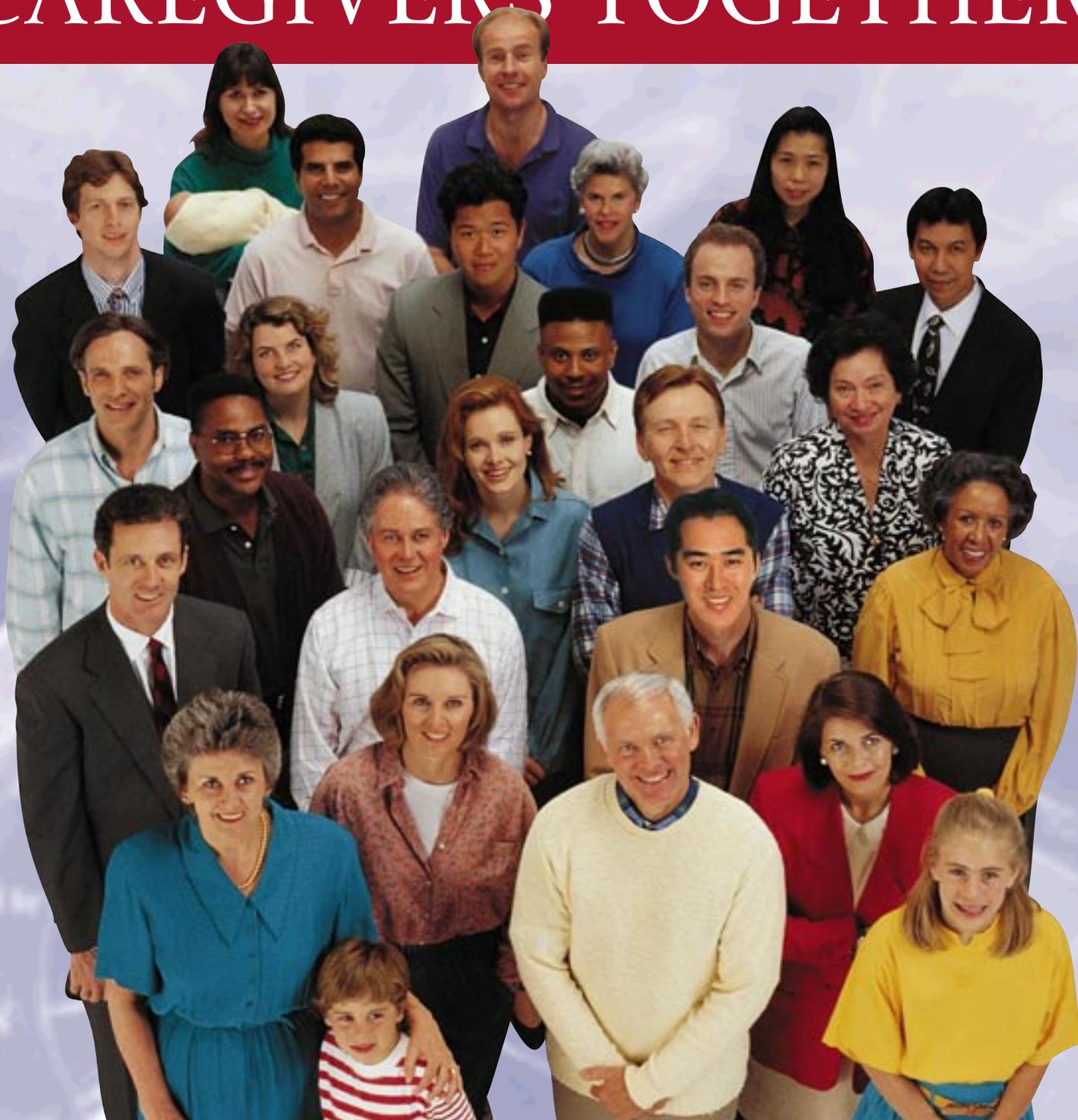


# CAREGIVERS TOGETHER



**ESTABLISHING YOUR OWN CARE-NET  
THE COMMUNITY CAREGIVERS NETWORK**

A PROGRAM OF THE  
ROSALYNN CARTER INSTITUTE FOR CAREGIVING



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# Caregivers Together

## ESTABLISHING YOUR OWN CARE-NET:

## THE COMMUNITY CAREGIVERS NETWORK

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**MAPPING THE ROUTE TO  
CARE-NET DEVELOPMENT**



## FOREWORD

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*There are four kinds of people in the world:  
those who have been caregivers, those who are  
currently caregivers, those who will be caregivers,  
and those who will need caregivers.*

Rosalynn Carter

**A** caregiver herself, former First Lady Rosalynn Carter was one of the first prominent government leaders to understand the importance of addressing the needs, emotional well-being, and problems of community caregivers. To that end, she created the Rosalynn Carter Institute for Caregiving (RCI), charging it with researching the needs of caregivers and improving their lives.

Since its establishment in 1987, the Rosalynn Carter Institute for Caregiving has been singularly devoted to the mission of promoting the mental health and well-being of individuals, families, and professional caregivers; delineating effective caregiving practices; building public awareness of caregiving needs; and advancing public and social policies that enhance caring communities. These goals are met by forming partnerships with professionals, groups, and individuals to deliver education and training programs, research, and program evaluation around care needs, and policy and advocacy efforts that promote healthy individual development and increase community caregiving capacity.

In 1990, the RCI leadership suggested using the 16 counties of the west central region of Georgia, the RCI's home region, as a laboratory to assess and meet caregiver needs. Mrs. Carter knew early on that the best way to meet the RCI's ambitious goals was to bring community leaders together into community coalitions. Thus, the RCI asked professional and family caregiving community leaders to become a part of a collaborative effort to improve the community's caregiving capacity. In early 1990, a group of professional and family caregivers, under the leadership of the RCI, formed the West Central Georgia Caregivers Network and adopted the name "CARE-NET" (caregivers network). From that original collaborative base has come the foundation for much of the caregiving research, education and training, program development, coalition development, and public advocacy that has emanated from the RCI.

In 1998, under a grant from the Robert Wood Johnson Foundation, the RCI established a second CARE-NET in southeast Georgia, thus demonstrating that the CARE-NET concept was replicable. Based on the successes of the first two CARE-NETs, in 2001 the RCI

submitted a proposal to the Administration on Aging (AoA) under the National Family Caregiver Support Program. The grant proposal was to form a partnership with the Georgia Division of Aging Services to establish six new CARE-NETs in six of the state's Area Agencies on Aging (AAAs) districts. Subsequently, in October of that year, the RCI was awarded the Establishing Community Caregiving Networks and Developing a Community Caregiving Capacity Index grant. One year into the grant, we built six new CARE-NETs. As of the fall of 2004, the Rosalynn Carter Institute for Caregiving has established a network of 12 CARE-NETs that spans the entire state. We also developed the *RCI Community Caregiving Capacity Index* (RCI-CCCI), which is intended for use by communities that wish to assess their caregiver strengths and areas of need.

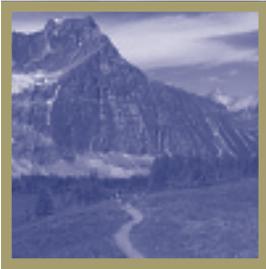
Thus, drawing upon the lessons we've learned in the past decade and with the establishment of the existing CARE-NETs, we have created this guide to help you build a coalition to improve the caregiving capacity of your community, whether it is large or small, urban, suburban, or rural, wherever it may be. The guide is meant to provide a practical, step-by-step process for planning and carrying out the vital task of challenging community leaders to focus together on a community's caregiving needs. While the guide has been developed in partnership with the AAAs, it is applicable to establishing caregiving coalitions across the life span with all groups. CARE-NET members are family caregivers and leaders across the community, including hospital administrators, business executives, school superintendents, hospice directors, governmental leaders, service providers, and all public and private entities that work with professional and family caregivers. All groups with an interest in the needs of caregivers are welcome. This practical guide, which has come out of our own experience, will provide the direction needed to start a CARE-NET in your own community.

Ronda C. Talley, PhD, MPH

James L. Dodd, PhD

Terry Elder, MA

## STEP 1: TRAVELERS ON THE CAREGIVING ROAD



*“Does the road wind uphill all the way?*

*Yes, to the very end.*

*Will the day’s journey take the whole day long?*

*From morn to night, my friend.”*

Christina Rossetti, *Up Hill*

**T**he caregivers of this world travel along an uphill, often rocky road that never seems to end. For so many years, our nation has focused on the care recipient, paying scant attention to those who provide the care required, whether that person was a family member, friend, or paid employee. It is only in the past decade that we’ve turned the spotlight upon these unsung heroes, both the professional and the family caregivers.

According to recent data, our nation faces a caregiving crisis. There are over 44.4 million American caregivers age 18 and over who provide unpaid care to an adult, and who need help in doing so. We know that 83% of caregivers are helping people who are related to them and one in four lives with the care recipient. Slightly less than half of caregivers of people who take medications say their care recipients need someone to oversee or manage their medication usage. About one-third of family caregivers are providing care at a highly involved level.

