:

Established in 1931, the **Greek Orthodox Ladies Philoptochos Society, Inc.** is the philanthropic arm of the Greek Orthodox Archdiocese of America that has offered 90 years of philanthropy through a multitude of programs that make a difference in the lives of people in the United States and throughout the world. Philoptochos fulfills its mission to "help the poor, the destitute, the hungry, the aged, the sick, the unemployed, the orphaned, the imprisoned, the widowed, those with disabilities and the victims of disasters through its National and Metropolis Boards and its 26,000 members in more than 400 active chapters, nationwide. Philoptochos responds immediately to needs and crises and its philanthropic outreach extends to each area of the country and throughout the world. In 2019, National Philoptochos distributed \$1.7 million in philanthropic aid.

Since 1987, the national office of the Society, based in New York City, has operated a **Department of Social Services** staffed by New York State licensed bilingual (English / Greek) social workers – the state in which Philoptochos is incorporated. We assist Greek Orthodox and Orthodox Christian individuals and families throughout the United States, as well as Greek and Cypriot nationals, regardless of their immigration status, who are in the United States. Persons assisted face issues of poverty and income inadequacies; health and mental health including life threatening illnesses, chronic and debilitating diseases, and conditions, uncovered medical and prescription costs; substance use, abuse, addictions, and co-dependency; hunger and nutritional deficiencies; housing and homelessness; aging, youth, and family services; and domestic violence including partner, elder and child abuse. Through supportive counseling and short-term interventions, we provide information about and referrals to local and broader resources such as nonprofit organizations and government agencies, as well as advocacy assistance to ensure they access the benefits and services to which they are entitled. When warranted and properly documented, we provide limited financial assistance to Orthodox Christians throughout the United States as long as our contributions can be made through direct bill payments to vendors (e.g., landlords, mortgage holders, medical providers, funeral homes, etc.) who also are in the United States. For more information, to request help or to refer someone in need, email socialwork@philoptochos.org.