

**POWERFUL TOOLS FOR CAREGIVERS:
THE WESTERN NEW YORK EXPERIENCE**

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Who is a Caregiver?

*Anyone who provides assistance to
someone else who is, to some degree,
incapacitated and needs help.*



Caregiving Risks

- High Stress
- Worry, uncertainty
- Decreased well-being
- Increased physical illness
- Diminished immune response

What is PTC?

- Psycho-educational program
 - not a support group
- 6-week series of classes (2.5 hours)
- Focus on caregiver self-care
- Scripted curriculum
- Train-the-trainer model

PTC Curriculum

- **Class #1:** Taking Care of You
- **Class #2:** Identifying and Reducing Personal Stress
- **Class #3:** Communicating Feelings, Needs, and Concerns
- **Class #4:** Communicating in Challenging Situations
- **Class #5:** Learning from Our Emotions
- **Class #6:** Mastering Caregiving Decisions

Self-Efficacy = Confidence



A person's belief that he/she can perform a behavior necessary to achieve a certain outcome or effect.

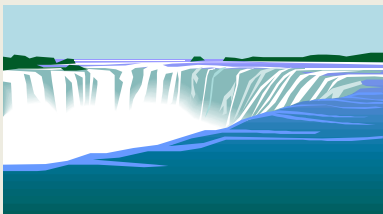
Strategies for Enhancing Self-Efficacy

- Skills Mastery
- Modeling
- Reinterpretation of Feelings and Attitudes
- Persuasion

Caregivers Learn To:

- Reduce stress
- Communicate effectively
- Make difficult decisions
- Improve self confidence
- Locate helpful information
- Bring balance into their lives

Bringing Powerful Tools



to Western New York

*POWERFUL TOOLS FOR CAREGIVERS:
WESTERN NEW YORK*

- Co-sponsored by The University at Buffalo, School of Public Health and Health Professions and the Erie County Caregiver Coalition
- Enabled by a grant from the Community Health Foundation of Western and Central New York in 2004

*POWERFUL TOOLS FOR CAREGIVERS:
WESTERN NEW YORK*

- Participant-trainees represented 16 agencies/organizations
- 23 class leaders were initially trained
- 4 Master Trainers trained in 2006
- 15 more class leaders trained in June 2006
- 12 additional class leaders from Allegany and Cattaraugus counties trained in 2007

Outreach to Culturally Diverse Communities

- Additional Community Health Foundation funding was provided in 2008 to target minority communities:
 - African - American
 - Hispanic
 - Native American



PTC transcends the boundaries of:

- Race/ethnicity
- Length of caregiving experience
- Age of caregiver/care recipient
- Relationship of caregiver to care recipient

People new to caregiving:

Tom, and
his son, Dave



**Basic PTC Outcomes
for Tom & Dave:**

- Increased self confidence
- Know where to turn for information and community resources
- Understand the importance of caring for themselves

The younger generation:

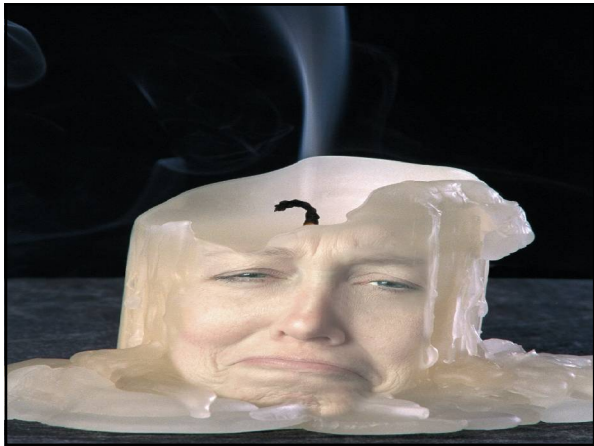
Daria and
her Grandma



**Basic PTC Outcomes
for Daria:**

- She controls her emotions, they don't control her
- Understands the importance of caring for herself

**The burned out
caregiver:
Pat**



**Basic PTC Outcomes
for Pat:**

- Increased self confidence
- Began using community resources
- Understands the importance of caring for herself

Some of the Tools

- Communication Techniques
- Guidelines for Managing Emotions
- Being Assertive, Not Aggressive
- Making an Action Plan
- Relaxation Techniques

Tool # 13

Assertive Communication:

DESC

Evaluation

- Pre-course survey
- Post-course survey
- Opinion and satisfaction surveys

CHARACTERISTICS OF CAREGIVERS (N=558)

AGE (mean): 59.3 years

SEX

Male: 13.8%
Female: 86.2%

RACE

White (Non-Hispanic): 90.0%
Black/African-American: 6.7%
Hispanic: 1.5%
Other: 1.8%

EMPLOYMENT STATUS

Not currently working: 51.9%
Employed, part-time: 15.4%
Employed, full-time: 32.7%

CHARACTERISTICS OF CARE RECIPIENT (N=558)

LOCATION

Same household: 45.2%
Alone in own home/apartment: 26.7%
With someone else: 8.1%
Nursing home: 4.5%
Multiple sites: 3.2%
Other: 7.4%

DISEASE (multiple designations possible)

Alzheimer's disease/other dementia: 41.5%
Heart disease: 18.6%
Parkinson's disease/other movement disorder: 13.1%
Stroke: 13.8%
Diabetes: 13.6%
Cancer: 8.5%
Other: 51.2%

