



Helping An Older Adult: A Caregiver's Journey

Project History

Why We Began this Journey

Caregiving for an older adult can be a natural and rewarding part of life. Taking care of those who cared for us or those who can no longer care for themselves is a way to give back to those we love or to the community in general. However, just like anything, aspects of caregiving can become stressful and even burdensome. Often, caregivers do not even recognize the fact that they are caregivers and/or become so consumed in their caregiving duties that they forget to care for themselves. Because of our daily work Central Massachusetts Agency on Aging clearly recognizes that caregiver stress and burden are significant national public health concerns. So many caregivers suffer from inordinate stress and burden, which in turn affects our society as a whole. The aim of the new Helping An Older Adult-A Caregiver's Journey is to aid caregivers in identifying their particular stresses and burdens, and, through education, help them to help themselves and the older adult in their lives.

In order to address caregiver stress and burden we first had to define the terms. We thought of caregiver stress as the point at which the amount of pressure, strain or tension caused by any aspect of a caregiving relationship has a negative effect on the caregiver's mental or physical well-being. While a normal amount of stress is natural and important, too much of it may have significantly negative effects on a caregiver's overall well-being. Caregiver stress is usually caused by caregiver burden. While caregiver stress refers to a specific internal feeling to be managed, caregiver burden is a more measurable toll on any aspect of our lives. Caregiver burden can be an amount of money spent, an amount of working time lost, a missed lunch with an old friend, or even suffering from depression. While some of us may feel guilty or weak for admitting that we are stressed or burdened by caregiving, it is a reality that is better faced than denied. Caregiving can be a beautiful and fulfilling experience, but, like everything else in life, there are often challenges.

The Journey

With caregiver stress and burden presenting such a large public health issue we looked to create a new page on Connection for Caregivers to address it. Our hope was that this page would offer two forms of support. The first was a survey that caregivers could take to gauge their own caregiver stress and burden. The second part was a wealth of supportive resource pages that would be available to caregivers to learn more about the various topics that relate to caregiving and the programs and service available. Because of this the Helping An Older Adult-A Caregiver's Journey has two tales to tell, that of the Caregiver CrossRoads and that of the Caregiver Check-up.

The Caregiver CrossRoads

We envisioned that the supportive information section, which we finally called The Caregiver CrossRoads, would be a multi-faceted resource for caregivers concerning all aspects of the caregiving relationship. *SeniorConnection* interns and volunteers diligently gathered information about the triumphs and struggles of caregiving. The initial goal was to be able to offer detailed explanations of various direct support services that may help caregivers of older adults, such as caregiver support groups, respite services, legal counseling, etc. Within each section of the individual supportive topics we planned that there would be a brief definition of the topic; an in-depth discussion of the topic; a direct link to our searchable database, The Guide to Elder Services, which would bring up a list of agencies/programs that offer specific services affiliated with the chosen topic; a glossary of terms affiliated with the topic; and a list of links to other helpful websites. In addition to providing information about elder care, each CrossRoad would carry the underlying message: As caregivers provide care for the older adult in their lives, they must remember to care for themselves. To accomplish these goals we created the Caregiver CrossRoads, which we hope offer clear and extensive information to educate caregivers of older adults about their journey.

the caregiver check-up

Central Massachusetts Agency on Aging sought volunteer collaborators to create a survey for caregivers of older adults to take which will measure their own amount of stress and burden. Our plan was that the survey would be easily accessed from our website. We asked for help to develop a new assessment tool and scoring methodology. Our goal for the survey has always been two-fold. Our primary focus was to help caregivers of older adults to learn where they fall on a continuum of stress levels. Upon completion of the survey, we wanted a caregiver of an older adult to receive a score. Our thought was that after a caregiver received their individual score they could compare it with scores of their peers. Secondly, as an Area Agency on Aging we are mandated to identify the needs of older adults and caregivers in our 61 cities and towns. It is our hope that the anonymous responses from the survey will provide us with additional data on the needs of caregivers who utilize our website, and the older adults they help, for our future planning.

CMAA partnered with the UMass Medical School, Population Health Clerkship to create a sensitive and accurate tool for measuring Caregiver Stress and Burden. The twelve students and the two doctors who facilitated the group put in a tremendous effort to create and administer a survey. The survey assessed the physical and emotional effects that the role of caregiving has on those individuals who provide such care. The students accompanied CMAA staff to community health fairs and also visited a geriatric physician's office where they were able to survey caregivers who volunteered. Other caregivers contacted the *SeniorConnection* Department to note their interest in participating. In total the students surveyed 102 caregivers. The results of the survey were presented to a group of individuals at our office as well as in a poster presentation at UMass Medical School. Their research found statistical results not unlike national information known about caregivers and their individual journeys.

The Journey Continues

Ultimately we hope that you, as a caregiver for an older adult will feel that your caregiver check-up survey results will help you to properly recognize and assess your own experience of stress and burden. We also hope that the Caregiver CrossRoads will ease your caregiver journey by offering supportive information. Remember, as a caregiver of an older adult:

You don't have to go it alone!

GRATITUDE

Thank you to all who helped us to address the public health problems of caregiver stress and burden. With full recognition of all of your individual time, skills and efforts CMAA offers a sincere appreciation to the following people who offered us so much support throughout this project.



Population Health Clerkship

Dr Carole Upshur
Dr Lee Hargraves
Lilly C.
Matt D.
Natasha D.

J. Tessa D.
Peter G.
Matt J.
Emilia J.
Alessandra M.

Juan R.
Michael R.
Chau T.
Kelley W.

In addition we would like to thank all the other medical professionals from UMass Medical School who helped educate the students about aging and caregiving issues.



Interns

Lori C.
John D.
Hayley G.
Camille L.
Michael P.



Volunteers

Madelyn D.
William D.
Zeenat I.
Eric L.
Lisa M.
Sondra S.
Jackie S.

Community Professionals

Chris MacWade

Executive Director, Family Services of Central Massachusetts

Dianne Sandman

Senior Paralegal, Community Legal Aid

Rachel Brown

Staff Attorney, Community Legal Aid

Robert Fahey

Social Service Coordinator/Veteran's Agent, Town of Franklin Mass

Dennis Goguen

Social Worker, Geriatric Medical Psychiatry UMass Memorial Health Care, Clinton Hospital Program

Lisa Krisinsky

Director, LGBT Aging Project

Julie McMurray

Manager, Central MA Regional Office, Alzheimer's Association

Gregory Mills

Public Affairs Specialist, Social Security Administration

Edwin Roth

Regional Director, Central Region, Serving the Health Information Needs of Elders Program

*We would be remiss
if we did not express our sincere thanks
to all of the caregivers who volunteered their time to help us
test the survey questions and gather preliminary results.*

*A special thank you to the community professionals who
helped us spread the word about this project.*