# CAREGIVER STORIES AND STRESS SOLUTIONS

# DR. TOM DELOUGHRY



# About the Author

My interest in the connection between the mind, body and Spirit is reflected in my career as the director of drug abuse and adolescent services in Child Psychiatry at Buffalo Children's Hospital, and as director of wellness and disease management for Independent Health, a managed care organization. I also served as a clinical assistant professor of Public Health and a research assistant professor of Family Medicine at the State University of New York at Buffalo, where I earned my doctorate in health education and behavior.

After my mother's death, I took a three-year sabbatical to direct a Franciscan retreat center. While there, I convened a coalition of social workers, nurses and physicians that also included Christian, Jewish and Muslim clergy. We collaborated to create *a simple mind-body-spirit program for seniors, adults and teens of any faith or no faith.* That effort, which produced this book (originally published as *What I Wish I Knew)*, was honored by *AARP's Social Impact Award*.

Caregiver Stories and Stress Solutions is a collection of:

- Stories about my stumbles and successes as a caregiver
- Strategies to help individuals and families solve the physical, emotional, social and spiritual pieces of their *Wellness Puzzle*.
- Research studies upon which these strategies are based.



Each piece can help or harm the other pieces.

The stories in the Introduction and the Epilogue are true. Initially, I wrote most of them to explore my thoughts about love and wellness. These stories include: *My Mother*; *What I Wish I Knew; The Liturgy Nazi; I Know Why I Got Sick* and *Grace*.

The stories about the Phelps family are imagined. They are: *Because of All the Pictures; A Different Person; Trapped; Yes, You Do; and Waiting 'Till Spring.* But they're based on real people, as well as my hopes and my fears...and maybe yours, too?

This book is dedicated to Tom and Loretta DeLoughry. They were my best teachers when my life was beginning – and, again, when their lives were ending.

And to Kathy DeLoughry, who taught me more about love than any book or preacher.

#### Introduction

My Mother 3 Youthful Energy and Elder Wisdom? 5 What I Wish I Knew 7 The Phelps Family 8 Like A Different Person 8 Helping Others is Good for You 9 Because of All the Pictures 10 Volunteer Opportunities 12 Trapped 14 The Satisfaction Skills 15 Assess Yourself! 16 How Joe Used the Satisfaction Skills 17 Acceptance and Forgiveness 21 Get and Give Support 22 Appreciating Differences: Cultural Sensitivity 23 Alzheimer's and Other Dementias 23 Love and Healing 25 Yes, You Do 26 A Poem for Any Problem 27 Prevent Avoidable Health Problems 29 Connect Your Care To Reduce Hospitalizations! 30 Don't You Dare Waiting 'Till Spring - Part I 32 Dying Well and the Satisfaction Skills 35 Advance Directives: Planning for End of Life Care 36 Hospice and Comfort Care 37 Waiting 'Till Spring - Part II 39 **Epilogue: Being Your Best** 41 I Know Why I Got Sick 41 Maybe I Forgot? 43 The Liturgy Nazi 44 Our Feelings Affect the Facts We See 48 Grace 50 **Research Studies and References** 54 Action Guide 56

# Introduction

You may think that you're holding a book. But I think you're holding a discussion starter and a planner that will help you be your best at any age. Let's begin with the last year of my mother's life.

#### My Mother

Bruises covered one skinny arm and her ankles were a swollen purple mess. Someone had helped her out of bed, but she barely made a dent in the little armchair that faced it.

The drone of her oxygen machine drowned some of her words. But I filled in the blanks from the warmth in her eyes and the smile on her lips near the cut that had just been stitched.

My mother was peaceful.

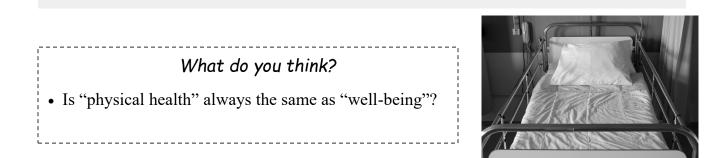
I couldn't connect her contentment with her typical crankiness, her frequent falls and last night's ambulance ride.

Yet, now there was a glow about my mother. It would grow for months, but I wouldn't understand it for years.

A few weeks later, my wife and I were walking along Lake Ontario. Ahead of us, two teen-age boys skipped from boulder to boulder, tanned muscles flexing in the sun.

As we approached, we realized that their shouts were curses - aimed at someone who wasn't there. The warm breeze carried their anger long after we passed.

I asked Kathy, "Who do you think is more well? ...my mother ...or those boys?" And neither of us knew how to answer.



That summer, when friends would ask how my mother was doing, I could never respond with just one or two words. So, usually, I'd say something like, "Well, physically she's a mess, but she's strong emotionally and spiritually."

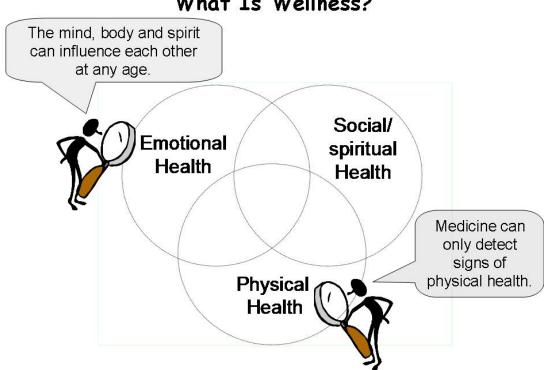
Now I believe that you're never too old to be well – regardless of the physical illnesses or limitations you have. You don't have to stop being well, just because your body is sick. In fact, peace of mind, joy and satisfaction can always grow – because love can always grow.

Love grows when we choose to let go of anger, guilt and fear. This book, and the related Living Well program (at www.LivingWellNow.INFO) will show you how.

You'll also learn to maximize the healing powers of medicine and reduce your risk of hospitalizations by connecting your care<sup>2</sup> and working closely with your doctor.

Love plays a crucial role in healing both the mind and the body. But sometimes the best, and most lasting, sign of healing is peace or joy – not physical change.

It is just as wrong to cure without caring, as it is to care without trying to cure. My hope is that this book will help you to do both.



# What Is Wellness?

#### Youthful Energy and Elder Wisdom?

Is it true that young people have more energy, but older people are wiser?'

Look at the chart below, taken from an annual survey<sup>3</sup> sponsored by the federal



Centers for Disease Control. It shows that the average elder (aged 75+) has about:

- Six "bad days" each month in which physical problems keep them from doing his or her normal activities
- Yet, despite the challenges of aging, they have less than two bad days each month in which emotions (such as stress or depression) keep them from doing their normal activities.

However, their "adult grandchildren" (aged 18-24) seem to have the opposite problem:As expected, they have fewer bad days (2.5) each month in which physical problems keep them from doing their normal activities.

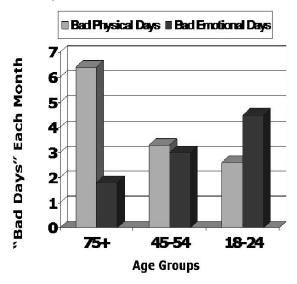
• Yet, despite their good physical health, these young adults have about 4.5 bad days each month in which emotions (such as stress or depression) keep them from doing their normal activities – more than twice as many bad day as their grandparents!

For most of us, peacefulness does seem to grow with age. However, it is important to note that, when elders become isolated or hopeless, alarming problems occur. This may explain why elders have the highest rate of suicide, despite their "typical" contentment.

#### What Do You Think?

- Which is harder...? Growing up? ... Or growing old?
- Is there really such a thing as "the wisdom of the elders?"
- How can you "speed up" the process of becoming more peaceful?

# Average "Bad Days" Each Month for Elders, their Adult Children and Grandchildren



Center for Disease Control Health Related Quality of Life Measures for New York State

#### The Same Steps Help At Any Age

I spent the first fifteen years of my career working with teens and their families, and the next fifteen focused mostly on working adults. For the past ten years, my programs have focused on well seniors, frail elders and their entire families.

Along the way, I've learned that the same steps that can help you when you're 78, can also help if you're 48, 18, or 8.

Later in this book, (when the Phelps are challenged with medical and emotional problems in *Yes, You Do*) you'll also learn about these steps, and how they can help you with *any* issue – whether it's medical, emotional, social or spiritual.

What I Wish I Knew

As my parents aged, taking care of them was like riding a roller coaster. My clearest memory is the day I plunged from being an expert to being embarrassed.

I had just received a national award from the American Managed Care Review Organization for improving the quality of care for diabetes and hypertension. I had also authored the American Lung Association's national program for emphysema and chronic bronchitis.

These were the very illnesses my mother had. Thus, when my sister and I started to explore home and community services for our mother, I figured that I would score big points in our ongoing game: "Who does Mom like best?"

Diane and I sat across from the social worker who explained our options in a flurry of agencies and assessments that I had never heard of.

Quickly, I changed my strategy from showing off to avoiding eye contact and taking good notes. And, slowly, it dawned on me that good health – especially for the elderly – involves much, much more than just good medical management.

"If I'm overwhelmed," I thought, "what is this like for someone with no healthcare background?" That's when I decided to write this book - about what I wish I knew *before* Mom needed any help.

It was a shock to realize that good medical management wasn't enough to help my mother.

I wanted to understand how I could help with daily tasks. So, I began by studying what health aides are required<sup>4</sup> to know, to help elders maintain independence.

Social workers tutored me in case management and how to find community services. I reviewed quality standards<sup>5</sup> for the 20 most common problems of the elderly and simplified them to help families at home. I gathered information about financial and legal issues.

And I learned that love is often the best medicine.

This book, along with a workbook, *Less Stress, Better Health and More Love*, address all of these issues. The stories published here also inspired a much longer story, **The Friendship Trilogy**. The stories in this book are include in *The Epidemics*, my third novel.

#### Understanding Isn't Enough

If this was a book about playing the piano, it would only take a little reading for you to "understand" how each note on a music scale relates to a specific white or black key on a piano. But would that understanding make you a musician? Of course not. You have to practice!

Similarly, you'll get little benefit from this book if you use it just to *understand* how you or a loved one can be well. But if you commit yourself to *practicing* the satisfaction skills each day, plus using the "poem for any problem," you'll find -- like a musician who practices daily -- that you can create new harmonies in your life.