These are not nameless, anonymous people. Nor are they a homogenous group. Instead, the nation’s caregivers represent a diverse medley of people who do everything from caring for lifelong spouses to caring for strangers. Some provide their caregiving 24/7, others just 40 hours a week, still others have varying care routines. Some are paid a pittance, most are paid nothing at all. As former First Lady Rosalynn Carter, a caregiver herself, says when she describes the myriad of caregivers she’s met over the years: Caregiving has many faces.

### Who are professional caregivers?

Professional caregivers provide paid care. They include:

- ★ Nurses (i.e. LPNs, CNAs, Aides)
- ★ Physicians (including all specialty areas such as ophthalmologists, oncologists, neurologists, etc.)
- ★ Psychologists
- ★ Social Workers
- ★ Pastoral and mental health counselors
- ★ Care or Case Managers
- ★ Home health care workers
- ★ Hospice workers
- ★ Faith-based spiritual workers
- ★ Physical/occupational therapists
- ★ Patient care technicians
- ★ Nutritionists
- ★ Teachers
- ★ Many other paid care workers

Here are just some faces of caregiving:

**The spiral of dementia.** He was her first and only



love. They forged a strong marriage. Raised four children. Were at the point in their lives when it was just the two of them and they could chart their own course, plan their own

activities, enjoy the benefits of their years of work.

Until one day, he began to act strangely. He became forgetful, often confused about the ordinary activities of daily living. The names of his children, grandchildren and friends began to escape him. Memory losses became more frequent. She took him to the doctor for a checkup where they received the dreaded diagnosis: Alzheimer's disease. As the terrible disease continued its inexorable progression, she found herself forced to take on tasks she'd never before encountered, such as looking after their finances and attending to his daily needs as she'd once attended to those of their children. He became abusive, unpredictable, and erratic in his behavior. Such behavior led to social isolation, for her as well as for him. And it wasn't too long before the love of her life had become a stranger, one she would be taking care of for many trying and emotionally draining years.

**The sudden family.** They were a happy couple, with satisfying careers, an active role



in the community, and two teenaged sons, one entering college, the other his last year of high school, on track to win an athletic scholarship. Then his sister, a single mother raising three teenagers herself, was diagnosed with late-stage ovarian cancer. She died a few weeks later.

Almost overnight, it seemed, the couple had to decide whether to place their 13- and 14-year-old nieces, and 16-year-old nephew, in foster care or bring them into their own home. They made the only decision they could, bringing the children home with them and suddenly finding themselves parenting five teenagers. The couple gave over their emotional and financial resources to that caregiving task, sur-

## Who are 'family' caregivers?

"Family" is a general way to include individuals who provide non-paid care.

They include:

- ★ Husband or wife
- ★ Mother or father in-law
- ★ Son or daughter in-law
- ★ Aunt or uncle
- ★ Grandmother or grandfather
- ★ Other relatives
- ★ Next door neighbor
- ★ Partner
- ★ Community member
- ★ Workplace colleagues
- ★ Spiritual or religious community members
- ★ Many other non-paid individuals

viving the emotional roller coaster of life with teenagers until all the children were in college or graduated, launched upon their own lives. Only then did this couple emerge from their caregiving journey, content they had done the best they could do and ready to resume their own life as a couple.

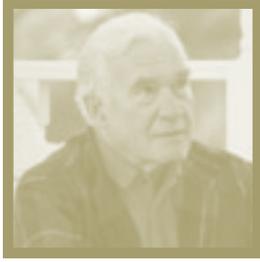
**The aging mother.** She was a healthy, independent, hard-working widow in her early seventies, a source of support and strength to her son and daughter-in-law, her daughter and son-in-law, and six grandchildren. Then, experiencing some discomfort, she went in for a medical check-up, where doctors diagnosed her with bladder cancer. Expecting only the best, she underwent surgery, emerging on the other side into a nightmare of pain and dependency after an operation that went terribly wrong.



Her son and daughter-in-law took her into their home and became her primary caregivers. With grown children of their own and active careers, they had been living a rich, full, and independent life, coming and going as they chose. Suddenly, all that changed as they shouldered the complex world of the caregiver. He found himself dealing with reams of medical bills and insurance claims, having to assume total responsibilities for his mother's financial affairs. His wife coped with providing the in-home nursing care of her mother-in-law, everything from bathing to toileting. His sister, who lived in another state and was raising three children herself, helped as best she could.

After three emotionally draining years, the old woman died. Her son, daughter, and daughter-in-law emerged from their caregiving roles with a lifetime of memories of a courageous mother who, in her suffering, drew them closer to her and to each other. "I became closer to my mother in those last three years than I had ever been," her son recalled. "We had many hours to talk, remember the good times, and experience what love really is. On the night before she died, I was sitting by her side in the nursing home where we finally had to move her. She looked over to me at one point and said, 'You know what is really wrong with me?' I said I knew of her medical condition, her struggle to deal with her depression over her pain and loss of independence, and her struggle to stay courageous in her dark hours. She said, 'No, that's not what's wrong with me. I am embarrassed. I have become a heavy burden to my children, and I never wanted that.' She died early that morning. I am glad that I was there for her in her need. I discovered the rewards of being a caregiver."

**The beloved physician.** He was born in rural Alabama, one of five children. His father was a schoolteacher and a Primitive Baptist preacher. From his earliest years, he wanted to be a physician and help people. He distinguished himself as a student in the Univer-



sity of Alabama and became one of the first southerners to attend the Harvard School of Medicine. After a residency there in internal medicine, Harvard recruited him for its faculty. But, cognizant of his family responsibilities and professional desires, he turned down the lucrative and prestigious offer to return to the South, where he began a rural practice.

Over the years, he achieved national and international recognition as a gifted internal medicine and heart specialist, publishing numerous articles in professional journals and remaining on the cutting edge of his specialty. When the American Medical Association filmed a series on medical practice in the United States, it focused on him and his life as a practicing physician. Some of the most prestigious medical schools in the nation recruited him to become their dean, but he stayed where he was. With all of the honors and recognition, he maintained his rural practice for more than 40 years, looking after the health of thousands of patients in rural Georgia. “I never wanted to be a full-time academician,” he said. “I wanted to be a practicing physician and care for people. I love what I do.” Today, however, he has a life-threatening disability and is facing major surgery. Today, “the beloved physician,” as his patients called him, is in the hands of other professional and family caregivers. Hopefully, they will care for him with the same compassion and expertise he showed as he cared for countless others.

**The burnt out caregiver.** He was a chaplain in the military, trained in the rigors of pastoral counseling, approachable, down-to-earth and compassionate. During his two tours in Vietnam, soldiers sought him out for both spiritual and emotional counsel. He became a caregiver to many as they confided in him their anxieties, anger, worries about families back home, broken hearts over lost girl friends, and fears over death or injury. He listened carefully and caringly as they relayed their haunting nightmares and sought answers for searching questions about the discrepancy between a loving and compassionate God and the horrors of war.



Ninety men who came to him for counseling were killed during that war. He performed his official duties as a chaplain in the death process, writing letters to families and girlfriends and carrying out the wishes of those who confided to him their final requests. He returned home from his second tour, served out his enlistment, and tried to re-enter civilian life in a pastorate. But his years of professional caregiving had drained him of his ability to care anymore. He could not reconcile his theology with his life experience. He resigned his church and his ordination, renounced his faith, shut out

the past and withdrew from involvement in community life. A lifetime of professional caregiving had taken its toll.

Yes, caregiving has a face. In fact, it has many faces. Whether one is caring for others as a trained professional, or as a family member educated “on the job,” caregiving brings with it a complex mixture of emotions along with its tasks and responsibilities. Often, these emotions and mental attitudes rise and fall like the tides. Joy and sorrow, love and hate, compassion and revulsion, holding on and letting go, faith and doubt, hope and despair, commitment and withdrawal. All are there in the heart and mind of the caregiver. Yet every caregiver also has needs that must be met. Ignore these needs, and the caregiver risks drowning in the tides of emotion and responsibilities the job brings.

Sooner or later everyone will be on the caregiving road, whether requiring care or providing care. So it makes sense to call upon the community to care about the caregiver through financial, emotional, and supportive resources. That’s where CARE-NET comes in. It can become a “travel guide,” steering a community along the road of caregiving and helping it develop the tools it needs to make that road as smooth as possible for both the caregiver and the cared for.

Now it’s your turn. We’ve worked to put together a road map to direct you in the creation and initial organization of your own community CARE-NET, based on years of experiences from our existing state-wide network of CARE-NETs. So “unfold” the map and begin navigating. Every caregiver has needs that must be met.

