

JUNIOR LEAGUE CAREGIVER PROJECT

HANDBOOK OF COMMUNITY ACTIVITIES TO SUPPORT THE CAREGIVER

I. INTRODUCTION

Jennifer Moore is a 45-year-old mother of three who is providing daily help for her 75-year-old mother who has Parkinson's disease. Like many other caregivers for the elderly, she also has a full-time job. Each morning she prepares breakfast for her family, helps her children get ready for school, discusses the day's schedule with her husband and leaves to go to her mother's house. For the next 45 minutes she helps her mother get up and dressed, fixes her breakfast and visits with her. Only after all of the needs of her children and mother are taken care of, can Jennifer go on to work. After work it begins again: a quick visit to make sure there is dinner available for her mother, a stop at the grocery store for her family's evening meal, cooking and, finally, spending some time with her husband and children. The weekends are filled with taking care of the routine chores that are necessary for her household as well as her mother. And, during work, she often makes phone calls to make sure that her mother's home health aide has arrived and that medical appointments are scheduled. Jennifer's schedule is tightly organized and one small snag can spell disaster for the day. Even with the help of a supportive husband, Jennifer feels tired most of the time and at times overwhelmed by her responsibilities. She frequently must miss school events important to her children to stay with her mother and hasn't had a day to herself for several months.

As the aging population increases, more American families will find themselves in situations similar to Jennifer's. Today it is estimated that 22 million households are involved in providing care for an older relative (NAC, 1997). Families are the first line of defense for everyone with health and long term care needs. In fact, about 80% of all the long term care services needed by the older population are provided by families or friends. And providing this assistance to an older person has far-reaching consequences for families, their work, their leisure time and their finances.

Today there are 35 million older adults in America. As the older population increases with the aging of the Baby Boom generation, this number will double. Most older adults are healthy and independent, needing only occasional help when an illness strikes. However, after the age of 85, the risk of needing long term care services increases dramatically. And, the fastest growing population group today are those over the age of 85.

Family caregivers provide benefits to society as well as their older relatives. It is estimated that the value of this activity to society is \$200 billion a year (Arno, Levine, Memmott, 1999). It is important that society recognizes the contributions of family caregivers and supports and encourages their continued engagement in caregiving.

The Association of Junior League International Inc. (AJLI) has identified family caregiving as a priority area. This focus will encourage local Leagues to design and implement supportive programs for their neighbors who are providing care for an elder. In this initiative, Junior Leagues can make significant contributions not only to the families involved in caregiving, but also to the nation as well through the power of association.

OVERVIEW OF HANDBOOK

This Handbook has been compiled to provide a blueprint to local Leagues in their efforts on behalf of caregivers in their community. The Handbook is organized in a way that allows each local League to make informed decisions about their approach, to lay the groundwork for successful projects and to implement programs that will make a contribution to their neighbors and friends.

In Section II an overview of Caregiving in America is provided that will enable the reader to gain an understanding of the range of activities families are involved in on behalf of their older relatives. This section contains information on trends affecting American families, caregiving situations and activities, the needs of caregivers and where caregivers go for help.

Section III provides basic information about getting started in a community activity. Regardless of the approach selected, local League members can locate information in this section that helps them lay the groundwork for their project. The section discusses designing and conducting a community assessment, an assessment of caregiver needs, identifying and recruiting community partners for the project, and ways in which the initiative can be marketed effectively to community caregivers.

Section IV contains seven distinct activities that a local League can select and implement. Each activity section contains step-by-step instructions for the design and implementation of the activity. Activities covered include:

- Developing a Community Resource Guide for Caregivers
- Setting up a Resource Library for Caregivers
- Developing a Training Course for Caregivers
- Planning and Implementing a Caregiver Fair
- Designing and Conducting a Community Forum on Caregiving
- Planning and Implementing Community Education
- Providing caregiver-specific content on your website

Deciding Upon Your Approach to Caregivers in the Community

As you deliberate about your own unique contribution to the caregivers in your community, it is important to consider a number of factors. Your contribution will be important to community caregivers if it is

planned to respond to needs in your community and if it brings to your community some of the special resources in your League membership. Some of the key factors you should consider when deciding upon a course of action include:

1. What special talents and/or abilities are found in your membership?
2. What types of activities has your League been involved in the past and what lessons have you learned as a result of these activities?
3. Given your League's structure, the types of long-term and short-term projects your League has effectively implemented, your League's record in working with community partners, is it better to develop a one-time activity or can the League sustain a project over time?
4. Which community agencies have you worked with in the past and which agencies or organizations do you desire to work with in the future?
5. Do you have any caregivers among your membership and how will they be used in your planning efforts?
6. How will this fit with the League's focus area for service?
7. How will any project addressing caregivers' needs fit into the placement process? Will members receive credit for participating in any and all aspects of the project, including development, piloting, attending meetings/workshops?

Your efforts will be appreciated and well-received if you are providing something unique to the community, if your response is based upon the needs of caregivers and if your response brings a new resource to the community that was not there for caregivers.

Your League will also benefit from your efforts through increased visibility and good will in the community. An important component of this win-win equation is working collaboratively with other organizations and agencies in the community. There is likely a group of agencies and informal support networks that have developed a response to caregivers in the community. Your efforts will be successful if you collaborate with this group either directly or indirectly. You may want to form partnerships with one or more organizations to either work with you on your program or help you publicize the program. At the least, it is critical that you meet with representatives of these organizations to let them know of your plans, ask for their advice and, if appropriate, their support and cooperation.

II. CAREGIVING IN AMERICA

Trends in Family Caregiving

Families have always provided help when it is needed. Older family members have always relied upon their adult children or other younger family members to help with chores and activities they can no longer manage due to episodic illness or chronic disease. In today's complex and fast-paced society this support continues regardless of competing demands of work or geographic distance. In fact, although most elders live on their own, the majority of the help they need continues to be provided by family members and not formal services. Only about 4% of the elderly reside in nursing homes today. The

remainder live in the community, primarily in their own homes. And, although most older Americans are relatively healthy and independent, when illness occurs or a chronic condition limits activity levels, family members are the most likely to step in to take care of everyday needs.

As mentioned earlier, about 1 out of every 4 households is involved in providing some help to an older adult. As the older population increases, this involvement is also likely to increase. There are several trends affecting the family and their ability to provide care and support to elders in the future. These include:

- Increasing numbers of “old-old” – over the age of 85 years.
- A decrease in family size due to lower birth rates.
- An increase in dual-earner couples.
- Increasing numbers of women in the workforce.
- An increase in the informalization of health care services.

As more women enter the workforce and increasing numbers of household contain two working adults; caregiving for an older adult is complicated by competing demands of work, child-rearing and geographic distance between the elder and adult children. The trend of informalization of health care services as a cost-savings mechanisms further complicate caregiving. Today more health care is provided on an out-patient basis and elders are released from hospital stays with a need for ongoing health care services. Many caregivers report that they do not receive adequate training from health care professionals to manage the care that is needed. And caregivers often feel unsure about their abilities to perform some of the care tasks.

Profile of the Caregiver

There are a wide variety of caregiving situations depending upon the circumstances of the older adult, their health and functional status and the family situation. Studies show that both men and women are involved in caregiving and that many young adults are providing care to either an older parent or grandparent. And some caregiving situations involve friends or neighbors instead of family members.

The “average” caregiver, however, is a woman in her late 40’s or early 50’s. She has children living at home, a husband, and a job. She spends more than 18 hours a week helping an older mother. And, her caregiving responsibilities have consequences for her work. She frequently must miss work, arrive late or leave work early and often must make phone calls to arrange medical appointments and services during work hours. Her caregiving responsibilities have also affected her family life and her personal activities. Increased stress levels as a result of caregiving place her at risk for illness and depression.

Although the average caregiver is a middle aged female, many caregivers are older spouses. Many caregivers – about a third of the caregivers today – are long-distance caregivers. Long-distance caregivers are faced with increased levels of concern and stress regarding the well-being of their older loved one and frequently are called away from work to travel to the home of the care recipient in order to manage situations that arise.