Work on yourself first. You'll gain better health of your mind, body and spirit. And your example will be a more powerful motivator than any book.

You will also benefit from using the strategies presented here to create a "caring team" of friends and family who help each other to achieve their goals - as described in two related books: *The Epidemics* and *Less Stress, Better Health and More Love.* 

#### For more information, please visit: www.FriendshipTrilogy.com

# The Phelps Family

The people in the Phelps family stories are a lot like me and some people I've known ...and maybe they're like you, too?

#### Like A Different Person

Well, of course I'm upset," Bernice said. "Your father will be in the hospital for another week and I'm not even well enough to visit on my own."

"Once he gets home," she added, "we'll both be stuck inside all winter. Last year was tough but I'm afraid this one will be worse."

Cindy was sorry she had asked. Usually her mother looked on the bright side, but she had done nothing but complain ever since she got in the car.

They pulled into the hospital ramp, looking for a spot that would shorten their walk.

"Remember a few years ago how Edith became my mother-in-law from hell?" Cindy asked. "All of a sudden I couldn't do anything right for her precious son and grandchildren."

"I remember that she nearly ruined our Thanksgiving dinner with her snide little comments." Bernice said. "And she gained so much weight! The exercise that woman needs is to push herself away from the table."

"Well, her weight is still an issue, but she's like a different person now," Cindy said. "The change seemed to happen after she got involved in the Community Caller program."

"What's that? "Bernice asked.

"Well, it's a program that trains people to volunteer as either a 'Friendly Visitor' or a 'Telephone Buddy'. Apparently, she learned a lot about community resources for seniors, but I think it was the stress management and communication training that made the biggest difference.

"She's a lot calmer now, and doesn't take her frustrations out on me. I even enjoyed her company for a whole day last week," Cindy added.

"Well, that's a little hard to believe," Bernice said. "But I have so much to worry about; I could never get involved in something like that."

The car stopped and Cindy turned off the engine. "Are you sure, Mom?

#### Helping Others is Good for You

Here's a quiz:

- 1. A group of seniors were assigned to either get a massage, or give a massage to an infant. Which group reduced their stress the most?
- 2. How much happier are adolescents who want to help others, compared with those who don't care about helping?

Answers:

L. The seniors who massaged the infants had a greater reduction in stress hormones. 2. The adolescents who wanted to help others were THREE times happier than the others.

Study after study<sup>6</sup> shows that helping others can improve *your* emotional and physical health.

- Consistent volunteering is associated with reduced depression in all age groups, and particularly in those aged 65 and older<sup>7</sup>
- People who volunteered were 30% less likely to experience physical limitations, even after controlling for lifestyle and prior health factors<sup>8</sup>
- A large California study<sup>9</sup> showed that those who volunteered more than four hours per week had an 44% reduction in mortality, after controlling for their health status

Evidence also shows that the opposite (i.e., being self-absorbed) is bad for you. For example, a study<sup>10</sup> of college students showed that "narcissists" (whose focus was on themselves) were more likely to have shorter romantic relationships. They were also more dishonest, over-controlling or violent than students who were more caring.

#### Because of All the Pictures

Donald wondered if the noise from his stomach was louder than the clunky heater of his rusty car. As he rounded the corner, he grabbed at the textbooks that slid across the seat. He figured his fingers had been cold for about a half hour.

He crunched his car against the snow bank that walled the little house from the street. The TV flickered in the front window and he knew Mrs. Phelps was waiting.

He caught a whiff of the chicken dinner as he opened the insulated chest in his trunk. "Still warm," he thought, remembering he just needed one since Joe was in the hospital. A minute later the rattle of the lock was followed by a creak and Bernice peered from behind the door.

"Ah, it's my favorite caterer" she said as he stepped in, repeating the same joke Donald had heard every Tuesday and Thursday for nearly a year.

He smelled the cookies before she gestured to the covered plate. "Here, I've made you some oatmeal raisins to make sure that meat stays on your bones," she said. "Come and sit for a minute and have a few with me."

"Oh, no, I'm running late..." he started to say, noticing the warm brown eyes behind her thick glasses. "Well, maybe just a few minutes."

"Good," Bernice said, turning on her cane. "I'll get you some milk to go with them."

She smiled a little as she put the glass down. "You know, I've always wondered... Why does a young man like you spend the middle of a busy day delivering meals to an old lady like me?" She sat next to a table cluttered with tissues and medicine bottles.

Donald stared out at the snow as he chewed. "Well, you know... I think it was because of all the pictures at my Grandpa's funeral. When I saw him as a young man with my Grandma, it really hit me: I'm a lot like him - and some day I'm going to be old, too.

"In the year before he died, I saw how much home-delivered meals helped him. There was also this Friendly Visitor program. Someone would come in to keep Grandpa company, so my Grandma could go shopping, have lunch with friends or just relax.

"So I decided I'd try to help other people who were, maybe, like my Grandpa ... or maybe like I might be some day." He shrugged, and saw that her eyes were sparkling now.

He reached for another cookie. "How's Joe doing?"

Suddenly, Bernice looked older. "Better, I think. But I don't know what we're going to do after he's discharged."

"Well, I'm not an expert," he said, "but here's how you can talk to people who have the answers," pulling a flyer from a large envelope. "This describes the best places to call for anything from 'affording what's best' to services to help you at home." He paused while she looked at each page.

"The best place to call, huh?" she said, holding it a little closer. "Maybe this will help."

A few minutes later, he steered away from the snow bank. "This is odd," he thought. "My hands are cold, my car's a wreck and I'm going to be late for my class. So why do I feel so good?"



#### What do you think?

• Donald didn't make the connection that he was a lot like his Grandpa until he saw the pictures at his funeral.

- How different are you than someone ....older than you? ...younger than you?
- How much satisfaction did Donald get from volunteering? ....How much satisfaction would you get?

# **Volunteer Opportunities**

Wherever you live, there are a lot of opportunities. Most communities offer similar programs (and similar benefits!) because they use the same state and federal funding sources. To learn more about the following, as well as other options, contact your local Office for the Aging or Department of Senior Services:

#### Senior Companion

- The Senior Companion Program brings together volunteers age 60 and over with adults in their community who have difficulty with the simple tasks of day-to-day living. Companions help out on a personal level by assisting with shopping and light chores, interacting with doctors, or just making a friendly visit.
- Senior Companions may receive a tax-free stipend if income eligibility requirements are met. Senior Companions also receive pre-service and monthly training, an annual physical exam, transportation assistance and supplemental insurance coverage while they are serving.

## Retired Senior Volunteer Program (RSVP)

- RSVP connects volunteers age 55 and over with service opportunities in their communities that match their interests and availability. From building houses to immunizing children, from enhancing the capacity of non-profit organizations to improving and protecting the environment, RSVP volunteers put their unique talents to work to make a difference.
- Volunteers are eligible to receive mileage reimbursement from their homes to their volunteer stations and back, or they can use their transportation expenses as a tax deduction. RSVP also covers volunteers with a supplemental insurance policy.

#### Your Own Organization

Don't overlook volunteering for a club or church you may already belong to. You may qualify for Senior Companion or RSVP benefits for something that you're already doing in your own organization.

#### Practice the Golden Rule

Whether you're helping someone as a volunteer, a friend or a family member, the Golden Rule stands out as a guide to follow.

This simple instruction – *Treat others the way you want to be treated* - is a good compass to navigate the complexities of relationships – whether you're paid or not.

As detailed in the following table, the notion of "doing unto others..." is central to all major religions<sup>11</sup>.

	The Golden Rule as Expressed in Major Faiths
Buddhism	"Hurt not others in ways that you yourself would find hurtful."
	Udana-Varga 5,1
Christianity	"Do to others as you would have them do to you." - Jesus (5
	BCE—33 CE) in Luke 6:31; Luke 10:27; Matthew 7:12
Confucianism	"What you do not want others to do to you, do not do to
	others." -Confucius (ca. 551–479 BCE)
Hinduism	"This is the sum of duty; do naught onto others what you
	would not have them do unto you" - Mahabharata 5,1517
Islam	"Hurt no one so that no one may hurt you" Muhammad, The
	Last Sermon. (570 – 632 CE)
Judaism	"Whatever is hateful to you, do not do to your neighbor. That
	is the whole Torah. The rest is commentary – Hillel the elder (50
	BCE-10 CE)

The heart of helpfulness, therefore, may be found in the volunteers, aides, professionals, friends and family who are simply treating others the way they would like to be cared for.

#### ...But Help yourself first!

When family caregivers become exhausted, or aides burn out and quit, elders are no longer able to stay at home. Thus, it's extremely important that volunteers or caregivers first take care of their own minds, bodies and spirits.

Help yourself first! You'll gain better health of your mind, body and spirit. And *your* example will be a more powerful motivator than any book.

#### Trapped

Confused, he was lying in a cold iron tube with a glass window. Trapped. Seeing but unable to move.

Years ago, he'd had flashes of that feeling. Confined on a plane. Stuck in a crowd with no way out.

Now, as Joe awoke, he knew he was trapped for real.

The hospital room smelled bitter, sweet and foul. And he knew the foulness came from him.

His sheets, heavy with urine, were cold on his thighs. Stretching out as far as he could, his hand strained to just inches from where the call button dangled. He waited, screaming inside.

"Hello?" he asked. Softly, so he wouldn't wake his roommate. Yet hoping that someone in the hall might hear. That someone would banish the stench and something could free him. That, after being in the hospital for five days, he wouldn't fall again.

He focused on his breathing for a minute. He quieted his mind by just focusing on the air moving in and out of his lungs – letting himself be grateful for each breath.

He repeated a phrase that gave his mind some peace, over and over with each breath. When fear or anger surged, he brought his focus back to his breath and his thoughts of peace. The sky outside his window turned from black to gray.

Footsteps squeaked in the hall and he called out. The aide hesitated in the door, then approached, looking like she hadn't slept for two nights.

"I need some help," he said, then looked down at the sheets. "First time anybody's had to change me in seventy-five years."

He had a hard time understanding her accent. But her smile told him she would help. "You're very kind," he said. "But I want to tell the head nurse that call buttons should be clipped within reach whenever beds are made up."

He rested, wondering if Bernice and Cindy would make it though the snow to visit again.