---

*Sooner or later everyone will be on the caregiving road, whether requiring care or providing care.*

---

***“My association with the Southern Crescent Care-Net has provided me with new caregiving resources, valuable networking with other formal and informal caregivers and caregiving workshop training that I can take back and implement in my community.”***

*Carol Brown  
Southern Crescent Georgia CARE-NET member  
Caregiver for elderly parents*



ROSALYNN CARTER INSTITUTE  
FOR CAREGIVING

# Travelers on the Caregiving Road: *Establishing your own CARE-NET*



Leading the Way to a CARE-NET



Preparing for the CARE-NET Journey

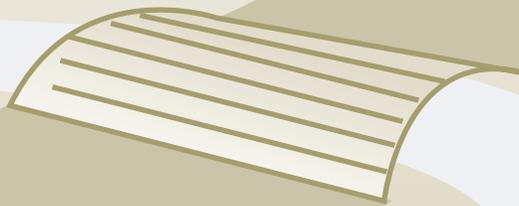
Setting Goals and Defining Strategies

The road to CARE-NET

On the Road to CARE-NET

Stops along the Way

On the Road Again



**CARE-NET**  
*...the caregivers' network*

If I Had to Take  
this Trip Again

## STEP 2: THE CAREGIVER'S TRAVEL GUIDE

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*“We are left alone with each other. We have to creep close to each other and give those gentle little nudges with our paws and our muzzles before we can slip into sleep and rest for the next day’s playtime...and the next day’s mysteries.”*

Tennessee Williams, *The Milk Train Doesn’t Stop Here Anymore*

### UNDERSTANDING THE CARE-NET MODEL

**A** CARE-NET is a collaborative network of representatives of professional and family caregiving agencies, educational institutions, and businesses, as well as individuals and other relevant groups, organized to assess and address caregiving needs. Sounds kind of bureaucratic, but, in reality, what it means is that CARE-NET exists to bring folks together for the express purpose of discussing, studying, and searching for solutions to specific problems or needs centered around caregiving, and, through its member group, provide for a community’s caregiving needs.

The coalition concept is nothing new. Community collaboratives, coalitions, partnerships, networks. . . call them what you will, this form of community networking has been around for as long as people have lived together. It is a highly effective method for addressing problems, prompting community initiatives, or effecting change.

#### **The CARE-NET serves many functions:**

1. It links professional and family caregivers into a supportive community concerned with caregiving.
2. It identifies and studies community caregiving strengths and needs.
3. It develops service and educational programs for caregivers.
4. It organizes community-based forums for public feedback on caregiving issues.
5. It develops a resource capacity for information on caregiving.
6. It provides a source of support for caregivers.
7. It fosters strong relationships among community leaders and provides a forum for them to work collaboratively, coordinately human and fiscal resources.
8. It educates the community about caregiving.

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***A CARE-NET is a collaborative network of representatives of professional and family caregiving agencies, educational institutions, and businesses, as well as individuals and other relevant groups, organized to assess and address caregiving needs.***

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## Benefits to Establishing a CARE-NET

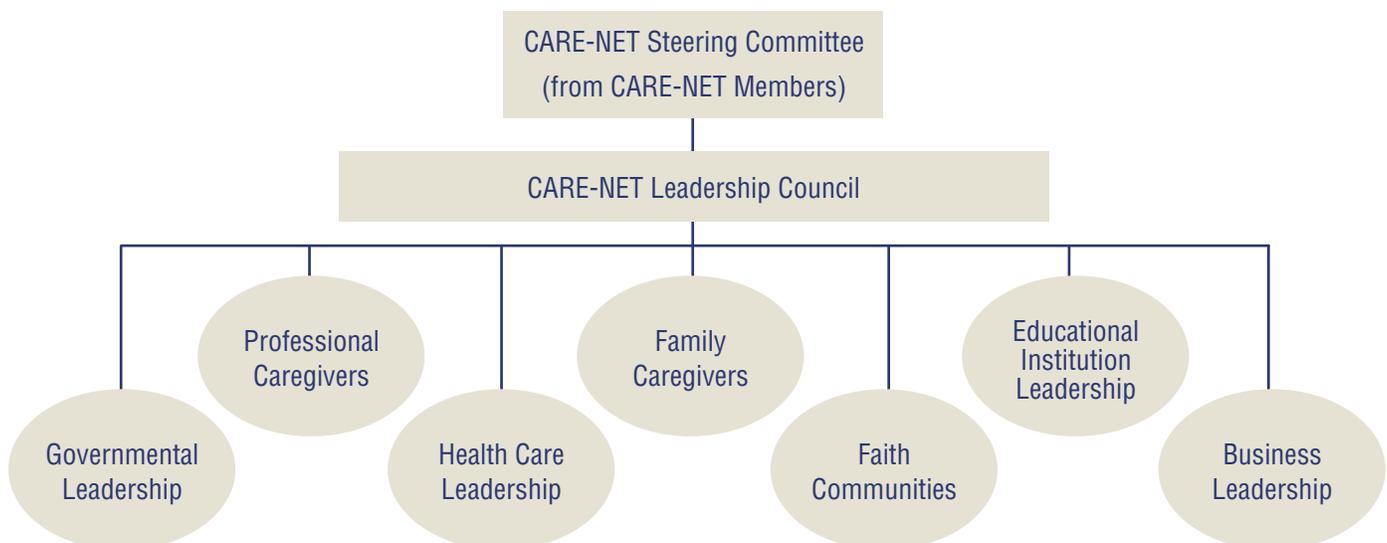
So what, you're saying? Why should I spend the time, money, and energy on establishing such a network? Well, consider the four major benefits such a cohesive community effort can bring to the caregivers and those requiring care in your community:

1. By bringing together community leaders from diverse agencies, groups, and individuals, it provides a forum for discussion and action on caregiving needs and priorities that benefit caregiving agencies, businesses, educational institutions, and professional groups, government agencies, faith-based organizations, and family caregivers.
2. By enhancing relationships among community leaders within the broad range of caregiving, it provides a framework for programs and funding that require collaboration and community support, which most do today.
3. Through community-wide networking, it offers a research tool and action-planning format for addressing community caregiving needs.
4. Through community-wide collaboration and assessment, a CARE-NET provides a ready-made mechanism to access funding and grant sources.

Working together, a caregiving coalition like CARE-NET can make a decided difference in the emotional and physical health of those traveling the caregiving road. It is now time to set your community on that journey.

The recommended organization of a CARE-NET includes a CARE-NET Steering Committee to provide guidance and leadership and a broader CARE-NET Leadership Council, the main CARE-NET body, from which the Steering Committee leadership may be selected.

### CARE-NET Structure



### STEP 3: LEADING THE WAY TO CARE-NET

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*“For if the trumpet give an uncertain sound,  
who shall prepare himself to the battle?”*

The Apostle Paul to the Corinthians

Whatever the enterprise, there must be leadership. Without a clear trumpet call to action, any goal will falter, any destination go unreached, no matter how good the intentions. This is particularly true when it comes to organizing a community caregiving network. Someone must muster the strength and commitment to pull together—and keep together—the constituency required to improve the lives of the community’s caregivers.

Creating a collaborative network of professional and family caregivers is no easy undertaking. To suppose that community leaders in the arena of caregiving will just jump on the bandwagon to be a part of such an effort is, at best, naïve. However, when properly challenged to respond to the needs of caregivers in the community, most will find the time to participate as long as you are very clear and specific about what you are asking them to do. That’s where a leader comes in.

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*When asked to respond to the needs of caregivers, most community leaders will do so.*

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Leadership style is a diverse, multi-dimensional trait. Some leaders are intensely driven, doggedly pursuing a defined goal according to a process only they can see. Others are charismatic, leading through inspiration and charm. Still others are friendly and amiable, drawing people into an enterprise through the sheer force of their personality, while others are more analytical, leading through their awesome command of the facts.

Neither is right or wrong. All have their strengths and weaknesses. For instance, while the driven leader may recruit many through sheer force of a will, he may also offend some because of inflexibility. The charismatic, enthusiastic, expressive leader may charm some, but turn others off by appearing long on excitement and short on detail. The amiable leader may find that some follow because of friendship, but others want more substance, a reason beyond sheer friendship and favors as to why they’re devoting their time and energy to a particular cause. And while the analytical leader may find some follow because of the sheer weight of the argument she makes, others will be turned off by what they perceive as a lack of spirit and inspiration.

Regardless of their own personal style, community leaders identified in your area for the

CARE-NET need to be conversant with some of the basic “dos” and “don’ts” of leadership:

1. Do be yourself and go with the leadership style that is uniquely you.
2. Do conduct a personal self-assessment about your strengths and weaknesses as a leader so you can build on your strengths and try to minimize your weaknesses.
3. Do be observant and try to see yourself as others see you. Use this understanding to alter your approach if necessary to achieve your desired outcomes.
4. Don’t try to conform to a perceived best style of leadership if it doesn’t fit you. Use a leadership style that works for you.
5. Don’t be too self-assured or too afraid to be honest with and objective about yourself.
6. Don’t just focus on your own behavior as you work to involve others in an enterprise. You are one in a group and are responsible for facilitating the group and providing leadership in the context of the group dynamics.