**CAREGIVING DEMANDS
(N=558)**

PERSONAL CARE
 Not at all: 52.5%
 Some days: 25.5%
 Daily, or almost daily: 22%

HOUSEHOLD HELP
 Not at all: 12.8%
 Some days, but not every day: 35.8%
 Daily, or almost daily: 51.4%

ARRANGING FOR CARE OR HELP
 Not at all: 17.8%
 Some days, but not every day: 53.3%
 Daily, or almost daily: 28.9%

PTC Outcomes

Improved:

- Self-Confidence
- Self-Care Behaviors
- Management of Emotions
- Use of Community Resources

OUTCOMES: SELF-CONFIDENCE (n)

TASK	p VALUE	EFFECT SIZE*
• Get help- with daily tasks (177)	<.0001	Moderate
• Use relaxation to cope (186)	<.0001	Very large
• Keep from feeling sad (185)	<.0001	Very large
• Do something to feel better (183)	<.0001	Very large
• Cope with stress (183)	<.0001	Very large
• Deal with increase in care needs (180)	<.0001	Very large
• Discuss matters with physician (152)	<.0001	Moderate/large
• Discuss needs with family (186)	<.0001	Moderate/large
• Talk with paid caregivers/staff (180)	<.0001	Moderate/large
• Talk with care recipient (182)	<.0001	Large

*Cohen's d statistic

OUTCOMES: SELF-CARE BEHAVIOR (n)		
BEHAVIOR, PAST WEEK	p VALUE	EFFECT SIZE*
• Total time: stress management/relaxation (200)	<.0001	Moderate
• Number of times in relaxation activity (200)	0.01	Small
• Total time exercising (200)	0.04	None
*Cohen's d statistic		

OUTCOMES: MANAGEING FEELINGS AND EMOTIONS (n = 200)		
FEELINGS IN PAST WEEK	p VALUE	EFFECT SIZE*
• Less critical of others	<.0001	Moderate
• Less easily annoyed	0.0001	Small/moderate
• Less angry	<.0001	Small/moderate
• Fewer temper outbursts	<.0001	Moderate
• Less guilt over not doing more	<.0001	Small/moderate
• Less self blame	0.06	None
• Less self critical	<.0001	Small/moderate
*Cohen's d statistic		

OUTCOMES: FEELINGS (n=200)		
FEELINGS, PAST WEEK	p VALUE	EFFECT SIZE*
• Calm and peaceful	<.0001	Small/moderate
• Down-hearted and blue (less)	<.0001	Moderate
• Been a happy person	0.006	Small
• Very nervous person (less)	<.0001	Small/moderate
• So down, nothing could cheer me (less)	<.0001	Small/moderate
*Cohen's d statistic		

OUTCOMES: USE OF COMMUNITY RESOURCES				
Service, Past Year (n)	Mean: post-%	Mean: pre- %	Mean Difference: %	p value
Care aide (198)	21	16	+5	.077
Placement in facility (198)	24	12	+12	<.0001*
Support group for CG (199)	52	24	+28	<.0001*
Case Management Service (199)	27	18	+9	0.01*
Counseling CG (199)	25	18	+7	0.057
Classes for med. information (199)	28	20	+8	0.026*
Transportation Service	22	15	+6	0.019*

**Success Factors:
Personal**

- Address universal caregiving challenges
- Encourage individual adaptation of tools
- Create opportunity for new approaches

**Success Factors:
Organizational**

- Central scheduling (one phone number)
- Support of the Caregiver Coalition
- Pool of trained class leaders facilitates forming teams
- Promotion of program by class leaders in locality or organization

Numbers That Add Up

June, 2004 – August, 2009

- Classes Scheduled: 106
- Classes that have run: 69
- Currently running or scheduled in the future: 8
- Caregivers registered: 792
- Caregivers who completed at least 4 out of 6 classes: 499

Participants said they now feel:

- More positive
- Less guilt
- Not as judgmental
- Able to use new ideas
- OK about how they feel
- Have new ways to communicate
- More confident
- More knowledgeable
- Don't second guess themselves as often
- More realistic about loved ones illness
- Able to put things in perspective
- More patient and understanding
- Able to approach family members with their needs
- Greater sense of peace
- Able to deal with conflict
- Less stressed
- Accepting of their own feelings
- Better equipped for caregiving
- Saying "no" is okay
- Able to deal with changes
- Able to set limits

What Caregivers Said About Community Resources

- I didn't realize so much was out there
- There's a lot there, you just have to ask
- Printed lists were helpful
- If they didn't have the info, the leaders tried to find it
- I received all sorts of pamphlets
- I needed the support group list
- I like the ideas to keep Dad safe
- I appreciated the adult day care and physician information
- I read everything – lots of good resources
- The handouts, discussions and answers to questions brought out untapped resources for all of us

What Participants Liked Best:

- Community Resources
- ALL the tools
- Group discussion
- Brainstorming
- Comfortable, relaxed setting
- Hearing others share their situations
- Realizing I'm not alone
- Leaders were well prepared, knew what they wanted to accomplish and what material to cover
- Buddy phone calls
- The upbeat way info was shared about serious stuff
- Practical ideas for dealing with stress
- Confidentiality
- Relaxation exercises
- Balance between leader and group input
- Identifying my feelings and realizing what may happen if I don't take care of myself
- Personal examples
- Focus is on the caregiver

For More Information

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