## The Satisfaction Skills

The satisfaction skills are practical steps that can help you or a loved one manage stress, improve your communications and even experience more love

In this section, you'll learn how Joe used these skills when he was trapped – and how they can make a difference in your life.

The satisfaction skills are prompts to change your thinking and behavior. This strategy – known to psychologists as "cognitive-behavioral" skills – has proven its effectiveness in helping the elderly<sup>12</sup>, caregivers<sup>13</sup> and youth<sup>14</sup> to deal with depression, anxiety and anger.





# Use the Satisfaction Skills

to communicate, manage stress, feel more love and find more peace of mind.



# Assess Yourself!

How often do you use the "satisfaction skills"?

## Awareness:

How often are you focused on goodness of the present moment, instead of being upset about the past or worried about the future?

	Rarely	Sometimes	Frequently
With friend or family:			
During doctor visits:			
In prayer:			

# Affirmations:

How often do you complin	nent others, or do something to help them?
With friend or family:	
During doctor visits:	
In prayer:	

# Assertiveness:

How often do you tell otl	ners what you want, think or feel?
With friend or family:	·
During doctor visits:	
In prayer:	

# Acceptance:

How often do you listen to others, accept their point of view, and forgive them? ... or forgive yourself?

With friend and family:	
During doctor visits:	
In prayer:	

Do you use each skill in all situations?

If you never or rarely use a skill, consider using it more often. If spirituality is important, assess how often you use each skill in prayer.

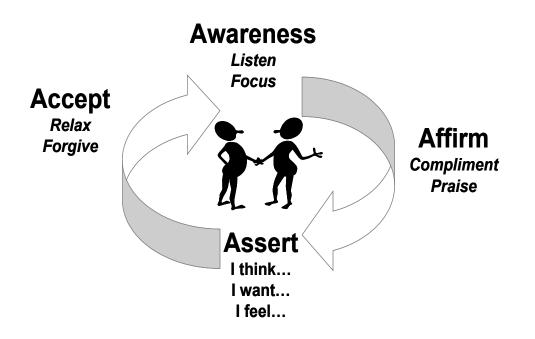
#### How Joe Used the Satisfaction Skills

Any one of the satisfaction steps may be helpful at any time. In *Trapped*, Joe used some of them again and again as he waited for help.

It's almost impossible to see or feel love when you're angry, guilty, fearful or stressed. The satisfaction skills can remove these "blocks to love"<sup>15</sup>.

These skills prompt you to find a balance between asserting what's important to you, while accepting and forgiving the past.

The satisfaction skills can be used in any order. But there's an advantage (especially in conversations and stressful situations) in starting with awareness, and then moving to affirmations, assertiveness, and acceptance. And then repeating the cycle, over and over.



#### Awareness

Awareness is the skill of focusing our attention where it's most helpful. It's easy to become so upset that we miss something important or good that's happening right now.

Joe was stressed about something in the present (i.e., his wet sheets). But he *chose* to focus his awareness on two other facets of the present: his breathing and the peaceful thought he kept repeating.

Most of us *stay* stressed because our mind is "stuck" focusing on something that happened in the past, or anticipating something that might happen in the future.

Yet, our minds are like searchlights. You *can* choose to focus on the past, the future or some aspect of the present. Try it and see.

The skill of focusing (described in the sidebar and taught on the *Never Too Old CD or DVD*) allows you to direct your attention to where it will be most helpful. The more you practice, the better you get at paying attention to what will help you the most.

Past problems and future fears can distract you from signs and symptoms that are important to notice. Anger, guilt and fear also keep you from experiencing peace of mind.

When it's time to plan, focus on the future. Take all the time you need - five minutes or five days – but don't spend so much time anticipating the future that you miss out on the present.

When you need to remember, focus on the past. Learn from your experience. But don't spend so much time revisiting the past that you overlook some solutions or goodness in the present.

# What do you think?

Present

• Why do *you* stay stressed? Is it because you're remembering something in the past? ... or anticipating something that might happen in the future?

#### Focusing

To practice the skill of focusing:

Sit quietly where you won't be disturbed for a few minutes

Take a few deep breaths - then let your attention stay on the sensation of your breathing.

When your attention wanders (which it will a dozen times each minute) let your attention come back to the sensation of your breathing.

Remember, it's training – not a "feel good" – exercise. The more you practice, the better you'll be at focusing your mind on the present moment – or wherever it helps you the most.

## **Affirmations**

Affirmations are positive statements or thoughts we make about others, as well as the positive thoughts we have about ourselves. In *Trapped,* the positive thoughts that Joe repeated were affirmations. So was his gratefulness for each breath and the compliment, "You're very kind" he said to the aide.

## Affirming Others and Gratefulness

Affirmations are practical, pleasant and positive ways to deal with other people

and appreciate the world around you. In this drawing, who is most likely to get help? The person with the flowers, of course!

"You did great!", "Nice try!" and "I like your haircut" are good examples of affirming statements.



Everybody wins if you have affirmations in your "skills kit" and you use them regularly. If you "affirm" people, they feel better and their stress level goes down. Then, they are more likely to notice the good things about *you*.

Remember, it is just as important to affirm yourself (by paying yourself a compliment) as it is to affirm someone else.

How often do you express gratitude for others and the world around you? Try making a gratefulness list each day for a week, and see if it changes your mood.

#### Using Positive Thoughts as Affirmations

Just thinking an affirmation can be helpful, and there are thousands that can help. For example:

- Live and let live
- This will pass
- I choose peace
- I have a right to my opinion
- Thy will be done
- Thank you
- Be here now

To get better at affirmations, make sure you practice using them every day.

#### Assertiveness

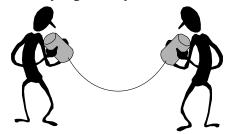
Assertiveness is the skill of telling people what you think, how you feel and what you want. If you don't tell people, how will they know?

In Trapped, Joe was assertive when he:

- Called out for help
- Told the aide: "I need some help."
- Said: "I want to tell the head nurse that call buttons should be clipped within reach..."

Good communication is impossible without assertiveness. Saying what you think and

feel can bring you closer to others, (or make you a more valuable member of the care team) – but <u>only</u> if it's well balanced by your awareness, acceptance and affirmation skills.



Chances are that others will respond to your assertiveness by telling you what *they* think, want and

feel. Understanding everyone's thoughts and feelings is an important step in problem solving.

#### More Energy and Less depression

Have you noticed how your heart speeds up when you tell someone what you think? Assertiveness can give you energy. When you "speak up," your natural hormones stimulate both your body and your mind. Thus, assertiveness may be enough to lift you out of a mild depression or the "snooze response" (see page 28).

If depression is long-lasting and affects the quality of your life, you might benefit from counseling and medications. However, you can lift yourself out of a typical "lifestinks" depression by just telling other people what you think, want and feel.

#### **Aggression or Assertiveness?**

Assertiveness is different from aggressiveness. Aggressive statements usually begin with "you" - and communicate something negative. "You are...[dumb, lazy, messy]," "You should [wake up, get a life, clean up, etc]...".

Sometimes it *is* appropriate to be aggressive instead of assertive. Certain situations require you to say: "You should stop!" or "You're hurting yourself."

However - in most social and care-giving situations – assertiveness (using those "I" statements) works better than aggressiveness. Think about the following:

Don't Be Aggressive, Be Assertive!			
Instead of saying	Try saying		
You're stupid!	I don't understand what you mean.		
You're a jerk!	I'm worried, angry, etc.		
You're ridiculous!	Here's what I think we should try		
I hate you!	I feel hurt.		

#### **Acceptance and Forgiveness**

Acceptance can be your "saving grace" when, despite your best efforts, a situation gets worse instead of better. It also helps when you're frustrated with others or disappointed in yourself.

Acceptance doesn't mean giving up, just like forgiving doesn't mean forgetting. Instead, acceptance, as taught in this booklet, means letting go of your anger, fear or guilt.

Both acceptance and forgiveness rely on other skills, and is a mix of:

- *Being aware* you've done your best (if not, try at least once more)
- *Affirming* the efforts that others may have put into solving the situation
- Sharing or asserting your thoughts, feelings and concerns with someone else, and
- Accepting that none of us know what is *really* best in any situation

When you accept or forgive, the goal isn't to "forget" what happened, or what you wished would happen. Instead, the goal is to *not dwell* on past actions or future fears, so you can see whatever goodness or beauty there might be in the present moment.

# Relaxation

To practice the skill of relaxation: -Sit quietly where you won't be disturbed for a few minutes.

-Gently tighten all the muscles in your face and mouth, then let go.

-Gently tighten all the muscles in your hands, arms and shoulders, then let them relax.

-Tighten your belly, then let go.

-Tighten all the muscles in your legs and feet, and then let them relax.

The more you practice, the better you'll be at relaxing your body – and even your mind – whenever you want.

Focusing and relaxation are skills that make it easier to accept. Focusing helps you keep your mind in the present, and relaxation calms both your body and your mind.

# Get and Give Support

Support is a wonderful medicine and, if you use the satisfaction skills, you'll get more of it – because using these skills can improve your relationships.

Did you know that social isolation is a greater health risk than smoking? (Smoking increases the risk of death by a factor of just 1.6, while social isolation does so by a factor of  $2.0^{16}$ ). Also, consider this:

- Social and productive activities are as effective as exercise in reducing mortality rates of the elderly<sup>17</sup>
- Support is a significant factor in improving outcomes among patients suffering from diabetes<sup>18</sup>, stoke<sup>19</sup>, HIV<sup>20</sup>, and depression<sup>21</sup>

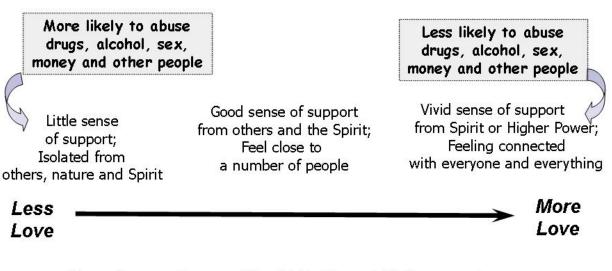


# **Choosing To Have More Support**

You can reduce the fear, anger and guilt that keeps you isolated by using the satisfaction skills. The more you choose to use them, the more benefits you'll give and get.