Caregiving Activities

Family caregivers are involved in a wide range of activities to support their older family member. In some cases, the family caregiver provides ongoing assistance with the Activities of Daily Living (ADLs) including help with bathing, toileting, mobility, feeding and dressing. More commonly, family members provide ongoing help with the Instrument Activities of Daily Living (IADLs). These activities include providing transportation, grocery shopping, housework, meal preparation, managing finances, arranging and supervising services, and managing medication.

In the National Alliance for Caregiving Study of caregivers (1997), about half of those surveyed were assisting with one ADL. Almost all (98%) of those surveyed provided at least 1 IADL. Most significantly, however, 12% of those surveyed were providing intense caregiving to an elder that required more than 40 hours of care per week.

Caregiving for an elder is often episodic in nature. After a short period of time of intense caregiving, there may be a stable period during which little assistance is needed. In other situations, caregiving is ongoing and can be intense. For example, when an elder has a degenerative, progressive illness such as Alzheimer's Disease, family caregivers are required to provide ongoing care that becomes increasingly intense as the elder's condition worsens. The average duration of caregiving is 4.5 years.

Some caregivers are providing help for more than one elder. The NAC survey found that almost ¼ of the respondents were caring for two elders and 8% were caring for three older family members.

Even when an older adult is assisted by formal services such as a professional home health care provider, family members continue to help. And, even if an elder enters a nursing home, family members continue to provide ongoing support and help. Almost ¾ of the NAC respondents reported that their elder was using one or more formal service. The most common service was special transportation and home health nursing. And, although there are many services in the community for older adults, some elders prefer to receive help from their family.

In addition, to providing whatever help an elder needs, family members are often involved in providing financial assistance. More than half of the NAC respondents provided financial help as well as instrumental help to their older family members. For those who did provide financial assistance, the average monthly amount was nearly \$200. This number likely underestimates the actual expenses of the caregiver since many reported that they did not keep records of these expenses.

Caregivers who work outside the home in either paid or volunteer capacity, their responsibilities often directly affect this aspect of their lives as well. The consequences of caregiving on work include:

- Missed days of work
- Late arrivals or early departures from work
- Phone calls to arrange services and check on the elder during work hours
- Reduced productivity
- Refusing promotions or relocation
- Taking leaves of absences
- Leaving the workplace

What Caregivers Need

Family caregivers report that their number one need is information about the condition affecting their older family member and available services. An important need of family caregivers who are managing the care of an elder is help with managing the insurance and financial paperwork. And, family caregivers who are involved in providing high levels of support to an elder need respite care so they can have some time for themselves.

The needs of family caregivers vary based upon the condition of the elder and the specific caregiving situation. Some caregivers need support for their efforts on behalf of their older family member; others need specific help with the tasks in which they are involved. All caregivers need recognition from others about the importance of their work.

Where Caregivers Go For Help

Most family caregivers do not view themselves as a “caregiver”. Rather, they report that what they are doing is being a “good daughter” or a “good son”. Because they do not identify with a group called “caregivers” they are likely to overlook public announcements for services for caregivers and therefore the services that are being offered to them.

For caregivers who are helping an elder with a specific disease, they often gain access to needed services through a disease-specific organization. For example, caregivers to elders with Alzheimer's Disease receive important support and linkages to services from the Alzheimer's Association.

Some working caregivers get information at work. Recognizing the difficulties employed caregivers often face as they try to balance their work and their family responsibilities, some employers have begun workplace eldercare programs to assist working caregivers. These programs provide information and help them find needed services; flextime arrangements to better manage their caregiving responsibilities, and support groups. Some employers help pay the costs of community services and other employers provide access to a geriatric care manager to assist in care planning. Caregivers, however, underutilize even these programs. Only between 1% and 4% of employee use workplace eldercare programs.

Because the family caregiving is widespread and most caregivers do not identify themselves as "caregivers", reaching them is difficult. Many caregivers find out about services from friends who are also involved in providing care. Others get information from community service resources, and still others find out about services to help from the Internet. And, finally, many caregivers find help through faith-based institutions and organizations. Often fellow parishioners provide assistance and some have interfaith volunteer caregiver groups that are available to help a family who is caregiving for an elder.

III. GETTING STARTED

In the Introduction section of this Handbook we discussed the factors that would be important in planning and implementing a successful project in your community. These include:

- Providing a unique contribution that is consistent with the talents and abilities of your membership.
- Ensuring that your project meets the needs of caregivers.
- Working in collaboration with other community organizations.

This section provides information you need to get started with your project and includes the following topics:

- Investigating existing community resources
- Designing and conducting a needs assessment of caregivers
- Identifying and recruiting community partners
- Effective marketing of your program

Community Assessment of Resources

Prior to making final decision on your project, it is important to investigate existing resources in your community. You will need to conduct an “environmental scan” to determine what is available in the community for caregivers, how well these resources are used by caregivers and how your particular initiative fits into this menu of resources. Ideally, your response to caregivers will fill a gap that is not currently met by existing organizations in the community. Determine where this phase of the project fits given your League’s structure and who in your League should lead the project, if this hasn’t been decided yet (e.g., Community VP, Training and Education Director, or a cross-functional team of Community Projects, Training and Future Projects).

Establish an internal strategic communications plan that ensures that every League member is educated about the project, its expected outcomes, and resource allocation (e.g., budget, committee assignments, volunteers). Be sure to include Sustainers in this communications plan. A sub-committee of members can easily manage the environmental scan of resources available to caregivers in the community.

The following steps will get you started on this environmental scan:

1. Call the Area Agency on Aging and request a copy of their community resource guide. If they do not have a printed resource guide, ask them for information about programs specifically designed to meet the needs of caregivers.
2. Call the United Way, local hospitals and any multi-purpose social service agencies in the community to determine if they publish a community resource guide.
3. Study local newspapers, including the weekly shoppers, to identify support groups, informational programs and/or publicized resources for caregivers. Compile a list of these programs.
4. Ask members to provide you with information about any caregiver programs they know about or have used themselves.
5. Ask your members to be alert to announcements in their church bulletins about programs for caregivers.

After your list of resources is compiled you can determine not only the scope of Services available in the community, but a list of key organizations involved in providing these services as well. At the end of this scan, you will have a list of available resources (resource directories, support groups, informational organizations, etc.) and a list of key organizations.

Your sub-committee can conduct a quick evaluation of the existing resources list to determine if there are any obvious gaps. For example, you might find a comprehensive list of services exists in a community resource guide, but that this guide is designed for an older population in general and not specifically for caregivers. This activity and the meetings with organizational representatives will ensure that your efforts are perceived as useful in the community and will be well-received and supported by both the professional community and the caregivers you are helping.

Needs Assessment of Caregivers

Assessing the needs of caregivers can be a complicated and resource-intensive task. Unless your League includes professionals with experience in assessing needs and conducting community research, this activity will be costly. Some Leagues, however, may elect this as their primary response to caregivers in their community. In that case, they are likely making a major contribution if a needs assessment has not been done in the past. A needs assessment not only establishes the range of needs of caregivers, but can also be helpful by drawing attention to this often overlooked group. A community can be sensitized to family caregiving by publicizing the needs assessment findings and new programs and initiatives may be developed by community organizations as a result of a good needs assessment. Whenever possible, take advantage of the work that has already been done. This may mean your first step in this may be to extrapolate information from community assessments that have already been conducted.

A community needs assessment of caregivers involves both focus groups of caregivers and a survey of caregivers. Focus groups are generally used to assist the researcher to develop a survey questionnaire that accurately reflects knowledge needed to understand fully the needs of caregivers. Often focus groups are conducted after a survey and preliminary analysis of data completed in order to add depth to the findings of the survey.

Focus Groups Focus groups are small groups of individuals who meet the criteria established to define a specific focus area – e.g., caregivers. There are professional focus group leaders and companies that will recruit focus groups members, develop a focus group protocol and discussion guide, lead the discussion and prepare a report. If your League includes a professional with expertise in focus group methodology you could manage this activity yourself.

A focus group of caregivers can be most helpful in raising issues of importance to caregivers, identifying a range of resources and help-seeking behavioral practices and “testing out” an idea you might have for a new program. A good way to begin might be to start with your League’s membership. Both Actives and Sustainers may be ideal candidates for participating in focus groups.