The leadership role in the development of a community CARE-NET may fall to an established community agency, a governmental unit, an independent agency, a citizen group, a consulting organization, a university, a business, or a dedicated individual. Whichever, one individual must ultimately assume the responsibility for shepherding the CARE-NET through to its completion as an established entity. This doesn’t mean the leader has to work alone without management, consultation, or group support, but that there must be a visible individual leader evident in the CARE-NET development process.

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*The leadership role in the development of a community CARE-NET may fall to an established community agency, a governmental unit, an independent agency, a citizen group, a consulting organization, a university, a business, or a dedicated individual.*

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## IDENTIFYING A LEADER

When a group, such as the local Alzheimer’s Association or a business, takes on the responsibility for starting a CARE-NET, that sponsoring agency should identify a program leader. If an entity outside the community, such as a state agency or county organization,

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*CARE-NETs may be city-, county-, or multi-county entities.*

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takes on that role, then a local community agency or organization partner must be recruited to lead the development process. For example, for one CARE-NET established by the Rosalynn Carter Institute for Caregiving outside of the local community, we identified a partner in Valdosta State University School of Social Work, which was several counties away, and the school dean designated a representative to facilitate establishment of the local

CARE-NET. CARE-NETs may be city-, county-, or multi-county entities.

Follow these steps to find a local partner to lead the CARE-NET development process:

1. *Carefully consider which community groups are interested in caregiving.*
2. *After researching possible partners, choose the agency or organization that appears to have motivation to work on caregiving issues and the organizational structure, resources, and contacts in the local caregiving community to start a CARE-NET.*
3. *Arrange a meeting with the organization's director to succinctly explain the CARE-NET history, purpose, function, and community benefits. A one-page fact sheet will help serve as a guide for a "to-the-point" presentation. (See the sample fact sheet and brief history of CARE-NET may be found on pages 35 and 36).*
4. *Clearly explain what you expect of the organization in its role as a CARE-NET partner. (A sample of expectations for a sponsoring organization may be found on page 37)*
5. *Ask for a commitment to participate in the establishment of a CARE-NET. If the director agrees to have his or her organization be the sponsoring partner, ask to have a local program leader named. Now you have your point person.*

### CARE-NET Leadership Options

- ★ A committed agency or organization
- ★ One dedicated individual with resources and a supportive organizational base
- ★ A group of local citizens involved in caregiving

Instead of one established organization, you may find that a local group of citizens involved in caregiving wants to start a CARE-NET. They may have the leadership, resources, and contacts to proceed with the process outlined in this guide. If not, work with them to enlist a local organization as a partner.

You may also find you have one dedicated individual who wants to start a community CARE-NET. Again, make sure that person understands the kind of resources and contacts necessary to take a leadership role and is willing to make that kind of commitment. If they're not, suggest they, too, find a sponsoring organization that is interested in helping caregivers and may be willing to start a CARE-NET with dedicated volunteer assistance.

Once you identify a leader, the homework begins. The leader must learn certain basic information, including:

1. *Familiarity* with the six leadership guidelines previously outlined (page 14).
2. *A basic understanding* of the CARE-NET model, its history, purpose, and community benefits. If the person needs more information than you have, contact the RCI, either via phone, e-mail, or by searching our website ([www.RosalynnCarter.org](http://www.RosalynnCarter.org)).

3. *An understanding* of the community boundaries within which the CARE-NET will be established. The boundaries may be already set by organizational decision, or the leader may be free to set them in consultation with the group. As noted earlier, CARE-NETs may be organized by communities, counties, or multi-county boundaries.
4. *An understanding* of community demographics and culture. This information may be available through the leader's organization, or by consulting regional development centers in the area, perusing local community and regional web sites, or conducting research in the local library.
5. *A basic understanding* of who the key community leaders in the caregiving community are—the professionals, public and private agencies, educational institutions, businesses, faith communities, hospitals and nursing homes, and public officials. To gather this information, start with what you know. Which organizations are in the business of caregiving? Who are the community leaders interested in caregiving? What contacts does the leader have who can provide advice about organizations and individuals important in the caregiving community? For example, a first stop might be the local Area Agency on Aging, universities, or public health centers.
6. *Enough familiarity* with professional and family caregivers to be aware of some of their needs and issues. The RCI offers the *RCI Family Caregiver Assessment*, which is an instrument to be used by the care manager to assess the needs of a family caregiver, and the *RCI Community Caregiving Capacity Index (RCI-CCCI)*, which is designed to help a community assess its strengths and weaknesses in helping caregivers, then use this information to develop action plans.
7. *How to enlist* the support of the caregiving community. Again, start with what is known. Seek the advice of existing contacts and networks. Turn to the leadership of any organization or consultant assigned to the project.
8. *The resources* or access to resources for meeting places.
9. *The resources* or access to resources for communications, including e-mail addresses, cell phone number, and web site.
10. *A core group* of community representatives and professional and family caregivers to help build the coalition.

Leadership in any enterprise begins with a commitment to achieve a desired goal or destination. With a clear focus and goal, armed with the knowledge of a community, its culture, movers and shakers, pertinent resources, and ways you can access those resources, as well as some awareness of the community's caregiving issues and needs, a leader can build a viable caregiving collaborative. This is the beginning of the CARE-NET journey.

## STEP 4: PREPARING FOR THE CARE-NET JOURNEY



*“Affairs are easier of entrance than of exit;  
and it is but common prudence to see our way out  
before we venture in.”*

Aesop, *Fables*

**T**he wise person is one who prepares for a journey before venturing forth. We have discussed the initial steps a CARE-NET leader should take. But that’s just the beginning. There still remains much more preparation before you invite other community leaders to join in a CARE-NET enterprise. “Do first things first” is the imperative here. The leader (hereafter referred to as “you”) needs to proceed with deliberation. That means you should:

1. Prepare a list of influential people in the professional and family caregiving community who should be approached about membership in the CARE-NET.
2. With list in hand, choose eight to 10 individuals who hold considerable clout and represent the broad base of caregiving in the community. This is the core group you should invite to a meeting to discuss organizing a caregiving network. Take some time to research just who you should invite, and how you should invite that person. Begin with established relationships and contacts, and work your way outward, asking each new person you recruit to help with future recruitments.
3. Think carefully about the best way to approach those you’ve targeted as core group members. A simple phone call may do for some. Enlisting a friend or colleague to make a personal contact may be best for others. Maybe you should make an in-person contact. In any case, this first approach should be a personal one. Your goal for this first contact should be getting the individual to the core group meeting to “discuss the possibility of forming a community caregiving collaborative.” Still, be prepared with a clear and concise explanation about

### Potential *Members*

- ★ Public and private service agencies
- ★ The medical/health care establishment
- ★ The educational system (schools and universities, public and private)
- ★ Caregiving organizations
- ★ Private social and psychological practices
- ★ Local and state legislators and other public officials
- ★ Police officers and judicial representatives
- ★ Business leaders
- ★ The faith community
- ★ Family caregivers

the benefits of having a local CARE-NET. Ask about the best meeting times and places, and promise to keep this first meeting focused, no more than an hour-and-a-half at most. If the invitee suggests sending someone else as a representative, stress that this first meeting is only a commitment to meet for a discussion, and for that you really value his/her input as a community leader. Of course, if your designated invitees simply can't meet due to preexisting commitments, for instance, then assure them you welcome their representative.

4. For the initial meeting, try to set a convenient time and place far enough in advance to accommodate people's schedules. Consider a breakfast or lunch meeting, which often works better with busy people's schedules. At the very least, make sure you serve refreshments.
5. Prepare a formal letter of invitation to this first meeting with time, date, location and agenda. (A sample letter can be found on page 39).
6. Prepare an agenda for this first meeting. (A sample agenda can be found on page 40) .
7. Plan to follow up with a personal call or e-mail contact to invited representatives.
8. Evaluate the response you get. If you have a positive commitment from at least eight people, then proceed. If you find that you do not have enough commitments for this first meeting, return to your initial "possible" list, and contact additional community leaders until you have your core group committed.

With this preparation done, there is one more vital thing the leader should carefully consider: the aims, goals, or objectives for this first meeting, and for the CARE-NET as a whole.

*“One of our CARE-NET members expressed a need for funds to continue her work with grandparents raising grandchildren. It was my “A-hah!” moment as I began to catch the concept behind the CARE-NETs. We brainstormed how various members could help meet her need.”*

*Kay H. Hind  
Executive Director, Southwest Georgia Council on Aging  
Sponsor Agency of the Southwest Georgia CARE-NET*

## STEP 5: SETTING GOALS AND DEFINING STRATEGIES

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*“Do you know how to lead an orchestra?” asked the professor.  
“No, and why do you ask?” questioned the student.  
“Because, an orchestra will play only what is in the  
mind of the conductor.”*

Dr. Paul Deutschberger to a student on ‘Clarity of Aim’

### CLARIFYING YOUR AIM

**M**anagement guru Peter F. Drucker called the orchestra conductor the one “through whose effort, vision, and leadership individual instrumental parts become the living whole of a musical performance.” That’s an apt metaphor for the role of the CARE-NET leader. If the leader isn’t clear about the program’s goals, then the core committee and the rest of the participants will flounder helplessly, wasting time and effort, and possibly dooming the entire project to failure.