As illustrated below, the more you use these skills, you'll have more love and support – and fewer problems.

Having More Love and Fewer Problems



# More frequent use of "satisfaction skills" ·····→

#### **Appreciating Differences: Cultural Sensitivity**

In *Trapped*, Joe "had a hard time understanding" the accent of the aide that helped him, but he affirmed her by saying, "You're very kind." As the world grows smaller and our country grows more diverse, it's increasingly important that we understand and appreciate people from different cultures – whether they're from a different part of town or a different part of the world.

You can avoid miscommunication and stereotypes by using the satisfaction skills to understand and appreciate. It doesn't matter if you're a professional, aide, volunteer or just a neighbor. We each have a responsibility to reach out to value the importance and value of others – regardless of whether their gender, generation, race, religion or sexuality is different than yours.

#### What Do You Think?

Imagine that you're in a foreign country:

- Mr A. deals with you by assuming that you are "just like every American"
- Mr. B. tries to be aware of your likes and dislikes; compliments or affirms when you do a good job; is assertive about sharing his goals and feelings; and accepts you for who you are
- Are you more likely to have a productive relationship with Mr. A. or Mr. B.?
- When you encounter someone from another culture are you more like Mr. A. or Mr. B.?
- How can you use the satisfaction skills to enhance your relationships with others who, at first, seem different than you?

#### **Alzheimer's and Other Dementias**

Few illnesses cause as much anguish, anxiety and anger as Alzheimer's and other dementias. It's easy to understand why both caregivers and their loved ones can become highly stressed.

The satisfaction skills can help you deal with someone who has Alzheimer's and other dementias. Consider using:

- o Awareness
  - Make good eye contact. Be aware of for patterns (e.g. He/she usually gets upset when...) physical discomforts or emotional triggers that may have triggered an outburst or other problems.

- o Affirmations
  - Remember to compliment or praise (e.g., I like your shirt; well done!) or be grateful whenever possible
- o Assertiveness
  - Make positive suggestions (e.g. I think it would be nice...; I think you might enjoy).
  - Share positive feelings (e.g., I feel good that you helped), but do not order or insist
- o Acceptance
  - Stay calm and accept that you will probably need to repeat the "satisfaction cycle" again and again

In *Trapped*, Joe was "screaming inside" because he couldn't get out of bed and help himself. Many caregivers feel a similar frustration when trying to help a loved one with dementia. Remember, that the same strategies that helped Joe (i.e., focused on breathing, repeating a peaceful thought) can make any difficult situation somewhat better.

#### **Enhance Your Spirituality**

Spirituality isn't important to everyone. However, if it is to you then you might consider how the satisfaction skills can also enhance your spirituality.

Awareness can open your mind to the blessings, love and goodness that surrounds you now.

*Affirmations* -- praising the wonders of creation and miracles of life -- are an uplifting and common form of prayer.

*Assertiveness* can be used to prayerfully describe your needs and feelings, and place them in God's hands.

*Acceptance* helps us recognize that we do not have the wisdom to predict the future or to understand God's will (e.g., as expressed in prayers like: "Thy will be done"). It helps us to trust.

If a prayer is "any thought that connects us to God or God's creations"<sup>22</sup>, then each of the satisfaction skills is really a type of prayer. It is most helpful to use *all* the satisfaction skills in our spiritual relationships or prayers, just as it's most helpful to use *all* of these skills in our personal relationships.

# Love and Healing

The following points summarize much of what is in the preceding pages. Can you use them to improve the health of *your* mind, body and spirit?

Love is a sense of oneness with the world, others and ourselves.

- The mind and body *can* be healed by love. The best, and most lasting, sign of healing is peace or joy not physical change.
- Spirituality is love, and so is God.
- Love is always around us.
- The experience of love and healing is just a thought, a word or a prayer away.
- Fear keeps us from experiencing the love and blessings that surround us.
- Prayer, forgiveness or the satisfaction skills can free us from fear.
- Prayer is any thought that reconnects us to love or to any part of God's creation.
- We can pray, and experience more love and forgiveness, by:
  - o Becoming aware of God's presence in nature, ourselves or each other
  - Being thankful for the goodness and blessings we have
  - Sharing what we think, want or feel
  - Accepting God's will
- The same skills (i.e., awareness, affirmations, assertiveness, acceptance) that help us to communicate and connect with the Spirit can help us to communicate and connect with each other.

#### What Do You Think?

- When you "assessed yourself" on page 17, what were your strongest skills? ...what were your weakest?
  - Make a plan to practice your weakest skills every day

# Preventing and Managing Illness and Other Problems

#### Yes, You Do

" I *do* want to go home," Joe insisted, sitting up in the hospital bed. "But, Bernice, you can't even take care of yourself, let alone a husband with a broken hip, diabetes and the flu!"

"Are you telling me what I can't do?" Bernice said with a hard look in her eye. "What gives you the right to lecture me? What about the flu shot you never got that could have prevented some of this?"

"Never mind about that, Bernice. It's just too much," he insisted, his voice rising. "Two sick people in a house that..."

"Dad," Cindy interrupted. "It's a lot but, as you always say, 'It's the hand we've been dealt, so let's play it.'

"When you think of all your problems at once," their daughter continued, "it *is* too much! What we need is a plan for each problem.

"So, let's discuss our options with the doctor, decide what steps to take, and then keep track of what works – and what doesn't" she added. For a minute the room was quiet.

"You know, I think we've got two issues going here," said Bernice. "There're the medical problems. God knows we've each got enough of those. And then - ever since we both got sick - there's been all this bickering."

She paused, meeting his eye. "Joe, we never used to be like this."

"So then we need two plans?" Cindy said, looking hopefully at her mother. "One to keep you out of the hospital? And another to keep your love going?"

"I don't know," said Joe.

"Yes, you do," said Bernice, reaching for his hand.

Medical problems can create emotional problems, even in the best relationships – and the same plan can help you with both of them.

In order to be your best, you need to:

- Plan with your physician, and others who provide medical emotional and spiritual care
- Take preventative steps to avoid problems
- Connect your care to avoid medical mistakes and unnecessary hospitalizations

# A Poem for Any Problem

The story, *Yes, You Do,* raises two important issues:

- Following a plan can help you from being overwhelmed
- A plan to "keep the loving going" can be as important – or more important – than the plan dealing with the medical issues.

You can help yourself or someone else to deal with any medical, emotional or spiritual problem by following this little "poem for any problem"

> Choose your goals and check your signs. Take some steps and learn each time.

This poem is both a *stress management* plan that can increase the joy in your life, and a *disease management* plan that can control <u>any illness</u>. For example, to control diabetes or high blood pressure you measure different signs (i.e., blood pressure, blood glucose). But the process, as outlined by the poem, is always the same:

Choose *goals* for your mind, body or spirit — and share them with others to motivate yourself!

# Choose Your Goals



LOVE · PEACE OF MIND · HEALTH INDEPENDENCE · HAPPINESS

...and Check Your Signs.



STRESS · SATISFACTION · DEPRESSION BLOOD PRESSURE · WEIGHT · CHOLESTEROL ABILITIES FOR ACTIVITIES · DRUG OR ALCOHOL USE





MEDICATION · THERAPY · SELF-HELP EXERCISE · EAT WELL · GET SUPPORT USE THE "SATISFACTION SKILLS": BE AWARE · AFFIRM · ASSERT · ACCEPT

# ...and Learn Each Time.



RE-CHECK YOUR "SIGNS" TO LEARN WHAT WORKS FOR YOU NOTE: A FREE, FULL-COLOR POEM FOR ANY PROBLEM POSTER IS AVAILABLE FOR DOWNLOADING AT WWW.THECHM.NET

Check your *signs* to "benchmark" where you're starting, so you can keep track of what works — and what doesn't.

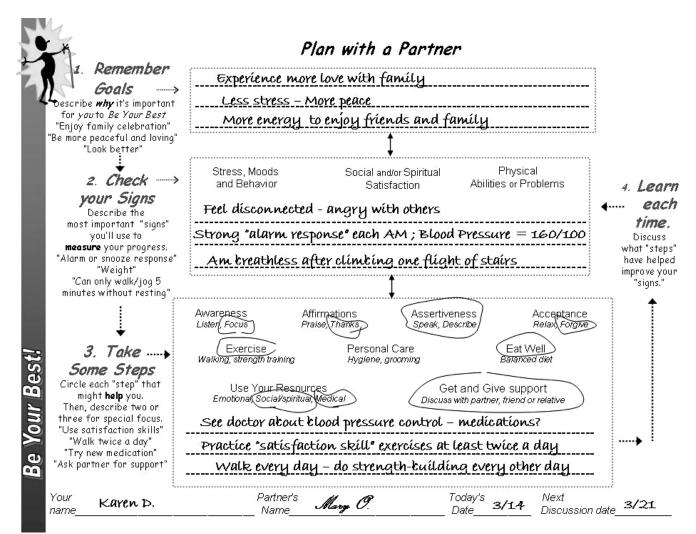
Note especially your signs of stress:

- The alarm response (i.e., tight muscles, rapid heartrate and breathing, fear anger)
- The "snooze" response (i.e., relaxed muscles, sighing, depression)

Take some *steps* — like exercising, eating well, getting support, taking your medications, managing stress and using the satisfaction skills.

*Learn* what works by tracking your signs and sharing that information with your doctor and care team.

Remember, even the world's best doctor doesn't know exactly what will happen when he or she prescribes a new medication! So use the "poem for any problem" to plan with a partner (i.e., a friend or a loved one) Then, update your plan and share it with your doctor, so you can both learn what is or isn't working.



#### **Prevent Avoidable Health Problems**

In Trapped, Bernice was angry with Joe because he didn't get his flu shot.

Flu and Pneumonia vaccines can help you stay healthy and avoid hospitalizations. However, according to the Centers for Disease Control<sup>23</sup>, people at high risk should be vaccinated. This includes anyone over 50, those with chronic conditions and anyone in contact with those at high risk.

The "Welcome To Medicare" checkup is an important – but frequently overlooked benefit – that's available to anyone within six months of beginning Medicare. It includes a comprehensive series of tests that can prevent or delay more serious illness.