Surveys of Caregivers Surveys of caregivers can be used to identify specific needs of caregivers in your community, preferences regarding help and support, and ways in which the caregivers get information they need to manage their caregiving responsibilities. If you are also interested in the range of caregiving activities, a survey is the best mechanism to discover this. In order for a survey to have meaning and result in findings you can rely upon, there must be a rational sampling design that ensures that, insofar as possible you have controlled for self-selection. For example, just asking newspaper readers to respond to a survey in the newspaper is not a good way to sample. Only those caregivers who read that particular newspaper (on the day the survey is published), and who have time to complete the survey, and who are motivated enough to complete the survey and send it in will be included in your survey. This means that you are likely overlooking a large percentage of caregivers whose needs may be very different from those who responded to your survey. The best way to develop a sample for a survey of caregivers is to randomly screen League and community members based upon a definition of caregivers and to interview those who are included as a result of the screen.

The survey instrument must also be a reliable and valid set of questions that have been carefully worded and ordered so that you are confident of the responses you are receiving. Questions must also be designed according to the type of analysis that is planned for the data. Pretesting the instrument on a selected small sample of participants will help you to determine if you will get consistent responses to the questions (reliability) that are pertinent to the information you are seeking (validity).

If your community has not assessed the needs of its caregivers, you can undertake this activity as your contribution to caregivers in a number of ways. These include sponsoring the caregiver needs assessment through your League, partnering with one or more other organizations in the community to conduct the assessment, or by influencing the local United Way or foundation to sponsor this assessment. Costs can be kept relatively low by partnering with a neighboring university or by using the skills of your League members.

Identifying and Recruiting Community Partners Community partnerships strengthen efforts and are also useful in publicizing your initiative. To develop community partnerships, you will need to develop familiarity with organizations in your community with similar interests in the caregiving community. This can be done through the environmental scan discussed earlier in this document. This can also be done by reviewing previous partnerships your chapter may have had with other organizations or identifying new organizations through linkages in place as a result of your members' community activities.

If this caregiving initiative is your first community-wide effort, you will want to take the time to meet with selected organizations to discuss your plans and invite participation. Even if these meetings do not result

in direct collaborative partnerships, they will engender good will and indirect participation through advice, linkages with professionals in the community and/or support in the publicity you need to have a successful program. Many organizations are willing to include information about your efforts in their newsletters at no cost, provide space for meetings or forums in their facilities, or copies of their mailing lists. Reaching out to your community demonstrates your commitment to sponsor a successful project and your interest in collaboration. Most importantly, this outreach will help you meet your own goals on behalf of your caregiving neighbors.

Effective Marketing of Your Caregiving Initiative Regardless of the type of project you are planning, success will be elusive without effective marketing efforts. Marketing to caregivers is a difficult endeavor since they are a diverse group of individuals and families. Since all types of families are involved in caregiving, it is important to focus your marketing efforts on venues that are community-wide and broad in scope. For example, you should attempt to use the media serving your community and seek to have as broad coverage as possible. Some useful activities include:

1. Asking partner organizations how best to publicize the League's efforts within their own organizations and working with them to reach their constituents (e.g., their newsletter, bulletins, announcements at meetings or during programs, and use of links to their websites);
2. Encouraging the local newspaper and community papers to write an article about your project and plans;
3. Seeking a spot on radio talk shows to discuss your project;
4. Purchase ads in newspapers;
5. Providing the disease-specific organizations serving your community with information about your project so they may include this information in their newsletters or directly refer their clients;
6. Preparing brief descriptions for inclusion in faith-based institutions and organizations bulletins.

A standard press release can be prepared for your event or resource and contain the following information:

- Who you are trying to reach;
- What you are offering;
- Times, dates and location of events;
- Information about costs involved, if any;
- The benefit of the event or resource to its intended audience.

It is also useful to provide some information about the nature of caregiving and its importance to the community. However, press releases are most effective when they are concise and easily read with the important information at the beginning of the release. And, make sure you disseminate information about your efforts to all of the support groups of caregivers you discover when you conduct your environmental scan.

You should also avoid any acronyms or short-cut language when trying to reach caregivers. Remember: many caregivers do not think of themselves as “caregivers”. It is better to address your marketing to those who are “helping an older adult” than to use the term caregiver at the beginning of your printed marketing material.

A. HOW TO DEVELOP A COMMUNITY RESOURCE GUIDE FOR CAREGIVERS

Introduction

Locating community resources can be a time-consuming and daunting task. For caregivers, who have very little time to spare, finding the appropriate resources for themselves or their loved ones can become even more of a chore. This Section will take you through the steps necessary to develop a resource guide for caregivers in your community

Purpose of a Resource Guide

The purpose of this resource guide is to assist you in developing a comprehensive list of resources for caregivers in your community. In this fast-paced, instant information era, the Resource Guide will become exactly what caregivers need to instantly access the services and material they need in a one-stop-shopping format. The detailed, step-by-step format will guide you through the process and enable you to create a resource guide that will become indispensable not only to caregivers but to professionals in the area who work with and/or assist caregivers.

What Makes a Good Resource Guide

A good resource guide will contain up-to-date information as well as targeted and comprehensive information. This means that the material you include must be recent and specific to the audience for which it is developed--the caregivers in your local area. This doesn't mean that the material has to be lengthy and in fact, the more material you can get in to a small space, the better and the more it will be used. No one likes to spend time looking up information in material that was developed to save them time--it simply won't be used.

Needs of Caregivers

According to the National Alliance for Caregiving, the typical caregiver is a woman in her mid-forties who works full-time and is married. Although the demographics may paint the picture of an average American

caregiver, caregivers are a diverse group with many different lifestyles, caregiving situations, and even more important, different needs.

In order to address the needs of caregivers in your community it is of vital importance to understand who those caregivers are and what exactly their needs are. There are a few ways to undertake the process of assessing the needs of caregivers and they include: conducting interviews with caregivers; conducting focus groups with caregivers; caregiver surveys; conducting informational interviews with local agencies who work with caregivers.

Conducting informational interviews, conducting focus groups with caregivers and caregiver surveys will be addressed in the section titled *How to do a Community Assessment of the Needs of Caregivers*.

What Should Your Resource Guide Include?

Your Resource Guide should include the following:

- Local resources--telephone numbers and addresses obtained by making contact with community agencies, organizations and professionals who work with caregivers and their families;
- National resources--these include 800 numbers and information easily accessed and relevant to caregivers regardless of their locale;
- Targeted information--targeted information, as discussed earlier, is information aimed specifically at the caregivers in your community. Information aimed directly at your specific caregiving audience will be easily obtained once you have assessed their needs and spoken directly with other organizations;

Steps to Take to Compile Information

1. Search for existing resource guides from other organizations;
2. Contact local agencies, professionals and caregiving organizations for information;
3. Begin to collect actual hard copy material, if available, from organizations to review;
4. Conduct a website search for additional information (see list of websites above to get started);

Specific Contacts to Make

When contacting individuals or organizations about community resources the most important questions you can ask are:

- What services or programs are available?
- How do individuals access services?
- How do individuals pay for services?

Area Agencies on Aging

The services available through AAA's are funded mainly through the Older Americans Act (OAA) but a variety of sources are used as well. AAA's generally coordinate with other agencies and/or organizations (hospitals, churches, etc.) in an effort to provide a diverse range of services that fit well with the needs of

caregivers and the elderly in their particular community. After having completed the needs assessment for your area you will have a better understanding of what types of services the caregivers in your community will need and want to access.

Services available through area agencies on aging include:

Information and access services; In-home services; Community-based services; Elder rights. The contact information for your local area agency on aging can generally be found in the blue pages of the phone book under "Aging" or "Social Services."

Caregiving Organizations

Caregiving organizations vary in the services and resources they provide and some cater only to consumers or have a grass-roots orientation, whereas others are strictly research-based and provide information to professionals and other organizations. For example, Children of Aging Parents (CAPS) is one of the oldest consumer caregiving organizations in the country and provides information to individual caregivers in the form of publications, newsletters, telephone counseling, and a website.

To begin collecting information in this area a short list of nationally recognized organizations is listed below.

