



The Mastocytosis Society

13th Annual Meeting

for Mastocytosis Patients, Caregivers & Physicians

October 20 & 21, 2006
Doubletree Hotel & Conference Center
Portland, ME

Caregiver Breakout Group

Facilitated by Karen Curtiss

For additional information on
Caregiving & Mast Cell Related Diseases
please visit the TMS web site:

www.tmsforacure.org

What it means to be a caregiver

Caregiving can be defined as providing unpaid assistance for the physical and emotional needs of another person, ranging from partial assistance to 24-hour care, depending on his or her condition.

Caregivers can provide a wide range of services, depending on the degree of disability, economic situation and living environment of the care recipient. Outside help may or may not be involved. The person being assisted is the care receiver. This person may live with the caregiver or live elsewhere.

Quite often, as the disability increases, there is a progression in the amount of hands-on care that is needed, from assistance with daily living tasks to round-the-clock care. The type and amount of care will also vary with the type of disease or disability, that is, someone with Alzheimer's disease will have different needs than someone with cancer, for example.

Caregivers can also be considered primary or secondary. The person who has the main responsibility for the individual is the primary caregiver. Secondary caregivers offer support to the primary caregiver. If the primary caregiver is a daughter, the secondary caregivers tend to be the son-in-law and the grandchildren. While secondary caregivers are usually family members, they can also be friends or non-relatives. Secondary caregivers tend to be less involved in personal care of the elder, but help with transportation, shopping and home repairs.

What is Family Caregiving?

Family caregiving is the bedrock upon which this country's healthcare system depends. The services provided by family caregivers represent 80% of all home care services and are conservatively valued at \$257 billion a year, more than twice the amount spent on paid home care and nursing home services combined.

Family caregivers provide a vast array of emotional, financial, nursing, social, homemaking, and other services on a daily or intermittent basis.

Caregiving itself is a multi-dimensional puzzle. For some it means providing 24-hour care for someone who can't dress, feed, go to the bathroom, or think for himself or herself. For others caregiving is an emotional roller coaster because a diagnosed condition has not exhibited debilitating symptoms - yet.

Caregiving can go on for a few years or for a lifetime. It means re-evaluating finances, re-evaluating job opportunities and making compromises.

Caregiving is learning how to work with doctors and other healthcare professionals so they treat you as an important member of your loved one's healthcare team.

Caregiving is wondering why no one ever asks how you are.

Caregiving is dreaming about being alone in your own house.

Caregiving involves learning about Medicare, Medicaid, social security and other public programs.

Caregiving is learning what it means to die with dignity and making sure that your loved one's wishes will be honored.

Caregiving is the joy you feel when your spouse says he/she felt good today.

Caregiving is hard work. Caregiving is pain. Caregiving is loving and giving and sharing. Caregiving is accepting and learning new things and going on, and on, and on. Caregiving is lots of questions and very few answers. Caregiving is being out of the mainstream.

Caregiving is all these things and a whole lot more.

Caregiving Across the Life Cycle (1998)

In the spring of 1994, NFCA conducted its first Caregiver Member Survey. The results were illuminating, and professionals and caregivers alike were very interested in the results. This past summer, a second NFCA Caregiver Member Survey was conducted with funding from one of our National Corporate Partners, Fortis Long Term Care Insurance, and technical know-how and logistical support from Fortis subsidiary AdultCare. There are several factors that make this survey noteworthy. First of all, it had a remarkable response rate of 35%. Secondly, it is one of the very few surveys of caregivers from all across America and all across the life cycle, thus shedding light on the common aspects among the members of the caregiving population. Thirdly, it is a survey of a group of individuals, many of whom are providing an intense level of caregiving, who have reached out for support. Finally, it is significant because it is a survey of individuals of whom over 60% have been caregiving for five years or more. Here then is a snapshot view of NFCA's members in the summer of 1997, based on our first preliminary analysis.

How Has Caregiving Affected You?

