TEAMING UP TO SUPPORT CAREGIVERS AT HOME AND IN THE WORKPLACE

Presenters:

Sheila Warnock
Founder and President
ShareTheCaregiving Inc.
aka Share The Care™

Gregory L. Johnson
Chief Advisor, Family Caregiving,
Office of the CEO
EmblemHealth
Presented by
Sheila Warnock, Founder & President,
ShareTheCaregiving Inc.
Co-author, Share The Care
THE 2030 CAREGIVING CRISIS HAS ARRIVED AHEAD OF SCHEDULE
AND IS DUE TO BECOME ONE OF THE MOST SIGNIFICANT SOCIAL AND ECONOMIC TRANSFORMATIONS OF THE 21ST CENTURY.

IT IS GLOBAL IN SCOPE.
The New York Times
“Nursing Homes Are Closing Across Rural America, Scattering Residents”

Forbes
“What’s Love Got To Do With It? When Caring For A Business and Caregiving Converge”

The Wall Street Journal
“The Call to Care for Aging Parents Comes Sooner Now”

The Washington Post
“Who cares for Volunteer Caregivers When They Get Sick?”
Shortages of:
- nursing staff
- LTC para professionals
- geriatric professionals
- nursing homes
- younger people

71 million Boomers
many live alone – no family
often in rural areas,
many with dementia,
Alzheimer’s disease,
frail elderly with
mobility issues
We believe it will take all of us working together:

- concerned friends/neighbors
- professionals
- volunteers
- faith communities
- government
- non-profits
- corporations
- coalitions
A Grassroots Evidence Informed Caregiving Model

Share The Care™
EVOLVED OUT OF REAL LIFE EXPERIENCES:

Susan Farrow

Sheila and Julia Warnock

Sukie Miller, PhD
“Susan’s Funny Family” organized the wedding

First Edition 1995
Our Mission: is to improve the quality of life for anyone who needs support and to reduce the stress, depression, isolation and economic hardship of their caregivers.

“One of the Best Health Consumer Books of 2004“

The Library Journal
“Seeding Share The Care™ in Your Community”
Training Program for health professionals and clergy
Accredited by the Northeast Multi-State Division of RN Continuing Education

Keynote
Conference Presentations Workshops Lunch n’ Learn

2008 Achievement Award for Cross-Generational Caregiving from NY State Coalition for the Aging and the Statewide Caregiving & Respite Coalition of New York
NO ONE SHOULD HAVE TO GO IT Alone

Our Mission is to improve the quality of life for anyone who needs support and to reduce the stress, depression, isolation and economic hardship of their caregivers.

HOW WE CAN HELP YOU:

**Caregivers & Friends**
Find information and support on how to form and maintain a STC group. [Read more]

**Health Professionals**
Get information and STC training so you can help your patients & families. [Read more]

**Faith Communities**
Start using STC as a way to support fellow members of your faith community. [Read more]

**Corporations**
Discover valuable resources and the STC model to support your caregiving employees. [Read more]

ABOUT SHARE THE CARE™ (STC):

**Why STC?**
Caregiving will touch everyone at some point in life yet most people don’t

**Who We Are**
We are a not-for-profit organization registered with the NYS Department of Health.

**Who We Help**
Our site was designed with all of your needs in mind. [Select your section]

**Take Action**
Click to visit our Take Action page.
TARGET:
• caregiver and concerned friends
• health professionals
• faith communities
• corporations

OTHER TARGETS:
• hospital people-centered care programs
  (discharge, support groups, resources)
• schools for nursing and social work
• community colleges, high schools
A PLAN of ACTION based on Collaboration & Teamwork to support Patient/Caregiver/Family/Group Members

To provide:
EMOTIONAL, SOCIAL & PRACTICAL SUPPORT
(Customized by need)

• AT HOME
• FOR HOSPITAL STAYS
• AT DISCHARGE
• DURING TRANSITIONS
• END-OF-LIFE
Starts with two friends:

- chapters 2-9 written to them with
- step-by-step instructions to prepare for the first (scripted) meeting
- systems to rotate responsibilities
- 23 forms (for meeting and everyday use)

They work with the family to figure out:

- who to invite
- what kind of help is or will be needed
- decide on date for the first meeting
People can choose their level of commitment

full member or free floater

No one does a job they’re not capable of or uncomfortable doing
THE FIRST MEETING:
The group meets, bonds, and learns about STC systems

They leave with a plan of action and a sense of commitment
A group supports the entire family

If a person has no family nearby, the group becomes “family”
THE GUIDEBOOK INCLUDES:

- going to doctor with patient
- 10 steps to making the hospital stay painless
- keeping a medical history
- managing medications
- getting medical equipment
- learning new skills from professionals
- hiring/working with nurses’ aides
- managing challenges as a team

The book rights to *Share The Care* are owned by ShareTheCaregiving, Inc.
• creating an emergency plan
• making home safe & comfortable
• “being with” someone who is ill
• helping get their affairs in order
• caregiving away from home – travel for trials and treatments

• a 2nd meeting to make adjustments due to a major change with patient
• dealing with emotional issues
• importance of a closing meeting
FULL LIFE CYCLE CAREGIVING

• difficult pregnancy, preemies, and multiple births
• parents caring for a seriously ill child/teen
• grandparents raising small children
• seriously or chronically ill, or disabled
• rehabilitation after surgery, an accident or combat
• older adults living alone in need of assistance
• end-of-life (palliative care and hospice)

• teens transitioning into foster care

The only limitation is imagination.
<table>
<thead>
<tr>
<th>Support Group Name</th>
<th>STC Group Name</th>
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<tbody>
<tr>
<td>Susan’s Funny Family</td>
<td>Shirley’s Share The Care Group</td>
<td>Mimi’s Circle of Care</td>
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<tr>
<td>Nadine’s Army of Angels</td>
<td>Keep Keith Kicking Kare</td>
<td>Julie’s Share The Care Group</td>
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<td>Share The Care Sangha</td>
<td>The Swimmers</td>
<td>Mrs. B.’s Bruhlgade</td>
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<td>The Lauerttes</td>
<td>Cappy’s Brain Trust</td>
<td>Nancy’s Share The Care Group</td>
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<tr>
<td>Peg’s Legs</td>
<td>Friends of Judi</td>
<td>Carol’s Funny Family</td>
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<td>Francine’s Funny Family</td>
<td>Janet’s Funny Family</td>
<td>Patsy’s Circle of Angels</td>
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**STC GROUPS HAVE BEEN DOCUMENTED 48 STATES AND 15 COUNTRIES**

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<td>Kaye’s Share The Care Network</td>
<td>Harriet’s Harem</td>
<td>Jeanie’s Share The Care Group</td>
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<td>Joel’s Circle of Care</td>
<td>Lois’s Funny Family</td>
<td>Dor’s Doers</td>
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<td>Cici and Austin’s Funny Family</td>
<td>Mark’s Share The Care group</td>
<td>Lois’s Funny Family</td>
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<td>Crew For Doris</td>
<td>Team Betsy</td>
<td>Nori’s Share The Care Group</td>
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<td>Anne’s Share The Care Group</td>
<td>Revettes</td>
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<td>Charlene’s Angels</td>
<td>Mimi’s Share The Care Group</td>
<td>Tony’s Share The Care Group</td>
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<tr>
<td>Marcie’s Share The Care Group</td>
<td>The Carollers</td>
<td>Karen’s Funny Family</td>
</tr>
<tr>
<td>Greg’s Share The Care Group</td>
<td>Marge’s Share The Care Group</td>
<td>Michelle’s Share the Care Group</td>
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EACH GROUP IS UNIQUE

Because of differences in:
- conditions
- circumstances
- age
- attitudes
- family situations (or none)
- cast of characters (friends)
- needs
- culture or language
- local challenges (urban, rural, suburban)
LEARN NEW SKILLS AND RAISE FUNDS FOR TREATMENT:

Peg’s Legs
HAWAII
Volunteer to learn ALS protocols

Francine’s Funny Family
NEW YORK
Fundraising
SPECIAL PROJECTS:

Jeanie’s STC Group
OREGON

Move family to a new house

Support wish to build her dream home in spite of terminal cancer

Bette’s STC Team
WISCONSIN
EMOTIONAL:
KEEPING CREATIVE PROJECTS GOING:

FOPAK
Friends of Phil and Kathryn Simmons
NEW HAMPSHIRE

Peg’s Leg’s
HAWAII
When home care no longer possible, many groups continued their support in assisted living, nursing home, and hospice settings.