- Caregiverzone
www.caregiverzone.com

- Careguide
www.careguide.com

- Carethere
www.carethere.com

- Family Caregiver Alliance
800-445-8106
www.caregiver.org

- Interfaith Caregivers Alliance
www.interfaithcaregivers.org

- National Alliance for Caregiving
www.caregiving.org

State Department on Aging/Disability

Every state has a department on aging offering information on state and local services. They should be able to provide information on local area agencies on aging--who to contact, what specific services they provide in your local area. The contact information for each state's department on aging can generally be found in the blue pages of the phone book under "Aging" or "Social Services."

Disease-Specific Organizations

Many disease-specific organizations have local chapters where caregivers and their family's members receive support and information. Most organizations offer toll-free helplines, community services such as support groups and social services. Below are just a few contacts to get you started.

- ALS Association
800-782-4747
www.alsa.org

- Alzheimer's Association
www.alz.org
800-272-3900

- American Cancer Society
www.cancer.org
800-227-2345

- American Heart Association
www.americanheart.org
800-242-8721

Professionals Who Serve Caregivers

Professionals who serve caregivers are generally private practitioners and therefore a fee is usually associated with their services. Geriatric Care Managers offer a wide array of assistance from arranging health services to supervising all health-related needs. Geriatric physicians specialize in the medical needs of the elderly and are trained in the area of geriatrics. Consultant Pharmacists provide assistance to caregivers in the form of medication management, particularly those who are providing care to someone with multiple chronic conditions.

- National Association of Professional Geriatric Care Managers
520-881-8008
www.gcm.org

- American Society of Consultant Pharmacists

Other Options in Your Community:

- Local hospice organizations;
- Family service agencies;
- Legal Aid and/or legal assistance organizations;
- Home health programs;
- Counseling programs;
- Local hospitals;
- Faith-based institutions and organizations;
- Libraries;
- Community Centers;
- Local chapters of support organizations such as your local AARP office;

Program initiatives of other service organizations, community centers, and culturally specific organizations that form natural links to the League's programs should be considered as well. Examples may include senior citizens/grandparents programs, Hispanic and African-American Chambers of Commerce, Women Owned Business organizations, Asian-American civic/citizens groups, the Urban League, community development corporations, and Native-American advocacy groups.

Contacting Organizations for Information

When contacting organizations or agencies for information identify yourself and your organization and let them know that you are developing a resource guide for caregivers in your community. This is also a good way to begin to set-up partnerships and alliances. Find out what they have to offer in terms of services or programs to caregivers, how caregivers pay for programs if there is a charge and if their programs are open to the public.

Keep track of the agencies or organizations you contact and who you spoke or who the contact person is. This will allow you to compile the necessary information for your resource guide. Be sure to exchange information when talking to others so that caregivers have access to you as well. Develop a timeline for making contact again to update your material. The AAA's are a good example of this so that you may be kept abreast of the NFCSP information as programs are implemented.

Where to Look for Information

After you have made contact with agencies and organizations in your local community and assessed the needs of your area's caregivers you will need to begin a search for materials and resources to include in

the resource guide. Information in the area of caregiving although plentiful, may be difficult to locate and even more problematic to sort through in terms of quality.

First, we'll address the issue of locating materials. You will want to begin by making contact again with those individuals with whom you initially spoke with when you were researching local caregiving organizations and those agencies who work with caregivers and their families. You can do this a few different ways: send a letter explaining what you are looking for and why--this is a quick way to reach a lot of organizations; make contact by telephone; make contact in person by actually visiting local senior centers, agencies, disease-specific organizations and hospitals (see Specific Contacts to Make and list of Other Options for Your Community).

What you are looking for and why: You are looking for resources for caregivers in your community. You are contacting organizations that work with caregivers and their families in order to include them in the local resource guide. Any other relevant information they have would be helpful as well.

Once you have located possible sources of information you will need to first find out if information you can use is available. When you have identified available resources the next step involves reviewing those resources. When conducting a review, which can address the issues of quality and timeliness, you should consider the following: is the material up-to-date (listings, references, etc.); is it relevant to the needs of our caregivers; is the information available to local residents or at least nationally?

One way to easily address the issue of not only locating information but also assuring the quality of the information is to look to an organization that has already done some of the work for you. The National Alliance for Caregiving (www.caregiving.org) has developed a resource center that is available on their website and would be useful in many areas including as a resource within the guide itself.

One important factor to keep in mind is that once you have located information for the resource guide--it doesn't end there. Identifying resources is a never-ending process. There are new materials and new information is constantly coming to light in the area of caregiving. There is also the issue of updating the material--new phone numbers, addresses and contacts. You will want to keep files on hand and ready to go for your next update if you decide to go that route.

Should You Include Web Listings in Your Resource Guide?

Web-based information can be a valuable resource for any type of material, particularly with the proliferation of caregiving websites. Inclusion of Internet resources must be made with the following in mind: quality of material, timeliness, and ease of use. Quality and standards are issues that are currently being assessed by a very few individuals and there are many sites that would not pass certain criteria if applied. Therefore, because there are no standards in place to assess the quality of caregiving and other related websites we will can only suggest that someone be assigned the duty of searching the sites for applicability to your needs as an organization and as would be relevant to the subject at hand and, in the

end, decisions be made by an advisory board or other control-type board. Another option is to utilize websites such as the one run by the National Alliance for Caregiving (NAC, www.caregiving.org). NAC's website includes a section on websites and ratings which you may find helpful.

Timeliness is an issue easily dealt with. When visiting a Website for possible inclusion in the resource guide pay attention to the dates of articles and other related items. Generally, the information should be no more than 5 years old. When examining legislative or other timely material the five-year rule would not apply (Medicaid or new program information).

Ease-of-use is also dealt with easily. If the site is easy to access, download times are relatively short and navigation is handled effectively and without much thought, we can ascertain that the site meets the criteria for ease-of-use.

The three issues referred to above are by no means the only ones to consider and you may encounter more as you delve into the World of the Internet. Should you decide to add websites to your resource guide be aware also, that updating becomes an issue for the guide itself.

Pros of Web resource inclusion

- Addition of valuable resources;
- Those with access to the Internet may find Guide more useful.

Cons of Web resource inclusion

- Updating becomes an issue for the guide;
- Assignment of website searches;
- Issues of quality, timeliness, and ease-of-use must be considered.

Getting Validation of Your Resource Guide

Before your Resource guide is finalized it is important to obtain feedback about its validity and expected effectiveness. This can be done through a review process and should include professionals who serve caregivers and caregivers themselves. You will need to decide how many reviewers you will have and also develop a guide for them that will tell them what they should be looking for. The number of reviewers will depend upon the number of caregivers in your community as well as the pool of professionals in the area. Three to five of each is probably a good number.

Individuals should be contacted prior to being sent the resource guide for review and a small honorarium is customary, if your budget allows for it. Set a date that they will be sent out and a date for return. The information will need to be reviewed upon return and modifications made accordingly.

Getting Your Resource Guide to Caregivers

Dissemination of your Resource Guide is one of the most important aspects of development and addressing this issue can actually be taken care of early on. By this time you have made many important contacts with local organizations and community agencies. Utilizing these organizations as resources for dissemination will be very effective. They will already have contact with caregivers and their families as well as contact with others who you may not have had contact with earlier in the project.

Networking with other organizations will be your most powerful dissemination tool. There are several ways to utilize the organizations in your network and they include: advertising--free or otherwise--if they have participated in some of the earlier aspects of the projects this can be brought up beforehand. Advertising includes leaving announcements, flyers and samples of the guide at community centers, hospitals, etc; enclosed mailings--some organizations put out a regular mailing to caregivers and their families or to other organizations. It would be useful to find out if it would be possible to include an announcement about the Guide; Announcements--these can be made at seminars, fairs and regular meetings and supports groups.

Another avenue for reaching caregivers will be caregivers themselves. By this point you will have already made contact with some caregivers in your local community through your assessments and evaluations and through contact with the organizations in the area. These caregivers will be interested in the guide and remember, word of mouth is very powerful. . There are many ways to reach caregivers. Utilizing your existing network as well as the network that you have established through your earlier work in the project will prove to be invaluable.

