



Prepare to Care:
From Information to Action!

EXECUTIVE SUMMARY

**The New England Family Caregiving
Town Hall Meeting
September 20, 2003**

**John F. Kennedy Library and Museum
Boston, MA**

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***“The whole fate of a family
is determined by
events that arise from (chronic) illness.”***

***U.S. Representative Edward J. Markey
At New England Family Caregiving Town Hall Meeting
September 20, 2003***

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Family caregivers made history on September 20, 2003.

On that sunny Saturday morning, 175 family caregivers and professionals who work with them gathered at the John F. Kennedy Library in Boston to voice their concerns and to articulate their dreams for a better quality of life for all family caregivers. They were joined by expert panelists at the Boston site – and by another 200+ New England residents who participated in a live, interactive webcast of the event. Some gathered at satellite sites in Massachusetts and New Hampshire, while others logged on via their personal computers in their homes.

Background

The New England Family Caregiving Town Hall Meeting came about thanks to the united effort of over 40 community organizations throughout New England. A full list of community sponsors can be found later in this report.

The New England meeting was one of several town hall meetings organized by the National Family Caregivers Association (NFCA) as part of a year-long celebration of its tenth anniversary. NFCA is a non-profit organization, headquartered in Kensington, MD, that is dedicated to improving the quality of life of all of America's family caregivers.

Purpose

From the outset, the committee adopted an inclusive approach, reaching out to include representatives from every organization concerned with the quality of life of family caregivers, regardless of the age or the diagnosis of the care recipients served by any particular group.

The committee set a dual purpose for the event:

1. To educate family caregivers about existing resources available to support them, and
2. To increase public awareness, especially among policy makers, of needed changes that will improve the quality of life of family caregivers and their loved ones.

Breaking New Ground

The New England Family Caregiving Town Hall Meeting broke new ground by uniting consumer and provider organizations across the lifespan, with representation from family caregivers caring for children and younger adults with disabilities as well as those who care for the frail or disabled elderly,

Participants opened a dialogue with government and business leaders, elected officials, and the media. In addition, the town hall meeting provided valuable information about existing programs and services that can help family caregivers persevere in their vitally important role.

Key Issues

Comments by the panelists and by family caregivers dramatically highlighted the need for improvements in public and private sector policies to deal with:

- Financial Burden - Provide monetary relief for financially-strapped caregiving families – in the form of expanded federal and state tax credits, easing existing restrictions that prohibit direct payments to family members for providing care, and enacting paid family leave legislation.
- Respite Care - Improve access to affordable, quality respite care, so that family caregivers can replenish personal energy and maintain their own good health. Enact the federal Lifespan Respite Care Act.
- Access to Information – Improve access to information about services and supports for family caregivers. Public programs, employers, health plans, community agencies, and the media need to more effectively convey this information to families who could benefit from available supports.

Follow-Up Action

The town hall meeting sparked follow-up action. Representatives of many of the 40 organizations that co-sponsored the event with the National Family Caregivers Association (NFCA) are mapping plans for an on-going family caregiving coalition to push for progress on key issues. Also, NFCA will present the findings of the New England meeting at a National Town Hall Meeting on Family Caregiving in Washington, DC in February 2004.

Thanks to the support of WGBH, the day's entire proceedings can be heard on the WGBH Forum Network via the National Family Caregivers Association website at <http://www.nfcacares.org/boston/html>. The archive of the webcast and on-line chat can also be accessed through the above website.

We thank all the partners, co-sponsors and financial supporters, listed below, who made this event possible.

John Paul Marosy, Central New England Representative
Caregiver Community Action Network (CCAN)
National Family Caregivers Association

*For a copy of the full report, contact **John Paul Marosy** at (508) 854-0431 or jpmarosy@bringingeldercarehome.com*

Co-Sponsoring Organizations

Partners

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Corporate/Foundation Sponsors

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Sponsoring Community Organizations

Key:

Bold = financial contribution

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Caregiver Community Action Network - CT

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 Massachusetts Council for Home Care Aide Services
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 Massachusetts Executive Office of Elder Affairs
 Mass Home Care (state association of Area Agencies on Aging)
◆Massachusetts Families Organizing for Change
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◆National Multiple Sclerosis Society, Central New England Chapter, Waltham, MA
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