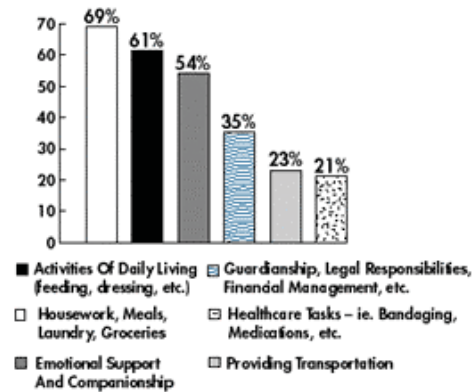
There are positives and negatives in most situations, and caregiving is no exception. These are some of the outcomes for NFCA's members.

POSITIVE OUTCOMES		CAREGIVING EMOTIONS	
Found an inner strength I didn't know I had	70%	Frustration	67%
Developed a closer relationship with the person I help	36%	Compassion	37%
Learned proactive skills	34%	Sadness	36%
		Anxiety	35%
		CAREGIVING DIFFICULTIES	
Negative Outcomes		Sense of isolation and lack of understanding from others	43%
More Headaches	27%	Having the responsibility for making major life decisions for loved one	33%
More Stomach Disorders	24%	Loss of personal and leisure time	36%
More Back Pain	41%	No consistent help from other family members	76%
More Sleeplessness	51%		
More Depression	61%		

How Do We Define Caregiving?

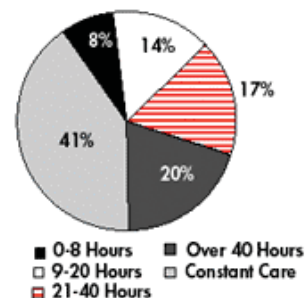
CAREGIVING RESPONSIBILITIES THAT TAKE UP THE MOST TIME

On the survey questionnaire, caregiving tasks were divided into six categories. This is a summary of how we spend our time.



HOURS PER WEEK SPENT IN CAREGIVING ACTIVITIES

NFCA's members are "heavy duty" caregivers, for the most part spending more than 20 hours a week on caregiving activities. Here is the breakdown.



Caregiving Statistics

The following statistics have been compiled from a wide variety of sources. The original source follows each statement or group of statements. Note: Survey statistics sometimes seem to contradict each other. That's

because each study or survey has its own methodology, its own set of variables, data sources, etc. It doesn't mean one is right and the other wrong. It does mean you need to understand how the survey was developed and constructed.

CAREGIVING POPULATION

More than 50 million people, provide care for a chronically ill, disabled or aged family member or friend during any given year

Caregiving is no longer predominantly a women's issue. Men now make up 44% of the caregiving population. *Source: National Family Caregivers Association (NFCA) Random Sample Survey of Family Caregivers, Summer 2000, Unpublished.*

Caregivers providing care for a family member over the age of 50 routinely underestimate the length of time they will spend as caregivers - only 46% expected to be caregivers longer than two years. In fact the average length of time spent on caregiving was about eight years, with approximately one third of respondents providing care for 10 years or more. *Source: MetLife Juggling Act Study, Balancing Caregiving with Work and the Costs of Caregiving, Met Life Mature Market Institute, November 1999.*

Most women will spend 17 years caring for children and 18 years helping an elderly parent. *Source: 101 Facts on the Status of Working Women produced by business and Professional Women's Foundation*

ECONOMICS OF CAREGIVING

The value of the services family caregivers provide for "free" is estimated to be \$257 billion a year. That is twice as much as is actually spent on homecare and nursing home services. *Source: Peter S. Arno, "Economic Value of Informal Caregiving," presented at the American Association of Geriatric Psychiatry, February 24, 2002.*

Caregiving families tend to have lower incomes than non-caregiving families. Thirty-five percent of average American households have incomes of under \$30,000. Among caregiving families the percentage is 43%. *Source: National Family Caregivers Association (NFCA) Random Sample Survey of Family Caregivers, Summer 2000.*

Of the estimated 2.5 million Americans who need assistive technology such as wheelchairs, 61% can't afford it. *Source: Lisa I. Iezzoni, M.D., M.Sc., 'When Walking Fails: Personal and Health Policy Considerations,' Research in Profile, a National Program of the Robert Wood Johnson Foundation, March 2002.*

Out of pocket medical expenses for a family that has a disabled member who needs help with activities of daily living (eating, toileting, etc.) are more than 2.5% greater (11.2% of income compared to 4.1%) than for a family without a disabled member. *Source: Drs. Altman, Cooper and Cunningham, 'The Case of Disability in the Family: Impact on Health Care Utilization and Expenditures for Non-disabled Members' Milbank Quarterly 77 (1) pages 39 - 75, 1999*