As a reminder, some of the organizations that may be useful in reaching caregivers are:

- Local caregiving organizations;
- Area agencies on aging;
- State units on aging;
- Professionals who work with caregivers;
- Local hospice organizations;
- Family service agencies;
- Legal Aid and/or legal assistance organizations;
- Home health programs;
- Counseling programs;
- Local hospitals;
- Faith-based institutions and organizations;
- Libraries and community centers;
- Local chapters of support organizations such as your local AARP office.

CONCLUSION

At this point you have begun to consider all of the tasks necessary for developing your Resource Guide. You now have the tools to develop a very powerful tool not only for caregivers in your area but also for

professionals who work with caregivers and their families. The foundation is in place in terms of purpose and inclusion--the why and the what--even the how has been laid out in a format that should easily guide you through the development process.

Some key items to remember:

- When contacting organizations or agencies for information be sure to identify yourself and your organization and let them know that you are developing a resource guide for caregivers in your community--these are the organizations that will be an integral part of your network;
- Find out what they have to offer in terms of services or programs to caregivers, how caregivers pay for programs if there is a charge and if their programs are open to the public;
- Keep track of the agencies or organizations you contact and who you spoke or who the contact person is, develop a timeline for making contact again to update your material;
- Be sure to exchange information when talking to others so that caregivers have access to you as well;
- Information should be accessible and up-to-date.

B. TIPS FOR INCORPORATING CAREGIVER CONTENT INTO YOUR EXISTING WEBSITE

Introduction

If you already have a website for your League, the task of adding material for caregivers should be a relatively simple one, particularly with the breadth of knowledge, resources and connections you now have in the area of caregiving. Not all caregivers have access to the Internet but hopefully, for those who don't that will be changing with the resources available to them through a possible Resource Library and through other resources you have made them aware of through the Community Resource Guide.

Adding caregiver material to your website will only complement the material that is already available to them through your site and will draw many more and varied visitors there as well. Some will stumble upon it by accident, as is often the case with the World Wide Web, and some will come strictly to view the caregiver material which will introduce them to your organization at the same time. Additionally, your current members or site visitors may appreciate the added content and word of mouth will add to the number of users of the site and the material thus increasing exposure for your organization.

Researching Existing Caregiver Websites

A good way to better understand how caregiver content is being formatted and utilized is to visit existing caregiver websites and see how they work, what you like and don't like. Eventually you will begin to piece together what will begin to look like a format that will fit your existing website.

Things to consider include: Content--articles, tips, links to other sites, resources; Accessibility--is the information easy to access? Timeliness--how often is material turned around, are current events updated

and is there local information? Format--what do the other sites look like and do you like the look--is it too crowded or confusing? Refer to previous sections for suggested caregiver websites to begin your search.

Addressing the Needs of Caregivers in Your Community

If your website is tailored to address the interests of a national group there are ways to include the local information we have been discussing throughout the previous sections. Your homepage can list sections that will lead visitors interested in caregiving material to either general information such as tips and articles and also to specific geographic information such as current events and local resources. If you have Leagues around the country the information can be tailored towards League-specific needs and information.

What to Include

Information that you will want to include on your website will vary depending on your interests and the needs of caregivers in local areas but basic information and material should include: Caregiver tips about managing stress and basic care, locating and utilizing resources--local and national, and references to your Leagues specific resources.

For ideas about additional material such as articles, reports, booklists or even chat rooms, visit the other sites as was suggested and keep track of what you feel will work best for your organization and what you will be able to handle in terms of resources (staffing, etc.). One very basic way to include caregivers is to simply have a list of your available resources and with that, a list of links to other caregiver sites. A short online survey may be useful as a tool to continue to address the needs of your visitors once you have some basic caregiver material up and running.

Conclusion

Incorporating caregiver content into your existing website can be a relatively simple project and done right, can complement existing material. Not only will be addressing the needs of caregivers on local and national scale and, at the same time you will be increasing exposure for your League.

To get a feel for what's available to caregivers in cyberspace visit other caregiving websites and begin to formulate your own ideas about what will work for your organization and fit with what you now know about caregivers in general. And, as was mentioned earlier, your caregiver content can be basic or may include many components depending upon available resources and what the needs of your specific caregiving population are. The Internet can be a wonderful way to increase awareness of many issues, your own organization and at the same time, assist caregivers.

C. HOW TO SET UP A RESOURCE LIBRARY FOR CAREGIVERS

Introduction

Resource libraries are a valuable tool for caregivers seeking information. A resource library affords caregivers easy access to needed information easily and conveniently. They can also provide a useful resource for the community at large, addressing the needs of not just family members and loved ones but professionals who work with caregivers as well and those who may have an interest in caregiving in general. The level of formality and breadth of resources can vary, but even those resource libraries that are small and informally managed can save caregivers time and effort in their search for information.

Purpose of a Resource Library

The main purpose of a resource library is to have a single contact point where caregivers can easily and efficiently gain access to the information and materials that can help them in their caregiving activities. Another important aspect of any good resource library is the choice for those utilizing the facility to stay and read or watch videos. The atmosphere of the library is important and should be conducive to those wishing to do a bit of research or stay and read up on a subject. This means that there should be, at a minimum, a reading or quiet area.

Tips:

- Visit your local library and notice the areas where people are reading;
- Visit your local coffee shop or bookstore and notice where people seem most comfortable;
- Ask those in your network if they have private areas or resource centers you can view as an example;
- Visit community centers or hospitals to view their waiting areas or libraries;
- Ask a question in your initial needs assessment about what would make caregivers most comfortable in a space such as your library.

Needs of Caregivers

A study by the National Alliance for Caregiving revealed that more than four in 10 (43%) caregivers report that they have less time for family and even more (55%) report that they have less time for leisure activities (NAC, 1997). This is something to keep in mind not only when setting up the Resource Library but throughout the project. Time is a major factor and something that caregivers feel they don't have enough of. It is imperative to find out from caregivers in your community what hours and days of the week the library should be open. You can set up the finest Resource Library in the country and it wouldn't matter if caregivers couldn't find the time during their day (or evening, as the case may be) to get there.

If you have conducted a needs assessment, you should have information about the types of resources that would be most helpful to the caregivers in your community. If you do not conduct a needs assessment, you can identify the types of information most helpful to caregivers by asking members of your chapter that are themselves involved in caregiving. Or you could identify areas of focus for the library by examining available resource material and selecting the material you believe would be most useful to you if you were caregiving. A committee whose responsibility was to identify content for a resource library is a good way to ensure that a broad range of needs are met.

When surveyed, 38% of caregivers didn't know what kind of information would be helpful to them (NAC, 1997). Part of the ongoing struggle in setting up the Resource library will be in attempting to meet those needs that even caregivers themselves aren't aware of until a particular situation arises. One way to address this is to have surveys or user evaluation forms available that address the materials or information needs of those caregivers utilizing the library. The surveys serve another function as well and that is that it shows the caregivers utilizing the library that you care about what they think and that you want to find ways to meet their needs. These surveys can be laid out on countertops in the library and reviewed monthly or on a basis that is convenient for staff or if one has been set up, for the Library Committee. Suggestions for the surveys include:

- How did you find out about the Resource Library?
- Did you find the library helpful in your search for information?
- What other types of information would you like to see included in the library?
- Other ideas about the library?

Other types of information and support that caregivers have reported to be helpful and that the Resource Library can easily address are: central source of information, information about paying for services, information about care recipient's condition (NAC, 1997).

Types of information caregivers are looking for

- A central source of information;
- Finding and using services;
- Paying for services;
- Information about care recipient conditions and diseases;
- Practical skills assistance;
- Information about financial issues--present and future;
- Psychological and spiritual information;
- Taking care of yourself when you are providing care.

What Makes a Good Resource Library

As discussed earlier, a good resource library will have the following elements:

- Seen as a central source of information
- Accessible--days and hours according to needs of caregiving community;
- Soothing atmosphere;
- Reading area;
- Viewing/audio room--videos, audiotapes;
- Surveys readily available to incorporate possible incremental changes in material.

Developing a resource library involves the following steps:

I. Identify a Location for Your Library

Ideally, the library should be located in a convenient location, easily accessible to caregivers in your community. A planning committee might be in order for this project as many of the members now in your network may have access to possible locations for the library such as unused offices or office libraries that are not being utilized. It should be secure to minimize the loss of materials.