Busy people will not stay involved in an enterprise, no matter how worthwhile it is, if they are unclear about its destination and have no way of knowing when they have arrived at a specified point, or evaluating the process that got them there.

So. What are your goals?

The primary goal of a CARE-NET is, simply put, is to involve community members in a collaborative effort to study a community’s caregiver needs and find ways to address those needs. Included in this goal is helping a community become more caregiving friendly. This goal should drive the entire process.

From there, additional goals follow, including:

1. To develop a broad-based, diverse coalition.
2. To create a visible organization.
3. To conduct a formal needs assessment.
4. To address caregiver needs as assessed.
5. To evaluate progress in meeting assessed needs.
6. To continue its activities until it is no longer viable as a community enterprise.

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*The primary goal of a CARE-NET is, simply put, is to involve community members in a collaborative effort to study a community’s caregiver needs and find ways to address those needs.*

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To meet your goals, you first need to define step-by-step strategies, kind of like a to-do list. For example, the basic strategies to reach the goal of organizing a CARE-NET include:

1. Setting up a core group of community leaders composed of eight to 10 leaders in the professional and family caregiving community.
2. Inviting the core group to an initial meeting to discuss the feasibility of organizing a local community CARE-NET.
3. Asking the core group to commit to becoming the steering committee to establish a community CARE-NET.
4. Asking the core group to suggest other professional and family caregiving leaders to contact and invite to become CARE-NET members.
5. Holding steering committee meetings as needed to enlist 15 to 20 additional CARE-NET members and create an organizational structure.
6. Developing and approving by-laws.
7. Planning a formal meeting to organize a community CARE-NET with a defined structure as contained in adopted by-laws.

A CARE-NET leader must always keep the program's main goal in view, as well as the goals that flow from it, while implementing the strategies that must be followed to meet those goals. Using this vision, you, as leader, can act in clear and confident ways.

*“It is truly exciting to observe the expansion of learning and support opportunities for caregivers of all kinds that are developing with the growth of the CARE-NET activities and collaborations.”*

*Nancy Harper*

*Chairperson of Southwest Georgia CARE-NET*

## STEP 6: GETTING STARTED



*“For all your days prepare,  
And meet them all alike:  
When you are the anvil bear—  
When you are the hammer, strike.”*

Edwin Markham, *Preparedness*

### ORGANIZING THE STEERING COMMITTEE

**W**hile the image of the leader of a community CARE-NET program as a hammer may be a bit strong, the idea of preparing to lead is sound. That means preparation for everything from that initial core group meeting to building community support. Let’s start with that first, all-important meeting during which you’re going to be organizing the steering committee:

- ★ Choose a meeting place that facilitates discussion. For instance, choose a comfortable room with couches and chairs instead of conference room. Or, if you’re meeting over a meal, ask for a private, i.e., quiet, room in the restaurant.
- ★ Prepare a written agenda for the meeting and follow it.
- ★ Provide copies of the agenda and CARE-NET fact sheet at the meeting, along with pencils and writing pads for note-taking.
- ★ Arrange for someone to record the proceedings.

#### First Steering Committee Meeting

In your first steering committee meeting, make sure your agenda includes the following:

- ★ *After providing a concise history of CARE-NET, using the materials provided by the RCI at the end of this book, stress its benefits to the community, especially activities and programs that will support the community’s caregivers. Then begin a discussion (that you lead) on the value of forming a caregiving coalition for your community.*
- ★ *As the discussion comes to an end, ask the group for its commitment to act as the steering committee to help organize and become a part of a local CARE-NET. Be specific about what you’re asking of them. (A list of the steering committee tasks can be found on page 41).*

- ★ *Urge participants to recommend other community professionals and family caregivers who should be invited to become members of the CARE-NET, and to bring a list of those names to the next steering committee meeting. If they immediately begin suggesting people who should be invited, encourage this. Ask if they are willing to make the initial contact and offer to attend any meetings with them. Promise to take care of the organization for such meetings, including following up with a phone call or e-mail, and sending letters of invitation to upcoming CARE-NET meetings.*
- ★ *Set the time and place for the next meeting. The primary agenda item will be identifying additional community leaders who should be invited to become members of the CARE-NET and its burgeoning organizational structure.*

You are now on the road to CARE-NET.

## STEP 7: ON THE ROAD TO CARE-NET



*“The traveler was active; he went strenuously in search of people, of adventure, of experience.*

*The tourist is passive; he expects interesting things to happen to him. He goes ‘sight seeing’.”*

Daniel J. Boorstin, *The Image*

### ASSESSING A COMMUNITY’S CAREGIVING CAPACITY

**A**s a CARE-NET leader, you need to find others willing to embark upon this adventure with you to improve the lives of community caregivers. You’re now ready to enlist additional community professional and family caregivers and to create a structure for the CARE-NET coalition you’re building. Start by following these steps:

#### **Second Steering Committee Meeting**

In your second steering committee meeting, make sure your agenda includes the following:

- ★ *Welcome and introduction.* Introduce the original members of the steering committee and any new invitees who are attending for the first time. Encourage each person to talk about their affiliations and interest in caregiving.
- ★ *The CARE-NET program.* Explain the CARE-NET program to the new members (and as a refresher for the steering committee). The one-page fact sheet you’ve prepared provides the perfect tool for this. Allow time for questions. Remember to emphasize the good the CARE-NET can do in addressing the needs of community caregivers.
- ★ *Steering committee commitment.* Clearly state what kind of commitment you expect of CARE-NET members and the steering committee. Ask them to again recommend other caregiving leaders to invite to future meetings. A beginning membership of 15 to 20 is ideal. Some steering committees may have this many members by this now. If not, seek out additional members. To this point, all involved become a part of the Steering Committee until the full CARE-NET is formed.
- ★ *Establish a structure.* Explain why it is necessary to create a structure for the coalition. Have a sample set of by-laws available for discussion. Either you, as leader, can provide these, or you could have worked with two or three steering committee members before the meeting to draft it (A sample set of by-laws is included on page 42-45).

If you have enough steering committee members, they are prepared to revise the draft by-laws and create a formal structure, and they are willing to suggest additional members, then move on to the agenda items outlined in the third meeting section below.

But it is far more likely, based on past experience, that your steering committee will, at this point, want additional time to study the proposed by-laws, consider the commitment you're asking of them, and think about additional community leaders who should be invited. If this is the case, set the time and place for the next meeting.

### **The Third Steering Committee Meeting**

Make sure you send a formal letter or e-note to steering committee members reminding them of the time and date of the next meeting. Include an agenda outlining the issues for discussion: adoption of by-laws for presentation to CARE-NET membership, commitment asked of CARE-NET members, and additional professional and family caregiving community leaders who should be invited to become part of the local coalition. Use the following agenda:

1. *Discuss expectations of CARE-NET members.* Allow time for members to discuss the commitment you're asking of them. Stress again that you're aware they're busy, involved community leaders, and that careful consideration will be given to any time and involvement asked of them. Emphasize the fact that they're not being asked to form a service agency, but to come together in a collaborative effort to study the needs of caregivers in their community and search for the ways and means of meeting those needs.
2. *Discuss and complete proposed by-laws.* Lead a discussion on a draft of the by-laws, using the sample by-laws as a guide. The goal of this discussion is to have a final set of by-laws tailored to the local community ready for presentation to the whole CARE-NET membership for adoption.
3. *Select CARE-NET officers.* Ask for volunteers and nominations of people to serve as CARE-NET officers. People may volunteer, or you may want to form a nominating committee to suggest a slate of officers at the next meeting. This slate of potential offices will be presented to the membership as a whole at its launch meeting for either adoption or vote. Commit to working closely with the officers in the future, and to help provide the necessary funds and organization for CARE-NET meetings and communication.
4. *Brainstorm a list of additional members.* Discuss other professional and family caregiving community leaders who should be invited to become CARE-NET members. Develop a list of these potential members and decide how they will be contacted and

by whom. Membership of a CARE-NET can start with 15 to 20 members, but can grow up to 30 or 40 depending upon the wishes and needs of the local coalition.

5. *Consider next steps.* Set the date, time, and place for the next meeting, during which the CARE-NET will be officially launched.

### **The Launch Meeting of the Full CARE-NET Leadership Council**

As always, make sure you have sent letters or e-mails to steering committee and prospective members confirming the date, time, and place of the meeting. Include an agenda and a draft of the proposed by-laws.