Always ask your doctor what's right for you, and whether you should have the following tests

- o Mammography
- o Pap-Test
- o Pelvic Exam
- o Prostate Cancer
- o Diabetes
- Cardiovascular Disease (cholesterol checks)
- o Glaucoma
- o Bone Mass Measurement

#### What Do You Think?

- Have you gotten the necessary vaccines, or talked to your doctor about whether you need them?
- Have you just started Medicare? ....or will you be joining soon? If so, ask your doctor about getting a "Welcome To Medicare" exam.

\_\_\_\_\_

• Have you and your doctor discussed what screening tests you should have? ...and when your next screening tests are due?

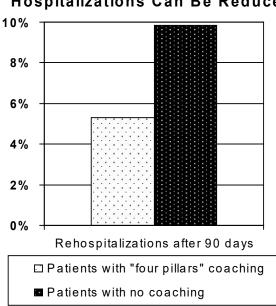
#### **Connect Your Care To Reduce Hospitalizations!**

If you receive care from more than one doctor, each doctor probably doesn't have enough information to provide good quality care.

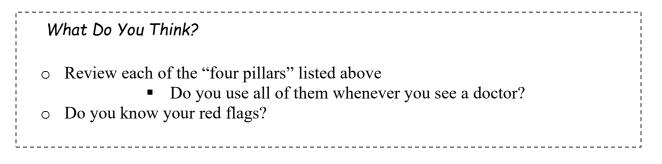
Who is the best person to inform your doctors and connect your care? You!!

You can reduce hospitalizations by nearly half if you take a more active role in your care, according to a study<sup>24</sup> in which patients were coached in *four pillars of care*:

- Bring a list of all current medications (or your pills) to each doctor visit
- Bring your health record with you each time you see a new doctor
- Follow-up with your doctor after hospitalizations
- Know your "red flags" (when to call your doctor immediately)



**Hospitalizations Can Be Reduced** 



## What Do You Think?

## Preventing Illness

- 1. In *Yes, You Do* Joe and Bernice were overwhelmed by all of their medical problems. Also, they were arguing.
  - a. Could Joe have prevented the flu which complicated his medical condition? ...If so, how?
  - b. What have you done to prevent medical problems? ... What more could you do?

# Dealing with Chronic Illness

- 2. How could Joe use the "Poem for Any Problem" to deal with his diabetes?
  - a. What were his goals? ... To be able to live independently at home? ... Any others?
  - b. What "signs" do people with diabetes need to check?
  - c. What other "steps" would Joe need to follow? Regular exercise? Good nutrition? Medications?
  - d. If you were Joe, how would you "learn each time" what is working?

# Dealing with Emotional Issues

- 3. How could Joe and Bernie have used the "Poem for Any Problem" to deal with their arguing/.
  - a. What goals might be important to them?
  - b. What signs should they watch for?
  - c. What steps could they take?
  - d. How can they "learn each time" what is working?

#### Waiting 'Till Spring - Part I

"It's so lonely here in winter. Maybe she could wait until the spring?"

I hated myself for asking, and hated God for making me ask. But the nurse kept talking about "letting go", and I didn't know what else to say.

The drone, drone of that damn oxygen machine sounds like a dying heartbeat. Heart problems slowed Bernice down, but it's the emphysema that's stopping her.

She's still young, at least to me. Other women her age are taking trips to Florida, babysitting for the grandchildren - even taking tap dance lessons. But Bernice gets exhausted just crossing the room.

I remember her walking towards me in the dining room on our one and only cruise. Her dress was a dark, silky blue that showed off her shoulders and her breasts. So what if she wore an old mother-of-the-bride dress for a fancy, formal night? She was prettier than anyone else in the room, and when she smiled... wow.

I'd only known her for a few weeks when I got a chance to really stare at her. Boy, we were young. She was a second grade teacher. I don't know why I was there, but I was sitting off to the side of her classroom, watching her teach. I could actually see the love pouring from her to the children – almost like it was something real. She was so gentle and her eyes were so soft.

I remember thinking, "Boy, I'd like to get in front of that!" And, I did. For more than forty years she's been my best friend and my wife. Now she's dying, and she wants to let go.

That nurse couldn't even look me in the eye. She said, "Bernice is very sick, and she's very tired. The two of you need to talk."

Talk! All we do is talk. At least, all Bernice does is talk. It amazes me that a woman confined to the house can have so much to say.

Most people seem bored by my stories, even before I start rushing and tripping over my words. I'm better at listening, I think.

I liked hearing Bernice describe our trips to her lady friends on the phone. The grass was always a bit greener, the mountains a bit bigger and the food a lot better than I remembered it. But she wasn't bragging. That's how she saw things.

She was fun to travel with. "Look, cows!" she'd say, delighted, as if she had never seen one before. Or, she'd marvel that we were in a restaurant that actually served brewed decaf coffee.

I always worried less than her. I guess it helps to have a short attention span.

"What do you mean, talk?" I asked the nurse. "I know she's dying. I know what kind of funeral she wants. I hate talking about this..., this...." 'Crap' was the most decent word that came to mind, but I didn't think I should say that in front of a hospice nurse.

"This is very difficult," I said as calmly as possible. "Are her medications okay?"

Lena pulled records from a big tote bag. She sighed while turning the pages, still not able to look at me.

It was getting dark, but I could still see the snow on the tree limbs. There'd be more by morning.

"Joe, the medicine she needs is love," Lena said. "She's ready to let go."

Let go. Damn it. The nurse was repeating herself, but I refused to. I couldn't face the winter without Bernice. Hell, I could barely pay the bills without her, let alone run the house.

"I've got to get supper ready. When will you be back?" I said rising from my chair.

Her headlights cut white tubes through the snow as Lena pulled away. I used to think

our house had a warm glow that could melt the coldest winter. Now our little speck is nothing but sickness and suffering.

There were still a couple of clean plates, so I figured I'd just microwave something and let the kitchen go.

In my normal state, I live like an animal. Well, maybe that's not fair to animals. Maybe a pig, but I'd read once that pigs would keep themselves clean if they were given half a chance. Not me. Whenever Bernice went to Ohio to see her sister, I'd live in squalor until the day before she got back. She hated coming home to a messy kitchen.

Bernice doesn't make it to the kitchen much these days. Has it been a week or two weeks since she sat there and had a cup of coffee? So, why bother cleaning, unless Cindy and her kids are stopping by? But the last time Cindy didn't call first, and now she says she's worried about me, too.

Worried, hell. I have enough to worry about without worrying that Cindy might worry.

Still, it's nice that she calls every day. Bernice especially likes talking to the grandkids. Allen, the oldest, is so smart it's scary. He's tells Bernice whenever the International Space Station is passing overhead - as if she could get out of bed and see it.

Bernice still favors Lean Cuisine when she has an appetitive, not that she ever really had a weight problem. I guess she doesn't want to look fat in her coffin. Tonight, she pushed the food away after a few bites.

"Lena says you're getting very tired," I said.

Her eyes filled with love and she opened her arms to me.

"Remember how we always said we'd go together?" I could hardly speak because my chin was trembling. "If you die, I'll miss you so much!"

I knew it was the exact wrong thing to say. I should be brave and loving and say she should go to God or whatever, but I didn't want her with God, I wanted her with me. I wanted her to be with me!!!

I hugged her too tight and neither of us could stop crying. Our bodies jerked back and forth as we sobbed.

All of a sudden it struck me: "I think this is the best workout we've given this mattress in years." We laughed, more than we had in months. Then, like babies, we cried ourselves to sleep.

I didn't miss the sex. Once, when we were young, we kept each other up all night and didn't stop smiling until after lunch.

But, lying in bed and holding her now – that was heaven to me. I didn't need to die to find paradise. I'd been in her arms almost every night for forty nine years. That's all I wanted. What could be better?

The idea for *Waiting "Till Spring* came from a training program<sup>25</sup> in which we were told about a difficult hospice case. The wife was dying and ready to let go, but the husband asked: "Couldn't she wait until spring? It's so lonely here in winter."

For years I wondered about the mix of love and neediness that might prompt this request. Then, I wrote the story to explore what those feelings might be.

#### Dying Well and the Satisfaction Skills

"Dying well" is a goal that, at some point, all of us need to consider. The final days can be a time of great closeness -- even a bittersweet celebration of a life well lived. However, for some it becomes a time of panic or despair.

Forgiveness is always crucial in finding peace of mind. As death approaches this is even more important. The satisfaction skills can guide you through the process of becoming closer with your loved ones. If spirituality is important to you, these skills can also help you become closer to your God.

## Advance Directives: Planning for End of Life Care

Advance directives provide instructions for your future health care, in the event you are unable to make decisions for yourself. It's a process of thinking and talking, supported by the completion of forms which include:

*Health Care Proxy* --This form, sometimes referred to as a "durable power of attorney" allows you to pick someone to speak for you about medical decisions when you are no longer able to do so for yourself. In New York, and many other states, it is a legally recognized form that can be completed without an attorney.

Consider the following steps from *Sharing Your Wishes*<sup>26</sup> to assure "peace of mind rather than tough choices"

- 1. Think about what is important to you and how you want to receive your care
- 2. Select a person to speak for you if you are unable to speak for yourself
- 3. Talk about your health care wishes with your agent, doctor and family members
- 4. Put your choices in writing, using a Health Care Proxy form

*Living Will* --This form is used to specify treatments that you would want, or not want, if you are terminally ill or have an irreversible condition. It is not a legal document in New York and other states, but it helps your agent and others to better understand your wishes.

*Do Not Resuscitate* (DNR) This form states whether or not you want cardiopulmonary resuscitation (CPR) to restart your heart and lungs if you are in a hospital or nursing home. At home and in other settings, a "Non-Hospital DNR" or MOSLT form is needed.

*Medical Orders for Life Sustaining Treatment (MOLST)* MOLST has been adopted<sup>27</sup> by New York state to translate people's preferences about end of life care into medical orders. In some states it is call POLST (Physician's Orders for Life Sustaining Treatment).

MOLST is based on communication between the patient or surrogate (the agent or spokesperson) and health care professionals. The MOLST form accompanies the person as he or she is transferred home or to a new care setting (e.g. long-term care or hospital). Although, the MOLST form summarizes advance directives, it is *not* intended to replace traditional advance directives such as the Health Care Proxy form and/or Living Will.