Another option might be to contact your local library and discuss a partnership with them. A partnership with a library is not only a great way to access space but to reach a large number of people as well. You can discuss starting a collection of caregiver materials for the local caregivers in the area and maintaining the collection at the library.

II. Identify Materials for Your Library

An individual or committee can review and select materials of most interest and highest quality for inclusion in the library. As mentioned earlier, a resource library should include a small video/monitor assembly to view videos and a computer with bookmarked Web sites. However, it is sufficient to have printed materials and videotapes to take out on loan. The library can also serve as a repository of information about community resources and events of interest to caregivers. Contact local and national caregiving, aging and disease-specific organizations for information on availability and prices of material.

III. Develop a Lending and Updating Plan for Your Library.

Identify appropriate policies about using the material to ensure its availability to a large number of caregivers. Decide whether caregivers can take something home, how long they can borrow materials, the policy for returning materials that may be needed by other caregivers, and what hours the library will be open. Identify a key individual or a committee to be responsible for maintaining the center and identifying new materials.

Where to Look for Material

- Identify and review material available from existing local and national caregiving organizations, hospitals, senior centers (see list in Developing Resource Guide);
- Conduct a web search and request available material;
- Determine which materials are no longer up-to-date
- Identify new resources through contact with existing network and other organizations you contact;
- Contact agencies and organizations with programs you would like to list-- confirm their information and obtain material;

Here's a list to get you started on your search for materials:

- AARP--www.aarp.com
- Alzheimer's Association--www.alz.org
- Administration on Aging--www.aoa.dhhs.gov
- Careguide--www.careguide.com

- National Alliance for Caregiving--www.caregiving.org
- Willogreen--www.willowgreen.com

Publicizing Your Resource Library

Put your existing network system to work and develop a system of memos and signs for them to publicize the library and encourage its use. Let the local Area Agency on Aging, caregiver support groups and any services tailored to meet the needs of caregivers know about your resource library, its location and hours and ask these organizations to help you publicize the library.

Develop a press release about the resource library, who may use it and what it contains. Remember that it is important to have ongoing information available to caregivers and to repeat press releases and public notices. A new caregiver might not have noticed the resource previously and would benefit from knowing about it when they begin their caregiving work.

Another source of publicity for the library can be the local paper, radio stations, and television news stations. Sometimes these venues will allow free or low-cost airtime for local public interest stories. And don't forget to mention the library to those whom you may speak with when making contact with websites, even if they aren't local--sometimes those running the websites will provide localized information or current events for their visitors.

Conclusion

As you may now be well aware, a resource library is a valuable tool for caregivers in any community and, for the community at large. The library serves many functions including addressing the important issue of one-stop-shopping or the central source of information that caregivers often say they are looking for.

Aside from the obvious, the library may well become, for some caregivers, a much-needed short-term respite from their hectic lives. This is where atmosphere and accessibility become an integral part of the planning. As was mentioned earlier, for caregivers to make use of the library it has to be open at times that are convenient for the caregivers themselves--and as varied as caregivers are themselves in their situations, their hours of availability may be just as different.

Finally, atmosphere is a very important aspect of the library. You may have the perfect hours, great materials but an atmosphere that is not inviting or conducive to the needs of the caregivers in your local community. Privacy is an important issue and caregivers should feel that they can come to the library and not only be able to relax for a few minutes, grab a bit of piece and quiet but that they can check things out or view videos without being interrupted or even seen. This is where, as was mentioned earlier, the viewing rooms come in handy and a privacy policy should be implemented for those who wish to check items out.

D. PLANNING AND IMPLEMENTING A CAREGIVER FAIR

Introduction

Caregiver Fairs are an excellent way to showcase the services and resources available to assist caregivers in your community. These fairs are open to the public and an efficient way for attendees to learn about services, organizations and caregiving issues. Fairs can be scheduled specifically for caregivers or combined with community health fairs. At a caregiver fair each presenting organization is given one or two display tables to showcase their printed brochures and information, display videotapes and provide an opportunity for interested attendees to talk about issues with professional staff.

Fairs are relatively easy to organize and generally attract large numbers of attendees and participating organizations. Services in the community find this venue a good way to market their services and appreciate the opportunity to reach large numbers of people on a personal basis as they browse through the exhibits.

Organizing a Caregiver Fair

The key to sponsoring a successful caregiver fair is good organization. This is an activity that is best managed by a committee who are charged with the following activities:

- Selection of an date and place to hold the fair;
- Identification of exhibitors;
- Determining what, if any, special activities would be held in conjunction with the fair;
- Planning a budget for the event;
- Identification of community partners;
- Identifying the target audience;
- Marketing the event to exhibitors;
- Marketing the event to the public.

Each activity is discussed below.

Selecting a Date and Location Review community calendars to ensure that your event does not compete with other events that would be reaching out to a similar audience. Determine if your community is conducting a health fair and if you could join forces with the sponsor(s) of this health fair to coordinate efforts and combine efforts.

Most caregiving fairs are organized for an in-door location to avoid the necessity to plan for alternative bad weather dates. The location should be a large space such as a gymnasium in a public school or community center or a convention center. The location should be easily accessible to community residents and offer space adequate to accommodate all of the organizations you hope to recruit as exhibitors. If you are planning some special events such as entertainment or films, make sure the location is adequate to accommodate these events.

Identifying Exhibitors Compile a list of community organizations that assist caregivers, provide information and support about specific diseases, and that provide services to older adults. You can refer to your community resource assessment if you conducted one or rely upon community information directories. Make sure that your list is comprehensive by reviewing the list with a few professionals in the community. And, make sure that the addresses, phone numbers and/or e-mail addresses of the organizations are current. Enter the information on your list into a database for ease in generating mailing labels, confirming participation and generating a master list of participants for planning purposes and distribution to attendees.

Planning Special Events Special events such as movies, speakers or music add excitement to a caregiving fair. If your community has a senior musical group, acting troupe or dance group, including them in your planning can attract additional attendees and provide an extra zip to the event. For example, a demonstration of tai chi can be educational and contribute to the enjoyment of the attendees. Ask your invited exhibitors if they have special demonstrations they would like to have included in the fair schedule or if they have ideas about any groups that could enhance the fair experience.

Planning the Event Budget Caregiving fairs do not have to be costly. They can also be self-supporting. It is usually possible to secure a location for the fair for no cost. However, there often is a cost associated with exhibit table set-up, advertising, refreshments and marketing. The most common costs include:

- Printing of flyers and posters to publicize the event;
- Reproduction costs for letters to exhibitors and postage for mailing;
- Facility set-up for exhibit tables, electricity and, if necessary, a stage for special events;
- Refreshments for attendees;
- Security (if required by the location);
- Miscellaneous materials for decorating such as tape, balloons, crepe paper, flowers and directional signs.

The cost of the caregiving fair can be defrayed by contributions of community partners and by charging a nominal fee to exhibitors to cover the costs of table space and electrical useage. The caregiving fair should **not** include a fee to attendees.

Identifying Community Partners Caregiving fairs are most successful when it is sponsored by more than one organization. Potential community partners include local hospitals, one or more disease-specific organization or faith-based organizations. These partners should be asked to share the risks associated with the costs of the fair and to contribute “in-kind” services or supplies to the event. “In-kind” services could include assistance with marketing, postage or reproduction services, shared mailing lists, or entertainment or special events.

Identifying the Target Audience Obviously, the key target audience is that group of community residents who are providing care to an elder. However, since this is such a diverse and ubiquitous group of residents, your marketing efforts will be most successful if you identify specific groups within the community to target. These groups could include:

- Faith-based institutions and organizations;
- Large employers;
- Caregiving support groups or organizations;
- Senior residences (e.g., assisted living facilities, nursing homes, and retirement communities);
- Civic organizations.

Marketing the Event to Exhibitors Reaching out to potential exhibitors and gaining their commitment to the event needs to be done before final confirmation of the date and development of community marketing materials. Ideally, this outreach to potential exhibitors would be done by phone to some key organizations to ensure their participation. Once your short list of exhibitors is committed to the event, you can begin to market the event to other exhibitors.