Make sure the meeting room is ready for the discussion, and provide pens and pads for note taking, copies of the agenda, the CARE-NET fact sheet, and the by-laws draft. The agenda should include the following items:

1. *Welcome and introduction.* Up to this point, you as leader have been conducting the meetings. Now, the new chairperson (who may be you) should chair the meeting.
2. *Summary of the CARE-NET.*
3. *Summary of the work of the steering committee so far.*
4. *Name your CARE-NET.* Naming format suggestions include:
  - ★ CARE-NET of City/County
  - ★ City/County CARE-NET
5. *Consent of those present to formally organize a local CARE-NET.*
6. *Presentation of suggested by-laws for adoption.*
7. *Presentation of slate of officers for adoption.*
8. *Topics for next meeting.* The focus should be on conducting a community caregiving needs assessment, such as the *Rosalynn Carter Institute Community Caregiving Capacity Index* (RCI-CCCI). To prepare for this meeting, ask CARE-NET members to think about the needs of caregivers in their community, how to document those needs, such as by using the RCI-CCCI, and possible ways to address identified needs, such as using the *RCI Action Planning Guide*. Community leaders who wish to use the RCI-CCCI should contact the RCI at (229) 928-1234 or [info@rci.gsw.edu](mailto:info@rci.gsw.edu) for further information.
9. *Next steps.* The leader should set a time to meet with the new officers to discuss future activities and prepare the agenda for the next meeting. Before adjourning, set the date, time, and place for the next meeting.

The local CARE-NET has been organized and is now prepared to embark on an assessment of local caregiving needs and activities that will help meet those needs. This is an appropriate time for the leader to assess the progress so far.



## STEP 8: STOPS ALONG THE WAY

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*“You do not ask yourself, what am I doing? You know. What you do ask yourself, what have I done?”*

Elizabeth Bowen, *The House in Paris*

### EVALUATING PROGRESS AND MAKING CORRECTIONS

While there is a time to ask yourself “What am I doing?” there is also a time to ask yourself, “What have I done?” At this point in the CARE-NET development process, you should take some time to reflect on the journey past. To help with this, consider some or all of the following questions:

- ★ Have I kept my goals in view?
- ★ Have I followed my strategies in reaching my goals?
- ★ Have my strategies resulted in the establishment of a viable caregiving coalition in my community?
- ★ Do I have the best professional and family caregivers of the community as partners in the CARE-NET? If not, how should I go about finding and involving these leaders in the coalition?
- ★ Do I sense enthusiastic support for improving the condition of caregivers in the community by means of a CARE-NET?
- ★ Do I sense an understanding of the purpose of a CARE-NET by the questions asked by its members? Have I answered their questions with clarity so they do have this understanding?
- ★ Is the direction for future action clear?
- ★ Are there some things I can do better to ensure that CARE-NET will not only survive, but also thrive?
- ★ Have I given CARE-NET members enough information in the materials distributed to keep them properly informed?
- ★ Am I where I want to be at this point in the journey?

Answers to these questions should point the way to the journey ahead. To quote one leader of a CARE-NET program, “I had the CARE-NET established with a beginning structure, but on reflection, I arrived at the conclusion that I did not have enough of the

top leaders of the caregiving community as members. I knew that we needed at least a few more of them to give the coalition the necessary input and influence it should have. So I decided to get a few more recommendations from the CARE-NET members regarding which leaders should be invited. I made personal visits to each of them, explaining CARE-NET and its purpose and benefits to our community. Three of the five I visited agreed to become members.” This leader took the time to reflect on the CARE-NETs needs, and then moved to get the results he wanted.

Answering the above questions during this time of reflection and evaluation will help you continue what is working and make the necessary adjustments in those areas that still need attention. For example, upon reflection, another leader felt that enthusiasm for the project seemed to wane after a second meeting of the new CARE-NET. The first meeting went well and enthusiastic support for the project was evident. In the second meeting, however, attendance was low and discussion lagged. So the leader made a personal call to a few of the members asking for their feedback on the last meeting. They concluded that the discussion during the meeting dealt primarily with the logistics of setting up a CARE-NET, but that specifics about possible activities were lacking. “We’re busy people, and we want to know about some of the activities that we are being asked to participate in,” said one member. “We can get enthusiastic about those kinds of things that will help caregivers in our community. We will give the time for that.” So at the third meeting the leader started the meeting with a discussion about holding a community-wide educational program on caregiving, to be followed by a community caregiving needs assessment. Members participated in this meeting with much more enthusiasm.

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*Answering the above questions during this time of reflection and evaluation will help you continue what is working and make the necessary adjustments in those areas that still need attention.*

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Another leader, after reflecting, concluded that some members lost focus between meetings. He decided to put out a periodic one-page letter reminding members about the issues they should be thinking about for discussion during the next meeting.

Most CARE-NETs will encounter some problems in the process of getting them off the ground. But taking the time to pause and assess the process will help you make the adjustments necessary to keep the process moving along towards its goals.

## STEP 9: ON THE ROAD AGAIN

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*“It is not the going out of port, but the coming in that determines the success of a voyage.”*

Henry Ward Beecher, *Proverbs from Plymouth Pulpit*

### MAKING PROGRESS

**A** planned journey is successful if you arrive at your desired destination. The same applies to the journey of bringing a CARE-NET to fruition. This “journey” should now be well underway. By making the necessary adjustments after careful assessment, you’re now ready to move your community CARE-NET onto the next step: achieving its goals. That begins with the next meeting.

Before the entire membership gathers for this fifth meeting in establishing a CARE-NET, the second of the full members, meet with the new officers to prepare. This upcoming meeting will focus on three things: beginning activities of the CARE-NET, preparations for a local community caregiving needs assessment, and naming an executive committee, which will work with the officers to prepare CARE-NET meeting agendas and provide needed information for distribution to the membership. Be sure they brief the officers on the following:

- ★ *Planning CARE-NET activities.* Be prepared to offer suggestions about possible activities for the coalition. For instance, one new CARE-NET decided to sponsor a workshop on the RCI program *Caring for You, Caring for Me: Education and Support for Professional and Family Caregivers*, 2nd Edition. Others may want to conduct community forums on caregiver needs, inviting caregivers to express their issues and needs. Still others within the membership may know of programs or funding sources readily available for other programs. Whichever you choose, make sure you and the new officers are specific about the proposed project, providing details as well as a broad explanation to the full membership.
- ★ *Planning for the needs assessment.* A valid and reliable community caregiving needs assessment is a must. The needs assessment is designed to enlighten a community about how it measures up on specific standards that define a community as “caregiving friendly.” It, along with the active CARE-NET, will play a vital role in your ability to access funding to support activities that improve capacity. When the RCI worked with

the Georgia AAAs to expand the CARE-NET model, it also developed a new metric called *RCI Community Caregiving Capacity Index* (RCI-CCCI) to assess community caregiving needs. If you wish to use this instrument in your community, please contact the RCI at [info@rci.gsw.edu](mailto:info@rci.gsw.edu).

- ★ *Naming an executive committee.* You and the officers should discuss establishing an executive committee of not more than eight CARE-NET members to prepare meeting agendas and to gather pertinent information for distribution. Come up with a list of names of people of the membership you think would make good executive committee members. You'll want to put these names before the entire membership for approval. Conversely, during the next membership meeting you might want to ask for volunteers for the executive committee.

Once the details of the agenda items are set for the next CARE-NET meeting, send a formal letter or e-note to members with the time and place of the meeting and agenda. Ask members to spend some time thinking about these items in preparation for decision-making. And don't forget to invite additional coalition members to the meeting with a formal letter of invitation or e-note as well as the agenda.

### **The Second Full Membership CARE-NET Meeting**

Prepare an agenda for this fifth meeting to establish a CARE-NET, the second meeting of the full CARE-NET leadership committee.

You already have the agenda prepared for this meeting:

- ★ Welcome and introductions
- ★ Planning activities of the CARE-NET
- ★ Preparing and conducting a caregiver needs assessment
- ★ Executive committee membership
- ★ Next steps
- ★ Time and place for next meeting

Whoever chairs this meeting, whether you as the leader or another officer, should welcome the attendees. Ask each member to introduce themselves and describe their caregiving role. Pay special attention to the new members present.

**New project.** The chair should then provide members with appropriate materials for any proposed projects that were discussed during the preliminary meeting between the leader and officers. Allow the membership to talk about the potential projects, as well as

suggest other projects for consideration. Settle on one program the CARE-NET will undertake. Ask for volunteers to serve on a CARE-NET task force, to meet and work out the program's details. Request that the task force members remain after the meeting (or plan another time to meet very soon) to begin work on the program.