IMPACT OF CAREGIVING

Elderly spousal caregivers with a history of chronic illness themselves who are experiencing caregiving related stress have a 63% higher mortality rate than their non-caregiving peers. *Source: Schulz, R. and Beach, S. R. Caregiving as a Risk Factor for Mortality: The Caregiver Health Effects Study, Journal of the American Medical Association, December 15, 1999, Vol. 282, No. 23*

The stress of family caregiving for person's with dementia has been shown to impact a person's immune system for up to three years after their caregiving ends thus increasing their chances of developing a chronic illness themselves. *Source: Drs. Janice-Kiecolt Glaser and Ronald Glaser 'Chronic stress and age-related increases in the proinflammatory cytokine IL-6', Proceedings of the National Academy of Sciences, June 30, 2003.*

Family caregivers who provide care 36 or more hours weekly are more likely than non-caregivers to experience symptoms of depression or anxiety. For spouses the rate is six times higher; for those caring for a parent the rate is twice as high. Source: Cannuscio, CC, C Jones, I Kawachi, GA Colditz, L Berkman and E Rimm, *Reverberation of family illness: A longitudinal assessment of informal caregiver and mental health status in the nurses' health study.* *American Journal of Public Health* 2002; 92:305-1311.

Family caregivers providing high levels of care have a 51% incidence of sleeplessness and a 41% incidence of back pain. Source: *National Family Caregivers Association, Caregiving Across the Life Cycle, 1998*

CAREGIVING AND WORK

Thirty-seven percent of employees don't believe that their organizations a real and ongoing effort to inform employees of the family -friendly programs that are available. Source: *Families and Work Institute*

Forty two percent of parents of special needs children lack basic workplace supports, such as paid sick leave and vacation time. Source: *Ellen Galinsky and James Bond The 1998 Business Work-Life Study - A Source Book, Families and Work Institute*

Women average 11.5 years out of the paid labor force, primarily because of caregiving responsibilities; men average 1.3 years. Source: *101 Facts on the Status of Working Women produced by business and Professional Women's Foundation*

American businesses loses between \$11 billion and \$29 billion each year due to employees' need to care for loved ones 50 years of age and older. Source: *National Alliance for Caregiving/Met Life Met Life Study of Employer Costs for Working Caregivers*

Both male and female children of aging parents make changes at work in order to accommodate caregiving responsibilities. Both have modified their schedules (men 54%, women 56%). Both have come in late and/or leave early (men 78%, women 84%) and both have altered their work-related travel (men 38%, women 27%). Source: *Sons at Work: Balancing Employment and Eldercare, MetLife Mature Market Institute, June 2003*

CAREGIVING AND HEALTH CARE

Over 40% of U.S. primary care physicians think they don't have enough time to spend with patients. Source: *The Commonwealth Fund Quarterly Report, Fall 2000 Volume 6, Issue 3*

Family caregivers provide the overwhelming majority of homecare services in the U.S., approximately 80%. Source: *US Agency for Healthcare Research and Quality (November 8, 2000). Long-term Care Users Range in Age and Most Do Not Live in Nursing Homes*

In 2000, 50 percent of caregivers reported that different providers gave different diagnoses for the same set of symptoms and 62 percent reported that different providers gave other conflicting information. Another recent survey found that 44 percent of physicians believe that poor care coordination leads to unnecessary hospitalization, and 24 percent stated it can lead to otherwise unnecessary nursing home stays. Source: *Partnership for Solutions, Chronic Conditions: Making the Case for Ongoing Care, Johns Hopkins University, December 2002.*

By the year 2030, nearly 150 million Americans will have some type of chronic illness, a 50% increase since 1995. Source: *Partnership for Solutions Harris Survey Johns Hopkins University, data presented at March 2003 conference, Washington, DC. And Partnership for Solutions, "Chronic Conditions: Making the Case for Ongoing Care," Johns Hopkins University, December 2002.*

Family caregivers who acknowledge their role are more proactive in reaching out for resources and talking with their loved one's doctor than non-acknowledged caregivers. Source: *National Family Caregivers Association, Survey of Self-Identified Family Caregivers, 2001*