Develop a concise informational letter and mail to your list of potential exhibitors. This letter is most persuasive if you include information about any co-sponsors you have for the event as well as a few of the organizations that have already committed to the fair. The letter should include date, location, times and any costs associated with participation. Include a return form that can be FAXed or mailed back as well as a phone number to call for more information. It is very important to provide a cut-off date for participants in order to encourage timely response.

As responses are returned, you should confirm receipt with those organizations that will be participating. Provide them with a copy of your press release developed about the event and request that they include information about the fair in their newsletters. If you have posters about the event, provide them to the participating organizations to post in their offices.

Marketing the Event to the Public Marketing the event to the public is key to a well-attended caregiving fair. The following marketing tools need to be developed:

- A concise press release with information about location, time, date, event and co-sponsors;
- Posters;
- Flyers;

Identify a list of media outlets that serve your community: newspapers, weekly shoppers, and radio and television stations. Provide each of these media outlets a copy of your press release and follow-up with them personally. In your follow-up ask if they will include the information in their calendar events and if they require additional information. Ask radio and television stations if they would like to interview someone from your League or a caregiver to promote the event.

Distribute posters to partners and exhibitors. Distribute additional posters to libraries, grocery stores, community centers and hospitals. If flyers are developed, ask partners and your League members to distribute these flyers to associates. Distribute both posters and flyers to large employers and request that they display them prominently for their caregiving employees' information.

Conclusion

A caregiver fair can be an important contribution to the well being of the caregivers in your community. It is a good way to help caregivers gain access to services and resources that can help them, and a good venue for caregivers to talk to one another about their activities. It is also an efficient way for your League to help caregivers since it is a one-time event that can be easily managed by volunteer League members. And, finally, planning and implementing a caregiver fair for your community, if marketed correctly, can be a high profile activity that demonstrates the commitment of the Junior League to the needs of their neighbors.

E. COMMUNITY EDUCATION FOR CAREGIVERS

Introduction

Community education for caregivers can be provided as a one-time event such as a community forum or as a series of educational sessions. Community education can serve to enhance the awareness of the community about their caregiving neighbors and the issues they face and to serve the educational needs of the caregivers themselves. A successful community education initiative is one that addresses unmet community needs, is organized in a way that fosters maximum participation by the intended audience, and addresses the educational needs of those in attendance.

Planning Your Educational Event

The best way to begin planning your educational event is to organize a committee that includes League members, selected professionals who work with caregivers and individual caregivers. This committee would be responsible for identifying the most appropriate type of educational endeavor, topics that would be covered, speakers, location and timing of the event, and co-sponsoring organizations. Before the first meeting of this committee you should explore any ongoing educational efforts serving caregivers or previous caregiver education efforts in the community. Your League leadership should also determine whether the most appropriate educational project is a one-time forum or a series of educational sessions and whom you hope to serve by your education project – the community in general or caregivers.

Planning a Community Forum

A one-time community forum can be effective in raising the issues associated with caregivers and fostering new community-based initiatives for supporting caregivers. Alternatively, a forum can be targeted specifically at community caregivers to foster their awareness of the community services and resources available to help them and to encourage them to make use of these resources. A caregiver-

oriented forum can also help caregivers to recognize that they are part of a larger group of caregivers who have many shared interests and concerns.

1. A Community Forum to Increase Community Awareness

Although an increasing number of families are providing assistance to an elder today, many communities have not fully developed special support programs or resources for these caregivers. There may not be, for example, adequate support groups for caregivers or volunteer programs to assist caregivers. A community forum designed to increase community awareness can foster expanded services and an increased recognition of the importance of the contribution made by caregivers to the community. For example, local newspapers may be encouraged to write feature stories about community caregivers and caregiving issues.

Action steps for the committee include:

- Selecting the topic
- Identifying key audience sectors
- Identifying a speaker(s)
- Identifying co-sponsors of the event
- Selecting a location, date and time
- Developing marketing material

A community forum is most successful if the topic it covers is timely, interesting and compelling. Although a general topic such as “caregiving today” might attract some attendees, a specific topic such as “Family Caregiving and Alzheimer’s Disease in Pittsburgh: Designing a Community Response” is likely to be engaging to a broader audience.

If, as the title above implies, the intended audience is professionals and laypersons working in community organizations as well as caregivers, the committee can develop a list of potential invitees, co-sponsors, and marketing venues based on this audience. This focus will also influence the selection of a speaker or speakers. Speakers can be identified from within the community, outside the community or both. Ideally, the forum would feature a keynote speaker who would foster enthusiasm for the event. Including one or more community caregivers as presenters adds to the relevance of the event as well as the compelling nature of the forum.

A community forum designed to mobilize support for caregivers is likely to be received well if it is scheduled during the workday. Since professionals and lay workers are the key intended audience, they would be more likely to attend if it was part of their work day rather than requiring them to give up their personal time in the evenings or on weekends.

Marketing this type of forum can be done effectively by reaching out to organizations in the community through personal contacts on the phone and mail. In addition, a press release can be effective in

fostering public involvement and media attention. If the forum seeks to involve the media, it is also important to personally contact the city editor of the local paper to request that someone be assigned to cover the forum.

A forum should include ample opportunity for discussion among the attendees and a focus on action steps for activities that would follow the forum. For example, small groups could be organized after the formal presentations to discuss possible community action steps to enhance the support available to caregivers. Each small group should have a discussion leader with an outline of topics to cover during the discussion and a recorder to write down suggestions of the group. Following these small group discussions, a plenary session should be convened to report to the larger group the activities identified by the small groups. The larger group should be encouraged to form a consensus on follow-up activities and to identify responsible organizations or individuals for each of the activities. Ideally, a report of the forum should be prepared and mailed to each participant after the event. This will remind participants of issues raised, activities that were identified as priority areas and foster ongoing dialogue within the community about caregivers and their needs.

2. Community Forum for Caregivers

The primary audience for a community forum for caregivers is, of course, caregivers in the community. A secondary audience would be professionals in the community who serve caregivers. In order to encourage participation in the forum, the forum should focus on a topic of interest to caregivers. Examples of topics that would appeal to a broad audience of caregivers would be "Health Care of the Older Adult" and "Taking Care of Your Own Health".

Speakers at a community forum for caregivers could be a geriatrician from the community who is not only willing to speak on health care issues, but to take questions from the audience regarding specific health care issues central to their caregiving responsibilities or a physician or health educator who would speak to self-care issues of caregivers. If you are considering a topic such as stress reduction or managing stress while caregiving, a speaker with expertise in this area could provide important information and a demonstration of stress-reduction techniques and strategies that would be of practical use to caregivers.

Regardless of your topic, a secondary goal of your forum should be increasing the access to community resources for those in attendance. Make sure that local organizations are present or provide brochures or pamphlets that could be displayed on an exhibit table in the registration area of the event. The more information you have on display, the happier your audience will be about coming to the forum.

You can also do an interactive session for caregivers that offers them an opportunity to discuss issues of importance to them and/or provide concrete suggestions regarding community initiatives that would help them in their caregiving. This can be done in small groups with assigned discussion group leaders as outlined in the previous section. These discussion groups could provide valuable information to professionals in the community and can be reported to them after the forum.

Scheduling a forum for caregivers can be problematic. Some caregivers have difficulty leaving the care recipient in order to attend a forum; others have small children making forum participation difficult. In general, scheduling these forums for the evening hours or during the day on the weekend is the best. If possible, childcare accommodations are desirable and, ideally, respite care arrangements are helpful.

Marketing the forum should be through newspapers, caregiving support organizations, faith-based organizations and retirement communities. Ideal co-sponsors include caregiving organizations, hospitals and disease-specific organizations in the community.

Planning an Educational Series

An educational series for caregivers can increase the knowledge and information available to caregivers and can foster relationships between caregivers themselves. When planning an educational series, there should be consideration to the latter goal as well as the basic educational goals. It is easy to foster friendships and relationships between caregivers by providing a social time prior to the beginning of the formal educational session or a social time after the session.