## The MOLST Form

- Contains actionable medical orders regarding life-sustaining treatments.
- Is recommended for individuals with an advanced chronic progressive illness or terminal illness or for anyone interested in further defining their end-of-life care wishes.
- May be used to limit medical interventions or clarify a request for all medically indicated treatments including cardiopulmonary resuscitation (CPR).
- Is a bright pink color that is easily identified in case of emergency.
- Accompanies the patient as he or she is transferred home or to a new care setting (e.g., long-term care facility or hospital).
- Should be reviewed and renewed periodically.

For additional information, please visit: www.compassionandsupport.com

Health Care Proxy	BRIGHT PINK COLOR FOR EASY IDENTIFICATION				
hereby appoint	SEND FORM WITH PATIENT/RESIDENT WHENEVER TRANSFERRED OR DISCHARCED				
	MOLST				
as my health care agent to make any and all health care decisions for me state otherwise. This proxy shall take effect only when and if I become una care decisions.	Medical Orders for Life-Sustaining Treatment Do-Not-Resuscitate (DNR) and other Life-Sustaining Treatments (LST) This is a Physician's Order Sheet based on this patient resident condition				
<ul> <li>care decisions.</li> <li>Optional: Alternate Agent         If the person I appoint is unable, unwilling or unavailable to act as my hea             appoint</li></ul>	and wishes. It summarizes any Advance Directive. If Section A is not completed, there are no respirations for this section. When the need occurs, <i>dirgt fullow</i> these orders, then contact physician. Any section not completed implies full treatment for that section. This form whole has realized and the reasonal methodically. The vertical balance with the fullow or resultations under if				
(name, home address and telephone number)	Section RESUSCITATION INSTRUCTIONS (ONLY for Patients in Cardiopulmonary Arrest): (If patient/resident has no pube and/or no respirations) Do Not Resuscitate (DNR)* [DNR=No cardiopulmonary resustantion, endotracheal introbation or mechanical venilation]				
as my health care agent to make any and all health care decisions for me, o state otherwise.	Chack One Box Only * For incepacitized adults, and/or for therapeutic or medical finity exceptions, and/or for residents of OMEL OMRDD or correctional functions, also complete resident sections of Supplemental DNR. Documentations Form, for Adults, For minor patients, also complete Supplemental DNR. Documentation Form for Minors, For patients in the community, also complete NYS DOH Nonhospital DNR. Form, unless located in Mource or Conducta Counties.				
c) Unless I revoke it or state an expiration date or circumstances under which remain in effect indefinitely. (Optional: If you want this proxy to expire, st here.) This proxy shall expire (specify date or conditions):	B Patient/ Resident Health Core Winners of Patient/Resident Signature Check if verbal constant Health Core Winners of Patient/Resident Signature of Verbal Constant Winners of Patient/Resident Signature of Verbal Constant Print Patient/Name Date				
i) Optional: I direct my health care agent to make health care decisions acc limitations, as he or she knows or as stated below. (If you want to limit yo health care decisions for you or to give specific instructions, you may stat here.) I direct my health care agent to make health care decisions in accor	Agent or Surrogate Decision- Maker Consent of PATIENT / RESIDENT WITHOUT DECISION-MAKING CAPACITY: This document Consent for Consent for Cons				
limitations and/or instructions (attach additional pages as necessary)	Complete one of the subactions of Section B Relationship to Patient/Resident.				
In order for your agent to make health care decisions for you about artifici	Winner: Segnature         Print Winner: Name         Date           plust witness HC-Marroyate segnature or verbal telephone consent)         Date         Date				
(nourishment and water provided by feeding tube and intravenous line), y know your vishes. You can either tell your agent what your vishes are or See instructions for sample language that you could use if you choose to i form, including your wishes about artificial nutrition and hydration.	C Physician Signature (Netherland Signature or Verbal Consent) Print Physician Name Date (Netherland Signature or Verbal Consent)				
	for Section 1 Puryteina Liesese *: Puryteina Phone Pager *: and B hts the responsibility of the physician to determine, within the appropriate period, (see below) whether this order continnes to be appropriate, and to indicate this by a note in the person's medical chart. The issuese of a new form is NOT required, and under the law this order should be considered valid unless it is known that it has been revoked. This order remains valid and must be followed, even if it has not been reviewed within the appropriate time period. The physician must review these orders as follows: Hoopital: a least every 7 Days; Nursing Home-Stalled Nursing Facility: at least every 60 Days; Nonhopital Community Setting: at least every 90 Days				
	Section ADVANCE DIRECTIVES: Patient/Resident has completed an additional document that provides guidance for treatment measures if he/she loses medical decision-making capacity:				
	Revised October 2005 © 2003 Rochester Health Commission This Document is consistent with New York State Law and is approved by NYSDOH. Page 1 of 4				

#### Hospice and comfort care

Hospice programs, for patients whose life expectancy is less than six months, are available in many communities. These programs may be available through nursing homes, stand-alone hospice centers or services provided at home.

Many nursing homes offer "comfort care." Similar to hospice, the goal of this program is to make sure the senior is as comfortable as possible in their remaining months. Some treatments and/or medications that might prolong suffering are stopped.

The decision to request hospice or comfort care is difficult. Should life be extended as long as possible? How important is the quality of life? What are the feelings and the wishes of the senior? What choices will help you experience the most love?

Social workers, nurses, physicians, family members and the senior you care for can each play an important role in the decision making process. The satisfaction steps (awareness, affirmations, assertiveness and acceptance) can help you navigate through these difficult times.

#### What Do You Think?

• Do you have a health care proxy or MOLST form, so your wishes about end-of-life care will be followed if you can't speak for yourself?

• Read the section on "End of Life Care" about choosing someone as a health care proxy. If you were Bernice, who would you choose as your proxy: Joe, Cindy or Susan? Why?

## Waiting "Till Spring

Bernice died on March 2<sup>nd</sup>, a little over a year ago. I was holding her and both our girls were with us. My throat ached so much from crying, I couldn't talk.

I remember snow on the way to the funeral, then not much else except wet pillows and a lot of darkness. Susan, our older girl, stayed over for a while to help and Cindy visited almost every day.

Depression has a sweetness I had never imagined. As you spiral down and feel worse, there's a comfort in the blackness that draws you deeper. I thought I could stop myself, but it drowned me. It lasted a long time.

The crocuses came up last week. Bernice always got excited about that. She said she hated the winter, but it seemed to me that she never really hated anything.

I have some good days now. Lena called and asked if I wanted to volunteer for Hospice. She says people who are sick need a good listener. I'm not sure about that, but I said I'd help out at the Golden Age center. Golden Age? That's a laugh.

Maybe someday I'll join Bernice on the Cosmic Cruise and see the love in her eyes when she smiles at me. I don't know, and my minister is kind of wishy-washy about it.

But more and more, I'm surprised by little glimmers of love. Of course, Cindy has Bernice's laugh, and Susan has her good heart. But sometimes when I see wildflowers along the road or sit with friends in church, I feel connected in a way that's different.

I wish I knew how to say it. ...It's like everything – each flower, each person - is a gift or a hint that Love is there – just waiting to be noticed. If I'm calm, and focus on just this moment, I see flashes of goodness shining in everything – and somehow I'm part of it. ...I never knew that before.

When I'm home, I play a little game with myself, to do just one thing to make a room look nicer before I leave it. Sometimes picking up the newspapers leads to wiping up some crumbs and rinsing a glass. I'm not so embarrassed now when Cindy and the kids come over.

Bernice would have liked that.

# What Do You Think?

- It seems like Joe is changing, or healing, toward the end of the story. He's feeling "little glimmers of love" and connected to nature and his friends. But it only happens when he's calm and focused on the present moment.
  - How do you think Joe uses the satisfaction skills to stay calm and be in the present moment?
  - How can you use these skills to find peace of mind?



#### EPILOGUE: Being Your Best

#### I Know Why I Got Sick

My mother almost died in the winter of 1995.

Each day she was weaker. Her doctors offered no answers and little hope. My sister packed her black dress and flew home.

Specialists examined her, but Mom continued to sink. Finally, I said, "Listen, nothing is helping. So instead of focusing on our frustrations, why don't we focus on love - right here in the hospital?"

My mother always had an opinion about everyone so, to keep the focus on love, we started to rate the "lovingness" of everyone who came into her room. Most of the nurses and many of aides got high scores, as did one of the physicians. Sometimes, we just sat and held hands, talking about the good times and waiting for the next contestant.

Part of the game was to love them back. Loving the ones with the lowest scores made us smile when they left.

The next day Mom was stronger. She walked the following day and was discharged by the end of the week.

Neither I, nor my mother's physicians, understood what nearly killed her. But I suspected that love was the medicine she needed.

Four years passed. My mother weathered my father's death and did well living independently. But as her emphysema worsened, she agreed she needed full time care.

One day, just after noon, we were under a tree near the creek that passed behind her nursing home. She was sitting in her wheelchair, a half-eaten sandwich still on her lap. I was lying on a blanket, starting to nap.

Faintly, I heard her say "I know why I got sick."

"What do you mean?" I asked without opening my eyes. My mother was sick so much, I was a little sick of talking about it.

"I know why I got sick," she repeated. "Remember, a few years ago, when you and Dad took me to the hospital? My hair was falling out and we all thought I was going to die."

I roused myself a bit, trying to recall. "Yeah, Diane flew home because we were so worried. I remember.... Why did you get sick?"

"I flunked my high-school equivalency exam."

"You failed your high-school equivalency exam?!?" My eyes popped open as I sat up. "When did you take it?"

My mother was a very bright woman who dropped out of high school before World War II to help her family. Although she had a successful career as a deputy Commissioner of Jurors, she was embarrassed that she never earned a high school diploma.

"I enrolled in the program about five years ago. Your father was the only who knew. All the kids in the class were very friendly and the instructor was nice. But I still had trouble with the math "

I could easily picture my elderly mother absorbing information about her fellow students. One of her hobbies was to discuss, in vivid detail, the life histories of people she barely knew and I never met.

Although her memory was sharp and she read one or two books a week, math – especially fractions - had always been difficult for her.

"I thought I finally figured out the fractions, and that I did OK on the test," she said. "But when I opened the letter with the results, I saw I had failed by just two points. Four days later you and Dad took me to the hospital."

"Just two points, how awful! ... That's why you got so sick?"