Over 40 percent of family caregivers provide some type of 'nursing care' for their loved ones, such as giving medications, changing bandages, managing machinery and monitoring vital signs. *Source: National Family Caregivers Association (NFCA) Random Sample Survey of Family Caregivers, Summer 2000 and C. Levine, Rough Crossings: Family Caregivers' Odysseys through the Health Care System. New York: United Hospital Fund, 1998.*

One-third of family caregivers who change dressings and manage machines, receive no instructions. *Source: Henry J. Kaiser Family Foundation Wide Circle of Caregiving, 1998*

The Common Bonds of Caregiving by Suzanne Mintz, President/Co-founder NFCA

What is caregiving and how do you define a family caregiver? What is the common thread that ties together those of us who care for spouses, children, parents, siblings, partners or friends who are chronically ill, frail, or disabled?

It certainly isn't the tasks of caregiving. They vary so much, from helping a developmentally delayed child learn new skills, to taking an aging parent to frequent doctors appointments, or suctioning a spinal chord injured spouse virtually every hour every day.

It surely isn't the number of years involved. Caregiving can last a few short months. It can last three to five years. At times, caregiving is a lifetime commitment.

Location varies from situation to situation. Although most caregiving goes on in the home, and most caregivers and recipients live under the same roof, talk to anyone whose parent is in a nursing home and you'll quickly learn that caregiving doesn't end when someone else is responsible for day to day care, or when caregiving takes place long distance.

If it isn't the responsibilities or tasks, and it is not the length of time, if it isn't the location - what is the essential bond of caregiving? What does caring for a spouse with multiple sclerosis have to do with caring for parents who are losing their independence, or a child with epilepsy.

In 1994, when the National Family Caregivers Association (NFCA) conducted its first caregiver member survey, we were seeking to find that common bond, to define the link between all caregivers. We found in no uncertain terms that the common bond of caregiving is its emotional impact. In 1997 when we surveyed our members again, we found the same thing.

The common bond of caregiving is the intense sadness we feel because someone we care about has suffered a brain injury, is losing their mobility, will never achieve normal life functioning. It is the sadness that comes from wanting the miracle of normalcy.

The common bond of caregiving is the upheaval of changing family dynamics that occurs because life has been turned upside down and because there is no set timetable for working through the painful stages of grief which caregivers and care receivers all experience in their own personal and private way.

The common bond of caregiving is the sense of isolation that comes from living outside the norm, from having everyday activities of life - dressing; walking; toileting; breathing, thinking clearly - that everyone else takes for granted, become such a big focus in your own life.

The common bond of caregiving is the frustration we all experience because it is so hard to get things done, because non-caregivers just don't understand, because healthy people park in handicapped parking spots, and because people who are supposed to have the answers often don't.

The common bond of caregiving is the stress we feel because we don't have enough leisure or personal time, and the common bond of caregiving is unfortunately often the severe depression that so many of us suffer.

These are the common bonds of caregiving that tie us to one another, that develop in us an innate understanding of each other's pain, each other's lost dreams, each other's fears.

These shared emotions, these very difficult emotions, are the common bond of caregiving. But there is another common bond, another shared emotion, that we don't recognize as often as we should. It is the inner strength that most of us never knew we had.

It is the fortitude to go on despite the pain. It is the wellspring of hope we always dip into. It is the power to make a difference. It is the clever way we solve a difficult problem. It is the knowledge that we have been tested by fire, and we have survived.

Our inner strength is the gift we have been given. It is the "pay back" for the pain, and although many of us would gladly trade it in for an easier life and our loved one's health and well being, we nevertheless ought to recognize its extraordinary value.

The problem is I don't think most caregivers do recognize it. I think most caregivers are so caught up in the act of caregiving that they don't step back and look at the extraordinary things they do. I think a great many caregivers don't even identify themselves as caregivers.

This is not surprising. The term caregiving does not exist in most dictionaries. Caregivers have not been counted in a U.S. census and are therefore not officially recognized as a significant minority. Caregiving and caregivers, are invisible.

I wish it weren't so. I wish caregivers were given their just due. I wish caregivers themselves would recognize their value, acknowledge their individual achievements. Empowerment is an overused word, but it is the one that comes to mind when I think of what I want for caregivers.