TRANSITIONS and EDUCATION:

Nadine’s Army of Angels
CALIFORNIA

Lynn’s STC Group
NEW YORK

Sherri’s STC Group
ALASKA

Dor’s Doers
TASMANIA

TEAM BETSY
COLORADO

Educate Group about MS
SPIRITUAL PRACTICES:

The Swimmers
WISCONSIN

Faith community of 150 has 50 Care Crew members. Last year they provided 7,500 hrs. worth of service

The Care Crew
NEW YORK
Special focus on Karen’s daughter

Karen Hill’s Funny Family

VIRGINIA

Bereavement Comfort & Support:

Mrs. B’s Bruhlrgade
HAWAII

Special focus on Karen’s daughter
HELP FOR ALL AGES:

Dolores’ Baker’s Dozen
WISCONSIN

To support for a 94 year-old baker who lives alone in rural area

The Diaper Darlings
TEXAS

Quadruplets!!!!
Within 10 days Lynn faced a diagnosis of terminal cancer and the unexpected death of her partner, Janet.
SOCIAL SUPPORT:

Harriet’s Harem
MARYLAND

has been Harriet’s support for
21 YEARS
from care to now preventing
social isolation

PREPARING MORE PEOPLE TO BE CAREGIVERS FOR THE FUTURE:

The Runners
MARYLAND

Have mobilized three times since 1997

Sick woman’s pals visit her daily — for 21 years

By Allison Klein
The Washington Post

It’s been about 21 years since Harriet, the black, had lost all her other body, multiple sclerosis rendered her unable to move or feed herself, or to even eat. So, four nights a week for more than a decade, Priskin, who had been a physical therapist in the Montgomery County, MD, hospital, helped to visit a whole schedule of her her body, sometimes to feed her, sometimes to read aloud about their day and put her interested in an hour or two. It’s been this way for 21 years.

“Girls don’t talk, people don’t talk, “Priskin, who has three children and six grandchildren, six grandchildren, and her husband at 54 years ago, Jerry Priskin. The woman’s friend, who has been a nurse who helped the woman during this period, has interviewed her to keep her healthy. In Harriet’s Harem, the health and social support of people who have been sick, have been important. She is a friend, a doctor, a QVC shopper.

“Now is living, she’s not just surviving,” Goldman, said, “She’s surviving.”

The women for an opioid treatment group were started in 1974 under Maryland. Priskin’s mobility was getting worse, she had to use a walker, and Goldman, and another friend were grateful to be included in the group, preparing food and staying with her. They would come before her husband went home from his job at the Department of Natural Resources, but the group, sometimes to read aloud, sometimes to feed her, sometimes to read aloud about their day and put her interested in an hour or two. It’s been this way for 21 years.

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“The Role of Unpaid Volunteers in a Group Caregiving Approach: Validation of the Share The Care Program” by Amy Hegener, PhD, Sheila Warnock & Alene Hokenstad was published in the *Journal of Gerontological Social Work* in 2016

Article available on request as well as a seven-page summary by researcher Amy Hegener, PhD
Data collected through on-line surveys, followed by telephone Interviews with a sample of survey of respondents to capture more qualitative information.

134 people participated in surveys and/or interviews. Most were from **US**. Other respondents from **Canada, Australia, the United Kingdom and Hong Kong**
Research Design:
No intention to demonstrate causation, but rather to explore impact program on the participants involved.

Mixed Methods:
• Online Surveys (n= 134)
• Structured Interviews (n=9)

Study limitations:
• Retrospective
• Sample lacked racial or economic diversity
• Non-experimental design

- Care Recipient (n=8)
- Caregiver (n=65)
- Group Member (n=61)
Group Characteristics:

- Three-fourths (75%) providing assistance to an individual with a serious or terminal illness.
- All groups were for adults, one-third (34%) were for senior citizens.
- Half (48%) lasted one year or longer.
- Three-fourths (76%) of group members contributed 1 to 6 hours per week.
Research Questions:

- Does participation reduce caregiver burden and burnout?

- Is there an association between participation and improved confidence in caregiving skills?

- Is there an association between Share The Care’s unique structures and processes and group members’ satisfaction?
Caregivers: Able to use their time more productively and spend more time with friends & family members outside of their caregiving responsibilities.
Caregivers: Better able to balance caregiving with other responsibilities

"Without our group, it would have been nearly impossible for me to continue employment while taking care of my sibling."

STC Caregiver Narrative Comment from Survey
Group Members: Overwhelming majority satisfied with both the helping experience and the care that was provided by the group.

Made a difference in the care receiver’s overall health and well-being. 93%

Increased their awareness of their own health. 73%

- Agree
- Do not Agree

- Agree
- Disagree
Evidence shows that Share The Care:

1. supports a care receiver’s ability to stay at home with necessary informal systems in place;

2. increases the caregiving preparedness of group members, enabling them to be more effective teammates; and future caregivers;

3. is replicable and its functionality can be applied across a variety of settings and circumstances;
and….