"I think so. I was so disappointed. I always wanted to be a high-school graduate,"

Even at 78, my mother's pride was so strong that it drew her back to the classroom. And, for a little while, the crush from her failure was so great that she didn't want to live. A disappointment made her sick - then love made her well.

As I pushed her wheelchair back into the building she joked with some aides who were taking a break in the afternoon sunshine. As always, my mother told me more than I wanted to know about their children, ex-husbands and current boyfriends. But I was glad the aides were her friends.

#### Maybe I Forgot?

I was shocked when my mother told me why she got sick – and I guess I still am.

For years I had wanted to be Mr. Mind-Body-Spirit. I meditated each day, went to dozens of retreats and read hundreds of related books and articles. But, when my mother nearly died, did it occur to me to ask her if she was feeling bad about something? Umm... Maybe I forgot?

Not exactly. I didn't forget, I assumed. I assumed that I knew what my mother was feeling. After all, as my parents aged, we spoke on the phone nearly every day, and I visited three or four days a week.

Thus, I assumed that I knew about all of the important issues in her life.

Wrong. Assuming you know is a big mistake. Sometimes it can even be life-threatening.

One of the reasons I "created" the satisfaction skills, is that I realized that I (and all of us) need reminders. We need to be reminded that staying connected requires ongoing communication – whether it's being connected with your mother, your coworker, your doctor or your God.

### Our Feelings Affect the Facts We See

For decades, I've been teaching: "Your feelings influence the facts you see." I realized, again, how true that was for me, as I finished writing this next story.

#### The Liturgy Nazi

"Remember, you should choose prayers your *mother* would have liked," she insisted.

Lily was the funeral coordinator. In the old days, I would have been talking to a priest. Instead, I was saddled with this stranger.

She recited steps to follow and rules to obey. Three minutes into the call, I wanted to hang up.

"We'll arrange a meeting tomorrow here at the parish" she declared. "It shouldn't take more than an hour and we can review the choices you have for the liturgy."

Some of my relatives were already on airplanes, and others would be arriving Saturday morning. I wanted the comfort of friends and family, not sixty minutes with a bossy church lady.

"Remember, think about a service your *mother* would have liked," she repeated. Did she think I'd selfishly pick *my* favorite prayers, and leave my mother's soul squirming in the coffin?

Just last night I had found her twisted in her bed - like a dead bird, starved and abandoned by the side of the road. Mary was a few steps behind.

"Oh, Grandma!" she cried. She hunched with grief and covered her face as she retreated back to the hall.

I kissed my mother's forehead. Two week earlier I had stood in the same spot by her bed, telling her that the nursing home offered something called "comfort care."

"It's like a hospice, Mom," I said. "They'll give you the medications you need to keep you comfortable, but no more trips to the hospital. We would just let nature take its course."

For years, she had told me she was ready to meet her Maker and be with my father again.

She closed her eyes for a few seconds, then looked at me while I held her hand.

My mother suffered terribly in her final years. Emphysema and heart disease had left her too weak to make it from her bed to her bathroom without help. The medications made her skin so fragile that a gentle brush could open a gaping wound. Her frequent falls were devastating.

One night she shuddered with pain for hours while physicians attended to more critical emergencies, despite my insistent complaints. The next afternoon, I found her teetering toward the toilet in her hospital room. I reached her just before she fell, but wasn't strong enough to lift her. She collapsed on my lap on the bed while I yelled for help that didn't come. I hoped that she was too sick to know she had urinated on both of us.

Crises were so frequent and prolonged that my wife, Kathy, and I would take our camper to the hospital. One of us would read or nap while the other maintained a vigil during the endless limbos between arrival, admission and discharge.

Three years earlier, my father received something akin to comfort care as he died. It was very sad and very sweet as we shared his final days.

Now, my mother had the same choice. Finally, she said, "I think I'd like to fight a little longer."

I said nothing.

"Sure, Mom, we'll help you!" was loud in my brain, but I was too exhausted or too selfish to speak. I was ready for the woman who gave me life to die.

I knew that love, or even common courtesy, required an encouraging word. She wanted life. My wish was for a peaceful death.

Six seconds can stretch forever. I held her hand, our eyes resting on each other. I condemned myself to guilt, and felt the flames of hell start to stir.

Finally, she spoke. "Maybe, you're right. I'm ready to go. Whatever God wills."

"We'll do whatever you want, Mom. I still owe you," I said, belatedly echoing something she'd heard before.

For more than a year, I'd seen my mother almost every day. I called when I didn't visit, amazed that a woman who was confined to bed could find so much to talk about. She often worried that I was neglecting my own life.

"I figure that, so far, you've done this much for me," I'd respond, spreading my arms almost as far as they would go. "And, I figure that so far, I've done this much for you," spreading my hands about two feet apart. "I'll let you know when I think we're even." Then, we'd smile because we both knew it was true.

I called at noon on Thursday and was surprised that she was up and eating in the dining room with the other residents. An aide wheeled her to the phone and we spoke briefly. Her voice was stronger and we ended by saying "I love you." It was one of the few days that I decided not to visit.

She went downhill quickly. A few minutes after seven, the nurse called and said Mom's breathing was labored, her skin color was bad and her lips had a blue tinge. I asked if she was dying, but the nurse just repeated the symptoms and encouraged me to come. I didn't feel alarmed, just weary.

Mary had joined us for supper, excited to talk about her wedding plans. She said she'd like to see her Grandma, and would follow me to the nursing home. Rather than rush, I finished my meal, enjoying the lilt of Mary's voice.

I encouraged Kathy to go to choir practice, and she said she'd keep her cell phone on. I assumed another long vigil was ahead, so I grabbed a good book and took the camper so I could sleep nearby in the parking lot. It was a familiar routine.

I must have been about five minutes away when my mother died. Her forehead was still warm when I kissed her.

The next afternoon I hung up the phone, grumbling about Lilly's rules and regulations.

"Just ignore the Liturgy Nazi," my sister advised and we laughed. "It's not her service, it's ours."

During the eulogy, I talked about the legacy of my mother's love. The whiskey flowed at the party that followed, and much of the bitter was drowned by the sweet.

What is love? A sense of oneness with someone? If so, my love certainly sputtered in those seconds I was silent. I wanted her suffering to end, but I wanted it more for me than I wanted it for her.

What do you do when emergencies become a daily routine, and months of sickness becomes years of suffering? How do you care for your mother, your wife, your daughters and yourself?

Sometimes I'm angry at myself for six seconds of silence when a spark flickered in my mother's eyes. I wasn't a perfect son and she wasn't a perfect mother. But, as she died, her love was greater than mine. I guess it always was.

Mostly now, the regret doesn't grow into guilt. I balance my seconds of selfishness against my years of caring. But I've never forgotten that I failed to speak.

If the Liturgy Nazi had known my mother, she'd have understood that my Mom would have wanted the prayers I wanted, and the songs that would comfort me.

If I had known myself better, my guilt wouldn't have twisted what Lilly said on the phone. I wouldn't have poisoned her words with my own wounds. I'd have sensed the solace in thinking about what my mother would have wanted.

I'd have understood that the Liturgy Nazi was just a sweet woman who was trying to be kind.

When we're stressed, it's hard to see our own anger or guilt without help. Sometimes the help comes in talking to someone. Sometimes it comes when you're sharing some pictures or writing a story.

An hour after my mother and I talked about comfort care I was talking to my wife: "I can't believe I didn't say anything when she said she wanted to fight a little longer!"

But it was years before I shared that with anyone else.

\*\*\*\*

## Feelings Influence the Facts We See

Our feelings influence the facts we see. For example, my guilt caused me to see only the negative about Lilly.

Think about the last time you experienced the alarm response (i.e., tight muscles, rapid heart rate and breathing, fear or anger). What did you notice about yourself? ...or notice about the world around you? The good things or the bad things?

When we're stressed, most of us have a tendency to focus on the negative. But if you only see the "bad", what kind of decision are you likely to make? A bad one!

The same is true for everyone. The four satisfaction skills (i.e., awareness, affirmations, assertiveness and acceptance) are crucial steps that can help you to manage stress. When you reduce your negative emotions, you have a clearer view of both the good and the bad in your life.



#### When the Problem is More than "Just Stress"

If the "snooze response" (see page 28) is deep and long-lasting, you -- or the senior you care for -- may have clinical depression. This is especially true if you feel hopeless, have difficulty making decisions, are often sad or take little pleasure in doing things. Depression can be caused by chemical imbalances in the brain and can be treated very effectively with medications.

Anxiety attacks, frequent dizziness or nausea are some of the signs that your "alarm" response needs more than the "satisfaction steps" suggested in the next section. Ask your doctor for advice.

Don't hesitate to speak to your doctor or a mental health professional if you are concerned about your moods and your behavior. There are many benefits to counseling, and many excellent medications that can help.

\_\_\_\_\_

#### What Do You Think?

• For years I told dozens of people how a bossy, insensitive "liturgy Nazi" tried to control my mothers funeral. I never suspected that she was probably just a sweet woman who was trying to be kind. ...How did I miss that? ....Has anything similar ever happened in your life? ....What did you do about it? ....What could you do about it?

• When has anger, guilt or fear influenced what you see? Do you always realize it right away? ...or does it sometimes take minutes or years for the truth to dawn? .

- Might anger, guilt or fear about something still be influencing what you see about yourself? ...or others? ...even yesterday or today?
- What are the benefits of forgiving yourself and others? ... What helps you to be forgiving? ...
- How might the satisfaction skills help you to forgive yourself and others?
- How do you care for yourself and your family when months of sickness become years of suffering?

## GRACE

It only seemed like a regular birthday party if you closed your eyes and listened. Looking around, despite a dozen balloons and too much crepe paper, it was obvious that we were celebrating in a hospital lounge,

Grace's smile beamed brightly beneath her bald head. After fighting cancer for three years, she had decided to trade a longer life for a better quality of life. Watching her laugh, I thought maybe she was right.

Grace was a business woman who became a hospital chaplain and retreat leader after her husband died. For years, I'd been good friends with her sister, Kathleen.

But I got to know Grace a lot better the day that ambulances brought both our mothers to the same emergency room within an hour of each other. As the time dragged between afternoon and midnight we caught up on our careers, our families and our frustrations. Then our mothers were admitted to different floors and we lost touch for a while.