Logistical Considerations

Caregivers are, as a group, extremely short of free time. The educational series should be designed to accommodate, as much as possible, the busy schedules of caregivers by being focused, scheduled at a time that is convenient for caregivers, and including information and resources that caregivers can take away with them to review at home. Once again, there is the problem of childcare or respite care for caregivers. Weekend scheduling or an evening presents the most opportunity for participation.

Alternatively, educational sessions can be organized for a large employer or in coordination with several area employers who agree to provide some time during the lunch hour for employees to participate.

And, finally, a series of educational sessions should be limited. A monthly session over 5 months or a series of weekly sessions that run over 4 or 5 weeks might be well-received. If possible, contacts should be made with caregiver support groups to determine the possibility of joining forces for the series and to elicit advice on scheduling, timing and location.

Topics of the Education

The focus of the educational series should be carefully framed to respond to the needs of caregivers.

Topics could include:

- Service resistant elders
- Managing medications
- Selecting and managing home care providers
- Caring for yourself
- Managing work and caregiving

- Balancing family needs with caregiving responsibilities
- Dealing with dementia

The important key to success in any education series is to identify a qualified educator/professional to design the educational series, work with you in planning and to conduct the educational sessions. You can find a community professional by asking caregiving organizations for referrals or by contacting your local university.

Resources for Caregivers

Your committee should develop a list of educational resources for caregivers to distribute to session participants. This list can be developed with help from your educational consultant and suggestions from leaders of community caregiver support groups. In addition, you will find a list of resources in this document that could provide a starting point. Caregivers should also receive information about community resources at each session. These resources can be gathered from community agencies.

Conclusion

Educational forums and sessions can be a valuable service to caregivers in your community. This activity can also provide assistance to community professionals who could benefit from knowing more about caregivers and who want to reach out to caregivers. And, finally, it is a way to showcase your League as an important community resource.

F. HOW TO DEVELOP A TRAINING COURSE FOR CAREGIVERS

Introduction

When it comes to taking care of their loved ones, caregivers tend to give fully of themselves leaving very little time or energy for their own personal needs. As a group, caregivers tend to put themselves last on their list of priorities. Not taking care of oneself can lead to many problems including increased rates of stress related illnesses, emotional issues such as depression and anxiety.

Caregivers often find themselves under pressure because they lack the skills necessary to carry out the basic functions of caring for the care recipient. These basic skills include assisting in the Activities of Daily Living (ADL's). ADL's include bathing, toileting, eating, dressing and transferring oneself in and out of a chair or bed. Fortunately getting caregivers to begin to put themselves higher on their list of priorities and teaching them the basic skills of caring for a loved one is an activity that can be addressed through proper education and appropriate training.

Purpose of Training Course

A training course for caregivers can serve many purposes which include learning to take care of oneself and acquiring the skills necessary to be able to care for their loved one which should include basic care, care management and crisis management. Caregivers can be trained in the skills necessary to care for their loved one in the area of ADL's, as mentioned earlier, and in Instrumental Activities of Daily Living (IADL's) which include, shopping, housework, money management and meal preparation.

Goals of Your Training Course

The goals of your training course should be to increase awareness of the importance of the caregiver taking care of him or herself, to increase communication skills between caregiver and care recipient and to provide skills education in the areas of ADL's and IADL's.

Addressing the issues listed above benefit the caregiver and care recipient in ways that affect not only that particular dynamic but also the environment as a whole for both parties. The caregiver may find his or her role more rewarding simply due to the fact that they feel less stressed and less isolated and now have more skills and someone or someplace to turn to. The care recipient may begin to experience an increased sense of satisfaction in spending time with his care provider as well as increased self-esteem and morale.

What Makes a Good Training Course

A well-developed training course will provide caregivers with the skills and coping mechanisms necessary to care not only for their loved one but for themselves as well. Legacy Health Systems has developed, as part of their *Caregiver Helpbook*, an education program for caregivers entitled, *Taking Care of You: Powerful Tools for Caregiving* (Legacy Health Systems, 1999) in which the following self-care tools are listed as being provided by their training program:

- Reduce personal stress;
- Change negative self-talk;
- Best communicate his or her feelings and needs to others;
- Set limits and ask for help;
- Deal with emotions such as guilt, anger, and depression;
- Make tough caregiving decisions;
- Deal with difficult situations.

The *Caregiver Helpbook* designed by Legacy Health Systems may be a good starting point in terms of researching what is available for training caregivers and the available education programs that you may be able to implement effectively and efficiently in your local area.

Identify Caregiver Needs

As mentioned earlier, you will need to find out several things about the caregivers in your community before implementing your training program. These include the following:

- Specific needs based on individual situation;

- Dependent care needs, including childcare and respite care during training;
- Time constraints--availability of caregivers;
- Current skill level of caregivers.

If you haven't conducted a needs assessment of caregivers in your community, you can get information about needs from professionals who work with caregivers.

Identify Materials for the Training Course

The materials you will need for training caregivers in your local area may vary but should include the areas discussed earlier (personal care, ADL's, IADL's). With your specific group of caregivers keep in mind that although the themes will probably not stray too far from the general areas of training, they may wish to have more or less information in certain areas; for example depending on your geographic locale, caregivers may need more information as related to weather or urban/rural settings (extreme cold or heat, isolation or safety issues). There may also be those who are providing long-distance care or caregivers who may be caring for children as well as parents or other aging or disabled relatives.

With your specific population of caregivers in mind, begin your search for materials that are relevant to their needs. You may find that you already have several leads in the area of materials due to your earlier work in the area of resources so keeping in mind the needs of your caregivers is always important in terms of inclusion.

Caregiver training is becoming more available as awareness of the needs of caregivers increases. This means that material in this area should not be too difficult to locate. A good place to start is within your existing network--hospitals, caregiver organizations, area agencies, disease-specific organizations and/or chapters. Cooperative Extension programs, run by local Universities, are also a valuable source in the area of training as well--Oregon State University and Washington State University are just two examples.

Where to Look for Material

- Utilize existing network--local agencies, caregiving organizations/support groups, hospitals;
- Contact Universities and University Extension Programs;
- Contact agencies and organizations with programs;
- Contact organizations that conduct regularly scheduled support groups.

Identify a Location for the Training

Again, this is where the network you have developed within your community will be a valuable source of information and resources. Caregiver training can basically take place wherever there is space for people to gather and work together. Ideal locations include classrooms, conference rooms, and lunchrooms. Contact your local library, community college, hospital, faith-based organization or other local entity either in your network or consider one that you have not yet contacted.

Things to Consider in Identifying a Center Location

- Dependent care such as childcare should be made available during training sessions, if necessary;
- Availability of caregivers and trainers;
- Accessibility;
- Work space;
- Facilities such as bathrooms or water fountains.

Identify Trainers/Partners

You will first need to find out whether caregiver training is already being conducted in your area.

Organizations such as local hospitals or hospices may already be providing some level of training for caregivers and in this case, a partnership or collaboration would be ideal. For example, if your local hospital provides training for caregivers who are preparing to care for a relative who is being discharged from the hospital they may offer basic training in ADL's. In this case, you may be able to supplement this training, based on your knowledge of the caregivers in community. An arrangement may be possible in terms of utilizing the current trainer and/or the training facility. Don't rule out several partners, which may mean less of a commitment from any one organization.

Publicizing Your Training Course

Publicizing your training course should be handled in much the same way as publicizing the areas of your project--Resource Library, Resource Guide. Develop a system of memos and signs and inserts to be distributed to local senior centers, hospitals, libraries and local agencies. Also, your growing network of individuals and organizations may be able to assist you in reaching caregivers by making announcements, posting signs and inserting flyers in their regular mailings or newsletters.

CONCLUSION

You may now be aware that when it comes to caregiving, the caregiver is usually the last to receive care. This is where caregiver training is imperative in not only educating caregivers about who they are caring for and the details of that care, but also how to care for themselves. A caregiver cannot care for someone else if he or she becomes ill themselves through increased levels of stress and anxiety.

Both the care recipient and caregiver benefit from training in many ways; caregivers acquire the necessary skills needed to care for their loved ones; caregivers may experience a reduced sense of isolation through meeting others during training and set-up their own networks; caregiver and care recipient may experience less stress and their experiences may be more positive when relating to one another through the acquisition of communication and other skills.