



Department of Veteran Affairs
Office of Care Coordination

INNOVATIVE CAREGIVER PRACTICES

A Resource Practice Guide



November 2006

With humble thanks....

This manual contains a sampling of innovative caregiver practices incorporated within VA. The VA Office of Care Coordination offers thanks to the OCC Caregiver Guidelines Group and all the contributors to this “Innovative Caregiver Practices: Resource Practice Guide”. It is our hope that innovative practices will be shared across programs providing a tool for growth and momentum that leads to positive and significant impact on our caregiving communities. Your comments and support for future editions are encouraged and appreciated.

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To submit your innovative practice for future publication please forward related information to Nancy.Campbell@med.va.gov and Laural.Traylor@va.gov

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Adult Day Healthcare: A Medical Model

Time and education are needed to orient providers and case managers about new processes to support clinical guidelines that have been developed.

The role of adult day healthcare is crucial in assisting veterans to stay in their homes and in the community. Currently White River Junction VA contracts with 16 adult day facilities throughout the state of Vermont and 5 counties in New Hampshire. Guidelines for entrance into the adult day facilities has been loosely guided with no stable foundation guiding us as to how many visits per month should be authorized. As a result of this, clinical guidelines have been developed to determine frequency of visits based on clinical complexity, ADLs, IADLs and caregiver burden. All these areas are weighed and put into a formula that displays a range of frequencies of visits. Guidelines were tested with case managers and providers and prompted revisions. The final result was the development of a caregiver burden scale.

A clinical guideline tool was built as a template under consults. When a referral is called in a consult is generated to the Primary Care Provider (PCP). Often the case manager or social worker will meet with veteran and/or their family to go over the information. The consult is completed, then the PCP reviews and signs off on the consult. The consult is then returned and data is input into an Excel spreadsheet for scoring. The caregiver burden scale is sent out to the caregiver at the time of the referral and usually is returned before the actual consult comes back. The turn around time is approximately 2 weeks.

Lessons Learned:

- Education is necessary to orient PCP's and Case managers about the new process and completion instruction of the consult.
- Time is needed to help providers get used to the new process and accept that authorization would be approved only for medical need and caregiver burden (not for socialization needs alone).

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Building an Educational Program for Caregivers of Veterans with Multiple Sclerosis

Caregivers said that they wanted more attention paid to their needs including stress reduction and community resources.

This program provided caregivers of veterans with multiple sclerosis education on selected topics and a chance to interact with other caregivers facing similar challenges. Topics chosen were those listed as highest priority by the caregivers. Our speakers were chosen as the ones most experienced in those topics. There were six sessions total, meeting once per week, scheduled for two hours.

Specific Diagnosis/Population Served: Multiple Sclerosis/ Caregivers of veterans with MS

Resources Needed: The most important elements were speakers with expertise in the topics, copying capability, conference room space, mailing list/cost for postage to notify people about the presentations, a coordinator to follow up on phone calls, copy, collate, and assist with room set up. Ideally the site could provide refreshments, notebooks and pens for attendees. A grant was obtained to fund notebooks and a part time coordinator. Our speakers included an occupational therapist, a physical therapist, a social worker, nurse, psychologist, chaplain and financial planner.

Topics included: The Emotionally Healthy Caregiver; Working with Cognitively Impaired Persons with MS; Planning for Future Care Needs; Managing Medical Aspects of MS; Financial Planning; Communicating with Health Care Professionals

Lessons Learned:

Planning such a program must begin months in advance because of the logistics involved. Caregivers repeatedly said they would have liked more time to interact with the speakers and with each other. Future programs should allow for extensive caregiver interaction.

Asking the participants (via survey) what they wished to learn was important as they know their needs best. The feedback was they wanted more attention paid to their needs including stress reduction and resources they could use in the community.

They were less interested in specific medical topics such as the latest treatment options.

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Caregiver Appreciation Recognition and Education (C.A.R.E) Day

A key goal of this program was to free up caregivers from their usual responsibilities if only for a few hours. Representatives from the community were invaluable resources.