4. ensures longevity and a successful caregiving experience through its structured system of care;

5. helps reduce the burden of the caregiver;

6. has a positive impact on the well-being of the caregiver, care receiver, and group members.
Share The Care™ for broad scale replication

The Program Model is:
• Low Cost
• Adaptable
• Sustainable

Addresses Multiple Policy Objectives:
• To decrease caregiver burden and social isolation
• To better prepare communities to meet the challenges of an aging society
• To improve end-of-life care
“It was the most rewarding experience of my life. It proved that I could contribute so much without feeling overwhelmed or overburdened. It taught me to trust others, to know the real meaning of "team work". Emotionally, being able to choose to help according to my strengths and to "pass the buck" where I felt I was weak was a Godsend!”

STC Group Member
Narrative Comment from Survey
For more information about the model, training and/or research study contact: swarnock@sharethecare.org
212-991-9688

Visit: www.sharethecare.org
EmblemHealth
Care for the Family Caregiver
Caregiving at EmblemHealth
Founded in 2001
KEEPING CAREGIVERS, CAREGIVERS; NOT CREATING MORE CARE RECIPIENTS.

Through resources, research, tools, and partnerships, we support the “silent patients,” the family caregivers.
The Impact of Caregiving to an Organization
WHO ARE CAREGIVERS AND WHY SHOULD EMPLOYERS CARE?

A Caregiver is anyone who provides unpaid care for relatives and/or loved ones.

Family caregivers are as likely to be employed as non-caregivers. The majority (74 percent) of adults with eldercare responsibilities have worked at a paying job at some point during their caregiving experience.

Work Accommodations Due to Caregiving for an Adult Age 50 or Older

SOURCE: NATIONAL ALLIANCE FOR CAREGIVING AND AARP, CAREGIVING IN THE U.S. 2009
CAREGIVING AND IMPACT ON EMPLOYEE PRODUCTIVITY

• “70% of working caregivers suffer work-related difficulties due to their dual roles.”

• “69% of working caregivers caring for a family member or friend report having to rearrange their work schedule, decrease their hours, or take unpaid leave in order to meet their caregiving responsibilities.”

• “49% arrive to their workplace late/leave early/take time off, 15% take a leave of absence, 14% reduce their work hours/take a demotion, 7% receive a warning about performance/attendance, 5% turn down a promotion, 4% choose early retirement, 3% lose job benefits, and 6% give up working entirely.”

• “Caregivers suffer loss of wages, health insurance and other job benefits, retirement savings or investments, and Social Security benefits.”
Our Corporate Approach
FOCUS OF THE CAREGIVING PROGRAM & HOW WE’VE GATHERED RESOURCES

Our areas of focus in developing content and partnerships.

- Family of Origin (birth family).
- Family of Choice.
- Seniors being cared for.
  (first thought for most)
- Seniors caring for seniors.
- Seniors caring for grandkids.
- Children as caregivers.
- Chronic condition care.
- Disease-specific care.
- End of life care.
- Long distance (Expats, third-country nationals).
- Veterans.
FOCUS OF THE CAREGIVING PROGRAM & HOW WE’VE GATHERED RESOURCES

• **New York City Partnership for Family Caregiving Corps. (NYCP4FC Corps.)**
  – Our partners in content development & delivery
  – Established by EmblemHealth to raise awareness among businesses about the economic impact family caregiving has on their bottom line, and to help them mitigate that impact.

• The Partnership is comprised of several organizations providing a variety of services.
  – EmblemHealth
  – ShareTheCaregiving, Inc.
  – Spiritual Conditioning for the Family Caregiver
  – SAGE
  – Aging in New York Fund
CARE FOR THE FAMILY CAREGIVER RESOURCES
Information and Resources for Today - Hope and Health for Tomorrow
A CORPORATE VOICE FOR FAMILY CAREGIVERS

Employee Campaign:
Care for the Family Caregiver

Corporate Engagement in Family Caregiving

The Corporate Leadership Council
THANK YOU
Gregory L. Johnson
Chief Advisor, Family Caregiving,
Office of the CEO
EmblemHealth
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Fellow: NYAM, NY Academy of Medicine

Please Visit:
corporatecaregivers.com
download.emblemhealth.com/careforthefamilycaregiver
facebook.com/careforthefamilycaregiver

You Are Not Alone Series on YouTube:
http://www.youtube.com/playlist?list=PLUthdkimXSzsHfYY_VuJAYvyuOTmCIqee