Empowerment for me means a sense of self confidence, a belief in one's ability to have some control over situations, a sense of pride, a feeling of self respect and self worth. For the most part, we use our inner strength to help our loved ones and to get through difficult caregiving days. We need to begin to use it to take better care of ourselves, to feel proud, to experience the beauty of self love.

I received a letter recently, actually an Email, from a member of the National Family Caregivers Association. She said that NFCA had become a great solace to her. She said that we made her proud to be a caregiver.

Proud to be a caregiver. I mulled the phrase over in my mind for quite some time before I realized that the true definition of caregiving is buried in that phrase, in the understanding that caregiving is a role that tests our abilities, our faith, and our character.

What is caregiving? How do you define a family caregiver? I think I have the answer now - you define family caregivers by their emotions and their spirit, by the sadness in their eyes, but also by the determination in their hearts. Caregivers are very special people.

Feelings experienced by a caregiver

Caregivers experience a wide range of feelings. Though most of them willingly choose to play a primary role in the care of their loved one, this role often carries with it conflicting emotions that must be dealt with. Among them:

Sadness and grief. Knowing that a person is in declining health and seeing it happen before your eyes can be difficult. Realizing that a loved one is suffering is often traumatic. Knowing that your husband, mother, sister, aunt or grandmother has a short time to live may cause you to begin grieving even before they die.

Fear and worry. Those of you who are taking care of someone in declining health may be plagued by fears. What will the future hold? How long will my loved one live? What if mother needs more care than I can give her? What if something happens to me, and I can't take care of her at all? How do I get extra help? Will we be able to afford this? Will I be able to hold on to my job or will they let me go? Will I have to quit? What if dad needs to be put in a nursing home - will I be able to do that?

Anger. Dealing with a loved one who is ill can be frustrating. Illness can affect people differently and some elderly persons may lash out at their loved ones out of their own fear, frustration, and growing dependency. The ill person might seem like a stranger. The caregiver needs to deal with her own anger; anger at the care receiver, at having to be the caregiver, at family members who may not be helping out, or at the doctors.

Guilt. The caregiver may feel guilty about many things, including guilt for not doing enough to change the situation or make the person happier, guilt for becoming angry with the ill person, for neglecting one's own spouse, children and other responsibilities. You may even feel guilty for enjoying time away from the loved one.

Fatigue. Being stretched in several directions can lead to fatigue. Caring for two households, caring for a person in ill health, dealing with the night-time wandering of an Alzheimer's patient and coping with incontinence are examples of things you may experience. In addition, having your own sleep interrupted regularly can lead to serious exhaustion. All of these things can last several months or even years.

Isolation. If you are the person primarily responsible for another's care, you may feel tied down and isolated. The person you're caring for might need to have someone nearby at all times, or simply not want to be left alone. Studies have indicated that caregivers experience a significant reduction in the amount of free time they have. You may feel that no one understands your situation or how you're feeling. It is important that you recognize these feelings of isolation and realize that they are normal.

Providing assistance for your care recipient can give you the opportunity to express love and appreciation for the support that they have given to you. Several studies have reported that when there is a strong bond established between the caregiver and the care recipient, caregivers feel less stress.

What are We Afraid of? Caregiver Fears... Rational or Otherwise by Karen Henderson

When you become a caregiver, your life changes forever. You cannot recapture the past, and in facing an unknown future, you may be overcome by fear. My own experience proved I was so busy trying to be the best caregiver possible for my father, that I didn't take the time to deal properly with all the fears that were accumulating at the back of my mind. I wasn't admitting to them or talking about them.

As a result, these fears become magnified; we can spend too much time facing them alone, feeling that there is no-one else out there who could really understand what it's like.

It doesn't have to be like this.

What are some of those fears we know too well?

The fear of financial problems related to caring for a loved one...that the money will run out while at home or that there isn't enough money to even consider institutionalization, no matter how desperately needed.

Fear that you'll fail as a caregiver -- that you won't be able to keep up the pace physically. How many times have you asked yourself: "How long can I go on doing this...how many more days, years, before I fall apart?" For how long have you tried against all odds to smile and say "We're managing, thank you. ?"