**Needs assessment.** The chair should then provide members with the appropriate materials for discussing a needs assessment of community caregiving capacity. Explain the various instruments available, ask if members are ready to decide which one they want to use, then, after time for discussion, call for a vote to proceed. If the vote is to proceed, suggest the executive committee (to be named later in the meeting) meet to discuss the implementation process for presentation at the next meeting. If the members ask for more time to consider the needs assessment item, schedule it as an item for further discussion during the next meeting. One option for a community caregiving needs assessment is the *RCI Community Caregiving Capacity Index (RCI-CCCI)*.

**Executive committee.** Explain the purpose of the executive committee and submit the names of members recommended for the committee or ask for volunteers.

**Next steps.** The chair should then review the next steps to be taken. They include:

- ★ the project task force will meet and come prepared at the next meeting to suggest an implementation plan for the membership's approval; and
- ★ the executive committee will meet to begin planning for a needs assessment and come prepared at the next meeting to suggest the process for membership approval.
- ★ Set the time and place for the next meeting.

At this point, you, as leader, have brought the CARE-NET well along the road to accomplishing its aims. Your next steps are clearly defined: implementing the first program and needs assessment. Once the first project has been completed, the coalition will have experienced a sense of working together to improve the lives of caregivers in the community. Once the community caregiving capacity needs assessment has been completed, the CARE-NET can begin focusing on the most pressing needs of the caregiving community and searching for the ways and means to meet some of those needs.



## STEP 10: IF I HAD TO TAKE THIS TRIP AGAIN

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*“The use of traveling is to regulate imagination by reality, and instead of thinking how things may be, to see them as they are.”*

Samuel Johnson, *Anecdotes of Samuel Johnson*

### EVALUATING AND PREPARING FOR THE FUTURE

**T**he leader who has established a working CARE-NET, and who has shepherded it through the journey to reach its destination, must now stop and evaluate the road taken. Consider the reality of the process and see the process as it has been. This requires reviewing the many steps taken, evaluating them, and, during that process, cataloging what worked, what didn't, and what should and could have been done differently.

This is particularly important for the CARE-NET leader who turns the organization over to others for future endeavors. You need to advise the new leadership about which paths should be avoided and which are safe to travel down.

The old adage is true—life is not a destination, but a journey. A CARE-NET needs to develop and continue to work on the task of helping a community become increasingly caregiving friendly.

As you continue down this road with your own community CARE-NET, leaders from other communities may request your assistance in establishing a CARE-NET in their areas. As a CARE-NET leader, you will be in the position to work with them to establish a another, new CARE-NET. With the experience of starting a CARE-NET and seeing it through to its goals behind you, you have immeasurable experience to offer other communities in starting their own CARE-NETs. That's why periodic and on-going evaluation is so important. Knowing what works and what doesn't is wisdom born of experience, an ability to dare to see things as they are, and by working to improve them, build a system that enhances the quality of life for both professional and family caregivers in your community or state.



## DOCUMENTS TO HELP YOU ALONG THE JOURNEY

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*Information Distributed to Potential CARE-NET Participants at the Start of the RCI CARE-NET Project Grant for the Administration on Aging, 2001-2004*

### ROSALYNN CARTER INSTITUTE FOR CAREGIVING CARE-NET PROJECT

#### Basic Information for Participants

1. Grant from Administration on Aging (AoA) under the National Family Caregivers Support Program
2. Funds awarded to the Rosalynn Carter Institute (RCI) for a field-initiated demonstration to develop and test new approaches to supporting family caregivers
3. The CARE-NET Project has two objectives:
  - a. To establish a network of caregiving communities within and among six of the Area Agencies on Aging following the CARE-NET model now operating in areas 6 and 11.
  - b. To develop a new metric, a Rosalynn Carter Institute for Caregiving Community Caregiving Capacity Index (RCI-CCCI), to help communities assess their caregiving strengths and needs and based on that assessment, to help address needs through an Action Plan.

#### What is a CARE-NET?

A CARE-NET is a collaborative network of representatives of professional and family caregiving agencies, educational institutions, and businesses as well as individuals and other relevant groups. Its purpose is to assist a community to assess and address its caregiving strengths and needs. As such, it works to accomplish the following:

1. Link professional and family caregivers and a supporting community
2. Study community caregiving needs as well as strengths
3. Develop service and educational programs for caregivers
4. Organize community-based forums for public feedback on caregiving issues
5. Develop a resource capacity for information on caregiving
6. Provide a source of support for caregivers
7. Foster relationships among community leaders
8. Educate the community about caregiving

#### Benefits to the Community for Participating in the Project

1. Offers a research tool and action-planning format for addressing caregiving needs.
2. Establishes a local community entity by means of collaboration on and assessment of caregiving strengths and needs as a ready-made mechanism for accessing funding and grant sources.
3. Brings together community leaders from diverse agencies, groups, and individuals as a forum for discussion and action on caregiving needs and priorities to the benefit of caregiving agencies, the business and educational communities, and individuals.
4. Enhances relationships among community leaders within the broad range of caregiving that will be a real benefit for the development of specific programs and funding requiring collaboration and community support.

## *A History of CARE-NET*

In 1990, the Rosalynn Carter Institute developed a process to assist communities to build caregiving capacities. These collaborative groups of local leaders working to provide high quality care in their communities were named Caregiver Networks or CARE-NETs.

The first CARE-NET was established in Georgia. The West Central Georgia CARE-NET, or CARE-NET I, addresses concerns of professional and family caregivers in a sixteen county region of Georgia. The CARE-NET is implemented through a Leadership Council composed of distinguished professional and family caregivers from various agencies and organizations in the region. Thirty-five organizations are represented in CARE-NET I. It began with four primary objectives:

1. to link formal and informal caregivers (now called professional and family caregivers) in the West Central Region of Georgia for collaborative endeavors
2. to oversee research conducted by the RCI
3. to develop service and educational programs to meet the needs of caregivers
4. to provide recognition and support for caregivers

In 1997, CARE-NET II, the South Georgia CARE-NET was created to serve an additional 18 counties. It is a joint project of the RCI and the Division of Social Work at Valdosta State University.

In 2001-2004, the RCI, under a grant from the Administration on Aging, partnered with six of the Georgia Area Agencies on Aging, strategically chosen to cover the state geographically, to form six more CARE-NETs. These are now operating in the areas known as Southwest Georgia CARE-NET, Atlanta CARE-NET, Southern Crescent CARE-NET, Georgia Mountains CARE-NET, Heart of Georgia CARE-NET, Altamaha CARE-NET, and Coastal Georgia CARE-NET, bringing 73 more counties into the CARE-NET process. In 2004, the four remaining areas within Georgia established CARE-NETS, making Georgia the first state to have a state-wide network of locally-lead caregiving coalitions.

For additional information, please contact:

Rosalynn Carter Institute for Caregiving  
800 Wheatley Street  
Americus, GA 31709  
(229) 928-1234  
info@rci.gsw.edu

*Commitment Form for Organizational Participation in CARE-NET*

**ROSALYNN CARTER INSTITUTE FOR CAREGIVING**

**Organizational Participation in the CARE-NET Program**

If you are interested in your organization partnering with the Rosalynn Carter Institute for Caregiving in the CARE-NET program, please indicate by replying to the following questions. Your reply does not involve a final commitment on the part of your agency at this time. You may reply on this single page form.

- A. Will your (Name of Organization) be able to commit a staff member as liaison to the RCI representative for a maximum of 16 hours a month during the length of the program?  
 Yes  No
- B. Will the (Name of Organization) liaison work with the RCI representative on the following:  
 Help to arrange an initial meeting at your office for a discussion of the program the most efficient and effective way to enlist support of local community leaders  
 Help to arrange an initial meeting with community leaders to discuss the project, answer questions and enlist their support  
 Help to arrange a meeting for a formal organization of a local CARE-NET  
 Help in setting up additional meetings of CARE-NET  
 Help the RCI administering the *RCI Community Caregiving Capacity Index (RCI-CCCI)*
- C. Would your experience of working with a broad range of community leaders and organizations facilitate the building of a coalition on caregiving?  
 Yes  No
- D. Will you commit to being a part of a local CARE-NET to assure its future?  
 Yes  No

*Please respond by (date) to (sponsor name, address) If you have questions, do not hesitate to contact us by e-mail at (e-mail address), or by phone at (phone number). Thank you for your response. You may also visit the RCI at [www.RosalynnCarter.org](http://www.RosalynnCarter.org).*

*Organizational Structure to Identify Potential CARE-NET Participants*

**Identifying Names of CARE-NET Participants**

	Human Services	Heath Care	Education	Business	Mental Health	Legal	Government	Faith
County*								
County								
County								
County								
County								
County								
County								
County								
County								

\*Cell names may be changed based on the CARE-NET boundaries and goals. For example, “city” or “organization” may be substituted for “county.”

*Letter of Invitation to Potential CARE-NET Participants*

Date

Name

Title

Agency

Address

City, State Zip Code

Dear (Name):

The Rosalynn Carter Institute for Caregiving (RCI) and the (Name of Group) invite you to join in the formation of a coalition on caregiving. Recognized leaders in caregiving both professional (working in a caregiving profession) and family (caring for a family or community member) in the number of counties known as (name of region) will convene to discuss the establishment of a CARE-NET. A brochure that describes the caregivers network, or CARE-NET, is enclosed for your review.