I perched on the edge of a table so I could look over Grace's shoulder as she opened her birthday cards. A sarcastic one drew hoots and groans from the crowd.

"Your Mom would have loved that" she said as she passed it to me.

I couldn't remember Grace ever meeting my Mom. There had been no opportunity for polite introductions that night we waited outside the emergency room. So I hesitated before saying, "How did you know her sense of humor?"

Grace said, "Well, my mother was out if it for most of that hospitalization, so I used to go downstairs to see how your mother was doing. She was quite a talker." She paused. "She never mentioned my visits?"

"No," I answered. "But my strongest memory from that time was how my mother seemed so peaceful. All of a sudden there was this glow about her. She still had her ups and downs for the next year, but mostly the glow kept getting stronger."

Someone handed Grace another card. As she opened more presents I wondered: Could Grace be the reason Mom changed so much? After all, Grace was a chaplain and had her own glow going most of the time. Soon, the guests began to leave. The doctor said Grace might live for weeks or months, and I suspected this might be our final goodbye. But I was still thinking about my mother.

After we hugged I said, "You know, I've been thinking about those visits you had with my Mom. What did you say to make such a difference?"

"It didn't have much to do with me," Grace smiled. "It was a choice your Mom made. She forgave."

#### Forgiveness

I've never learned what issues were troubling my mother during the last year of her life. But I suppose it doesn't matter.

What matters is that she let go of the negative feelings that kept her from seeing all the caring and all the Love that surrounded her - not just from her family.

What do you think?

When my mother's life was at it worst, she – in many ways – was at her best. Grace's comments helped me understand more about the sudden peacefulness I wrote about in the first story.

Do you think my mother "started to glow" (see page 3) because she: :

- Talked to a good, accepting listener, like Grace?
- Affirmed that the good she had done greatly outweighed any bad?
- Asserted that she wanted peace of mind more than past, petty problems?
- Accepted her flaws and the flaws of her friends and family?
- Became aware of both the good and the bad in her life?

I believe that any one of those steps could have been enough for her – and they are enough for the rest of us.

I often think about Grace saying, "It didn't have much to do with me. It was what your Mom did." My mother became more aware of the goodness inside her and around her, after she talked, affirmed, asserted, accepted.

But Grace created an opportunity, and my mother took advantage of it.

In the same way, this book is an opportunity to choose how you will improve the wellness of your mind, body and spirit. Will you take advantage of it? ...And all the other resources that surround you?

I think we all know someone like Grace who can help us.

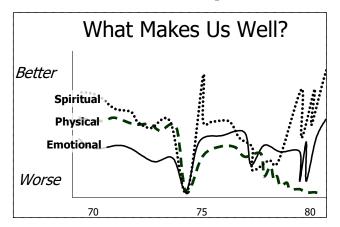
## Being Your Best: Peace of Mind Can Always Grow

What is wellness? In this book, I've presented it as "being your best" – a state of optimal physical, emotional, social and (for many people) spiritual well being. Each is important. And each can influence the others, for good or for bad at any age.

My parents aged well and died well because their emotional, social and spiritual health

was strong – even when my mother couldn't walk and my father couldn't button his own shirt.

We're never too old to be well, because peace of mind can always grow. The graph at right illustrates how this unfolded in my mother's life. Even though her physical health declined, her spiritual and emotional health helped her to be her best.



How we age depends, in part, on the choices we make. My hope is that the stories you've read, and the strategies you've considered, will help you to be your best – whatever your age.

Your	Circle each "step" that might <b>help</b> you. Then, describe two or three for special focus. "Use satisfaction skills" "Walk twice a day" "Walk twice a day" "Try new medication" "Ask partner for support"	3. Take Some Steps	<b>4</b>	"Weight" "Can only walk/jog 5 minutes without resting"	most important "signs" you'll use to <b>measure</b> your progress.	2. Check	Describe <b>why</b> it's important for <i>yau</i> to <i>Be Yaur Best</i> "Enjoy family celebration" "Be more peaceful and loving"	1. Remember Goals
Partner's		Exercise Walking, strength training	Awareness <i>Listen, Focu</i> s			→ Stress, Moods and Behavior	""""""""""""""""""""""""""""""""""""""	
השקים	Use Your Resources Emotional, SociaVspiritual, Medical		Affirmations Praise, Thank					Plan with
Todavis	Get and Discuss with pa	Personal Care Hygiene, grooming	Assertiveness Speak, Describe	-		Social and/or Spiritual Satisfaction Al	-	Plan with a Partner
Jo No√f	Get and Give support Discuss with partner, friend or relative	Eat Well Balanced diet	Acceptance Relax, Forgive			Physical Abilities or Problems		

## **Research Studies and References**

<sup>1</sup> DeLoughry T. *Never Too Old To Be Well: A Mind, Body and Spirit Program for Well Seniors, Frail Elders, Their Families and Aides* (booklet, Video DVD and Computer CD) Grand Island, Center for Health Management (see: www.theCHM.net)

<sup>2</sup> The section on "connecting your care" was developed based on the "Transitions of Care" research of Eric Coleman, MD at the University of Denver Medical Center (see: www.CareTransitions.org). Our adaptation of his work was supported by a grant from the Community Health Foundation of Western and Central New York

<sup>3</sup> Centers for Disease Control "Health Related Quality of Life – Prevalence Data by State." Downloaded from the World Wide Web: http://apps.nccd.cdc.gov/HRQOL/ , June 1, 2008.

<sup>4</sup> Centers for Medicare and Medicaid Services (CMS): §483.152 Requirements for approval of nurse aide training and competency evaluation for long-term care; and §484.36 Home Health Aides Services

<sup>5</sup> Centers for Medicare and Medicaid Services. *Resident Assessment Protocols* in <u>Resident</u> Assessment Instrument (RAI) Manual Appendix C

<sup>6</sup> Many of the studies in this section are drawn from: Post, Steven and Jill Neimark (2008) "<u>Why Good Things Happen To Good People: How to Live a Longer, Healthier and Happier Life</u> written by Stephan Post and Jill Neimark New York: Random House (2008) For more information, visit www.WhyGood Things.Happen.com

<sup>7</sup> Musick, MA and WilsonJ (2003) Voluneering and Depression: The Role of Psychological and Social Resources in Different Age Groups <u>Social Science & Medicine</u> 56(2) 259-269
 <sup>8</sup> Luoh, MC and Herzog, AR (2002) Individual Consequences of Volunteer and Paid Work in Old Age: Health and Mortality. <u>Journal of Health and Social Behavior</u> 43 490-509

<sup>9</sup> Oman D et al. (1999) Volunteerism and mortality and community-dwelling elderly <u>Journal</u> of <u>Health Psycholog</u> 4, 310-16

<sup>10</sup> Twenge, J. (2006) <u>Generation Me: Why Today's Young Americans Are More Confident,</u> <u>Assertive, Entitled and More Miserable than Ever Before</u> New York: Free Press <sup>11</sup> Armstrong, Karen (2006) <u>The Great Transformation: The Beginnings of Our Religious</u> <u>Traditions</u> New York: Knopt

<sup>12</sup> Kraus CA et al. Use of cognitive behavioral therapy in late-life psychiatric disorders. Geriatrics. 2007 Jun;62(6):21-6.

<sup>13</sup> Lopez M and M Cresop Analysis of the efficacy of a psychotherapeutic program to improve the emotional status of caregivers of elderly dependent relatives. Aging Ment Health. 2008 Jul;12(4):451-61.

<sup>14</sup> David-Ferdon C. NJ Kaslow Evidence-based psychosocial treatments for child and adolescent depression J Clin Child Adolesc Psychol. 2008 Jan;37(1):62-104.

<sup>15</sup> Foundation for Inner Peace (2007) <u>A Course in Miracles</u> (3<sup>rd</sup> Edition) Mill Valley, CA: Foundation for Inner Peace

<sup>16</sup> House, J. S., K. R. Landis, et al. (1988). "Social relationships and health." *Science* **241**(4865): 540-5.

<sup>17</sup> Glass, TA, Leon CM, Marottoli, RA and Berkman, LF (1999) Population based study of social and productive activities as predictors of survival among elderly Americans *British Medical Journal*;319:478-483 (21 August)

<sup>18</sup> Sarkadi A, Rosenqvist U (2001) Field test of a group education program for type 2 diabetes: measures and predictors of success on individual and group levels. *Patient Educ Couns* 44(2):129-39.

<sup>19</sup> Black TM, Soltis T, Bartlett C. (1999) "Using the Functional Independence Measure instrument to predict stroke rehabilitation outcomes" <u>Rehabil Nurse</u> 24(3):109-14, 21.

<sup>20</sup> Avants SK, Warburton LA, Margolin A.(2001) "Spiritual and religious support in recovery from addiction among HIV-positive injection drug user". *J Psychoactive Drugs* 2001;33(1):39-45.

<sup>21</sup> Oxman TE, Hull JG (2001) Social support and treatment response in older depressed primary care patients. *J Gerontol B Psychol Sci Soc Sci* 2001;56(1):35-45.

<sup>22</sup> DeLoughry, T. (2008) "Spirituality and Eldercare" in <u>Spiritual Dimensions of Nursing Care</u> (edited by Verna Carson and Harold Koenig) Philadelphia: Templeton Press

<sup>23</sup> Center for Disease Control (2007) Influenza (Flu) For more information, please visit: www.cdc.gov/flu

<sup>24</sup> Coleman EA, Parry C, Chalmers S, Min SJ.The Care Transitions Intervention: Results of a Randomized Controlled Trial Archives of Internal Medicine. 2006;166:1822-8.

<sup>25</sup> I am grateful for a three year grant from The Community Health Foundation of Western New York and mentoring from Pat Bomba, MD, Executive Vice President of Excellus Blue Cross/Blue Shield. Their support and guidance enabled my colleagues and I to better understand and serve people as they enter the last chapter of their lives.

<sup>26</sup> 'Sharing Your Wishes" Information Booklet (2005) Buffalo, NY: Community Health Foundation of Western & Central New York

<sup>27</sup> For more information about MOLST, please visit: www.compassionandsupport.org

# Action Guide

An Action Guide for individuals, families and organizations is available online at: www.theCHM.net. It includes:

- Discussion Guides
- PowerPoint Presentations
- And much more