Fear of the inability to handle the emotional stress. You finally start to understand what the stress is doing to you; you're afraid you'll never regain your original self...that person filled with energy, curiosity and optimism.

Fear of having to watch a loved one's pain and suffering. Feeling helpless to stop or even control it.

Fear of making the wrong care decision, leading to an unexpected outcome and the possible wrath of other family members

Fear of dealing with a loved one's incontinence. Can I change my father's diapers? How does he feel when I have to do this?

Fear of dementia...that your loved one will no longer be able to recognize you.

Fear of aggression caused by illness; how will you deal with a loved one's violence towards you?

Fear of being unable to advocate well enough, or of being unavailable the one time it really matters.

Fear that your loved one's needs will be sacrificed to those of the system.

Fear of seeing your own future in a loved one who is deteriorating.

Fear of losing your 'self'...of becoming so involved in caring for another that your identity is lost; your needs remain neglected and unfulfilled.

Fear of facing the future alone, of losing the comfort of an embrace, the assurance of unconditional love.

Finally, the tremendous fear of admitting to emotions you are 'not supposed to feel'...frustration, anger, a momentary desire to strike out or to flee.

All caregiver fears are real...for no other reason than they exist. Are they rational? Each of us has to decide this for ourselves; we may need help to do this. If you have trouble talking with the person you care for, talk to someone who has been there or talk to a professional. Communicate how you are feeling; learn how someone else has dealt with their fears.

It's not wrong to be afraid; it goes with the territory. It is wrong to suffer alone and in silence.

I have felt the blessings of caregiving...I better understand and feel compassion. I appreciate and accept my strengths and weaknesses; I am a better personnel manager, accountant, researcher and advocate. I have built up shared memories with my father that will stay with me forever. I have given back.

No one can perform the act of caring without help. Remember that we are after all only human; caregivers aren't perfect although we can kill ourselves trying.

Please accept support. Remember the joy you bring to those you love and thank yourselves every day that you care.

Caregiving Risks, Dangers and Rewards

What Are Some of the Risks of Caregiving?

- clinical depression
- lack of privacy
- restriction on a social life

What Are Some of the Dangers of Caregiving?

- personal illness/stress
- potential for abuse of person being cared for
- burnout
- suffering from grief/loss
- depletion of income
- feelings of isolation, loneliness
- legal/ethical issues -- power of attorney, substitute decision making

What Are Some of the Rewards and Joys of Caregiving?

- a new relationship with person being cared for
- a chance to give back
- a sense of accomplishment
- development of new skills, knowledge, i.e. advocacy abilities
- increased compassion, growth
- new relationships with others through support groups
- the building of memories

One thing I know I have to continually be aware of: **to stop grieving for what used to be and find joy in the present.**

The Caregiver's Bill of Rights

I HAVE THE RIGHT.....

TO take care of myself. This is not an act of selfishness, but will give me the capability of taking better care of my relative.

TO seek help from others even though my relative may object. I recognize the limits of my own endurance and strength.

TO maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.

TO get angry, be depressed and express other difficult feelings occasionally.

TO reject any attempt by my relative (either consciously or unconsciously) to manipulate me through guilt, anger or depression.

TO receive consideration, affection, forgiveness and acceptance for what I do from my loved one for as long as I offer these qualities in return.

TO take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.

TO protect my individuality and my right to make a life for myself that will sustain me when my relative no longer needs my full time help.

TO expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in our country, that similar strides will be made toward aiding and supporting caregivers.

- Jo Horne

10 Tips for Family Caregivers

- Choose to **take charge** of your life, and don't let your loved one's illness or disability always take center stage.
- Remember to **be good to yourself**. Love, honor and value yourself. You're doing a very hard job and you deserve some quality time, just for you.
- **Watch out** for signs of depression, and don't delay in getting professional help when you need it.
- When people offer to help, **accept the offer** and suggest specific things that they can do.
- **Educate yourself** about your loved one's condition. Information is empowering.
- There's a difference between caring and doing. **Be open to technologies and ideas** that promote your loved one's independence.
- **Trust your instincts**. Most of the time they'll lead you in the right direction.
- Grieve for your losses, and then allow yourself to **dream new dreams**.
- **Stand up for your rights** as a caregiver and a citizen.
- **Seek support** from other caregivers. There is great strength in knowing you are not alone.