This introductory meeting will be held on (day, date, time) at the (location at town) (directions). Refreshments will be served, courtesy (name of agency). It is our sincere hope that you will be able to participate in this community-wide coalition of caregivers.

Please contact (name of leader) at the (name of agency ) at (phone number) or (e-mail) address by (date) to confirm your attendance. (Name of leader)'s business card, along with information on the CARE-NET program, is enclosed. If I can be of further assistance, please let me know.

On behalf of the Rosalynn Carter Institute for Caregiving and (name of lead agency), I welcome your involvement to improve services for caregivers and look forward to meeting you on date.

Sincerely,

Name

Title

Enclosures

## *Sample Agenda for Intitial CARE-NET Meeting*

On Letterhead of the Lead Agency

Name of the Lead Agency

### **CARE-NET Program Meeting**

Day, Date, Time

Location

Town, State

Welcome and Introductions	Name Title
Explanation of the CARE-NET	Name Title
Benefits of CARE-NET to the Community	Name Title
Questions and Answers on the CARE-NET	Name Title
Suggestions of Participants to Enlarge the CARE-NET	Open
Organization of a CARE-NET	Name Title
Schedule Date, Time, and Location of Next Meeting	Name Title
Closing	Name Title

### *The Role of a Steering Committee in the CARE-NET Process*

1. The committee is composed of a core group of community professional and family caregiver leaders brought together to form a local CARE-NET.
2. The committee members are the first community leaders to be acquainted with the scope, purpose, and value to a community of a CARE-NET.
3. The committee members are to be given ample time to ask questions about the CARE-NET process and its importance to the caregiving population of a community.
4. The committee should be the first group to come to a consensus that a local CARE-NET should be established in the community.
5. The committee should suggest the names of other local community leaders to be invited to become members of a caregiving coalition, and help in the initial approach to the invitation to these leaders.
6. The committee should take the lead in the formal establishment of a local CARE-NET, at which time the committee will have done its initial work.

*Example of CARE-NET By-Laws for original CARE-NET established by the  
Rosalynn Carter Institute for Caregiving*

**CARE-NET BY-LAWS**

Proposed for Adoption by Leadership Council

(Date)

**ARTICLE I**

**Name of Organization**

The official title of the organization shall be “The (Name of Group) Caregivers’ Network of the Rosalynn Carter Institute for Caregiving.” The acronym to be used will be “CARE-NET of (Name of Sponsor).”

**ARTICLE II**

**Philosophy and Purposes**

- 2.1 **Philosophy.** The CARE-NET is designed to promote greater integration of services provided by public and private human service agencies, consumer groups, and educational organizations. By focusing on a region with long standing social, political, and economic ties, resources can be mobilized and used productively to benefit citizens of (name of region served). The specific intent is to assist professionals, family members, and friends engaged in caregiving activities for persons with physical or mental illnesses or disabilities across the lifespan through a linkage between a broad-based network and the Rosalynn Carter Institute for Caregiving (RCI).
- 2.2 **Purposes.** The purposes of the (name of CARE-NET) are to:
- a. Link family members and friends engaged in caregiving activities with professionals from diverse disciplines, human service agencies, and academic institutions in order to form partnerships so that helping becomes a shared responsibility.
  - b. Identify needs of persons engaged in caregiving activities and develop appropriate service and educational programs to address those needs.
  - c. Provide recognition and support to persons engaged in caregiving activities.
  - d. Develop a capacity for dissemination of information about caregiving resources within the region.
  - e. Provide a vehicle for conducting demonstration projects which contribute to implementing the mission of the RCI.
  - f. Advocate for improved and better integrated services in the region.

## ARTICLE III

### Geographic Area Served

The CARE-NET serves people in a (number)-county (list counties) region in (location).

## ARTICLE IV

### Leadership Council

- 4.1 **Number.** Membership of the CARE-NET Leadership Council shall not exceed 40 persons.
- 4.2 **Membership.** All members of the Leadership Council shall either work or reside in the (location). There shall be three categories of membership on the Leadership Council: Organizational Representatives, RCI Representatives, and At-Large Members.
- a. **Organizational Representatives.** The director (or his/her designee) of the following organizations in the (name of region) shall be members of the Leadership Council:
- West Central Georgia Area Agency on Aging (AAA)
  - West Central Georgia District Public Health Office
  - West Central Georgia Regional MHMRSA Board
  - West Central Georgia Regional Hospital
  - DFCS District Office
  - Easter Seals of West Georgia
  - Middle Flint Council on Aging
  - Direct Service Corporation
  - Middle Flint Behavioral HealthCare
  - New Horizons Community Service Board
  - Columbus Regional Healthcare System
  - Sumter Regional Hospital
  - Crisp Regional Hospital
  - Magnolia Manor
  - The Pastoral Institute
  - The Bradley Center of St. Francis
  - Habitat for Humanity International
  - Columbus State University
  - Three Rivers AHEC
- b. **RCI Representatives.** Rosalynn Carter, the executive director of the RCI, and the deputy director of the RCI shall be members of the Leadership Council.
- c. **At-Large Members.** At-large members may be persons caring for a family member or friend, front-line professional care providers, clergy, representatives of business or industry, college or university students, or community leaders with a demonstrated interest in caregiving. Every effort will be made to maintain diversity in terms of gender, ethnicity, county of work or residence, and the specific illness or disability for which care is provided.

- 4.3 **Selection for Membership.** At-large members will be selected by the Executive Committee of the Leadership Council. Recommendations for at-large membership may originate from any source and will be forwarded, with justification for selection, to the Executive Committee for consideration.
- 4.4 **Terms.** At-large members will serve a term of three years, beginning on January 1 of the first year and ending on December 31 of the third year. Upon recommendation of the Executive Committee, at-large members may serve two additional terms on the Leadership Council. Additional terms of service must be approved by the entire Leadership Council after recommendation by the Executive Committee on a case-by-case basis. No limits shall be placed on the length of service of ex-officio members.
- 4.5 **Removal.** Any member of the Leadership Council may be removed from office, for cause, at any meeting of the Leadership Council by affirmative vote of two-thirds of the membership then in office. Members who are absent from three consecutive quarterly meetings of the Leadership Council will be contacted and considered for removal from membership by the Executive Committee.
- 4.6 **Chairperson.** The (fill in title) or (her/his designee) will serve as Chairperson of the CARE-NET Leadership Council.

## ARTICLE V

### Executive Committee

- 5.1 **Number.** A minimum of five and a maximum of 10 persons shall comprise the Executive Committee of the Leadership Council.
- 5.2 **Eligibility.** Only members of the CARE-NET Leadership Council are eligible for membership on the Executive Committee.
- 5.3 **Selection.** The Chairperson of the Leadership Council shall select candidates for membership on the Executive Committee for approval by the Leadership Council. Recommendations will be solicited from the Executive Committee.
- 5.4 **Chairperson.** The Chairperson of the CARE-NET Leadership Council shall also serve as Chairperson of the Executive Committee.
- 5.5 **Terms.** Members of the Executive Committee shall serve two-year terms, with no limits on length of service. All terms will be renewed at the beginning of odd-numbered years 2005, 2007, etc.

## ARTICLE VI

### Meetings

- 6.1 **Quorum.** A quorum shall consist of those present after having been duly notified that a meeting is taking place.

6.2 **Convening.** The Leadership Council will meet quarterly, at a date and time set by the Chairperson in consultation with the Leadership Council. Additional meetings may be called at the discretion of the Chairperson.

**ARTICLE VII.**

**Amendments**

- 7.1 **Proposals.** Any Leadership Council member may propose amendments to the by-laws. All proposed amendments shall be submitted to the Executive Committee for study and recommendation.
- 7.2 **Notification and Voting.** These by-laws may be changed or amended at any meeting of the Leadership Council by a two-thirds vote of those present, provided, however, that written notice of the substance of the proposed amendment shall be mailed to all Council members at least ten days before the meeting at which such amendment is to be considered.

**ARTICLE VIII.**

**Adoption**

These By-laws shall become effective when adopted by the members of the CARE-NET Leadership Council present and voting at a regular meeting.

(0/00/0000)

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## THE ROSALYNN CARTER INSTITUTE FOR CAREGIVING

Through research, education, and training, the RCI:

- ★ Promotes the mental health and well-being of individuals, families, and professional caregivers
- ★ Delineates effective caregiving practices
- ★ Builds public awareness of caregiving needs
- ★ Advances public and social policies that enhance caring communities

These goals are met by forming partnerships with professionals, groups, businesses, universities, and individuals to deliver education and training programs, research and program evaluation, and advocacy to promote individual development and increase community caregiving capacity.



ROSALYNN CARTER INSTITUTE FOR CAREGIVING  
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