For many veterans, remaining in their homes and community is only possible because they have access to an informal caregiver. The Geriatric Clinic and Parkinson's Disease Research, Education & Clinical Center (PADRECC) at the Philadelphia VA Medical Center (PVAMC) developed an annual Caregiver Appreciation Recognition and Education Day (C.A.R.E Day) program. The C.A.R.E. Day program takes a holistic approach to the educational portion of the program. Interdisciplinary professionals present on a variety of topics. The goals of the program are: 1) to provide family caregivers with practical knowledge and resources to improve their caregiving skills 2) to educate caregivers about positive coping techniques and strategies to maintain hopefulness 3) to recognize and show appreciation for the work that caregivers do.

Specific Diagnosis/Population Served: Family caregivers of patients enrolled in the Geriatric Clinic, Home Based Primary Care (HBPC) Program and Parkinson's Disease Research, Education & Clinical Center (PADRECC)

Resources Needed: Hospital-wide support is a key element in providing the appreciation and recognition components of the C.A.R.E. Day event. A key goal of the program was to free up caregivers from their usual responsibilities, even if only for a few hours. To enable caregivers to attend, they were invited to bring the veteran patient with them. A PVAMC recreational therapist and social workers stayed with the patients in a separate room, allowing the caregiver to devote their full attention to the C.A.R.E. Day program. Representatives from community agencies were invaluable resources for program participants. They answered questions and provided handout materials

Outcomes (if any):

Caregivers were receptive to a program designed especially for them, as evidenced by at 37% acceptance rate to invitations to the C.A.R.E. 2005 Day program.

Lessons Learned:

Each year on the C.A.R.E. Day evaluation form, many caregivers note that they appreciate the opportunity, which C.A.R.E. Day provides, to talk with other caregivers.

For More Information Contact:

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Community Agency Fair

Informing employees about community resources is vital to meeting the needs of our veterans and their caregivers. It is also helpful to staff who personally provide care for their own family members, friends and neighbors.

One of the Cincinnati VA Medical Center's strategic initiatives was better education of all staff about available community resources and services. The desire was to supplement available VA resources, and address veteran and caregiver needs more comprehensively. This was accomplished in 2 ways. A widely publicized one day community agency fair was held in the Cincinnati VA Medical Center Auditorium for all organizations used by VA social work staff. About 50 agencies sent representatives, along with promotional and educational materials that were distributed to staff. Secondly, laminated cards were made listing the most frequently used community resources, and 1200 of them were distributed, going to every single service, so that every single employee would have one.

Specific Diagnosis/Population Served: All clinical and administrative staff throughout the VA medical center.

Resources Needed: Space to accommodate several hundred individuals for one entire day; several hundred dollars to cover costs for invitations to community agencies; creation of promotional materials to publicize the event to employees, provision of nominal refreshments and reproduction of the laminated cards.

Outcomes (if any): Several hundred employees attended the Fair and one education contact hour was received. There were positive comments, from both employees, and agency representatives about the value of the fair in sharing knowledge and making contacts. Staff, veterans and caregivers were pleased about the easy access to vast amounts of information in a single location.

Lessons Learned: Informing employees about community resources helps our veterans and their caregivers, **and** meets a personal need of staff who provide care to their own family members, friends and neighbors. By helping them better deal with their responsibilities, their ability to continue performing their jobs in the most optimal way is enhanced. Don't take it for granted that those in the community know what VA is all about. Many community agencies have a difficult time keeping up with VA's changing regulations, new initiatives and programs. Such fairs are a great public relations tool.

For More Information Contact:

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Caregivers: Integral Ingredient in the Recipe for Success of CCHT

Care Coordination, Home Telehealth has great promise for caregiver screening, support, education and health maintenance promotion.

The caregiver is often the integral ingredient that binds the connection between the healthcare staff and the veteran. The care coordinator has an opportunity to coach, support, empower, educate and promote wellness (mental/physical) of the caregiver as well as the veteran. Much can be learned from talking with vets/caregivers about what enrollment in the Care Coordination/Home Telehealth (CCHT) program has meant to them.

Specific Diagnosis/Population Served: Veterans (and their caregivers) with multiple/complex comorbidities

Veterans related the following positive outcomes: Able to relate personal actions to CC/HT measures; Pays more attention to his health; Describes more awareness of early CHF symptoms; Feels more involved in care decisions; More comfortable/prepared to discuss long range care planning; Better attitude –“I don’t yell at people so much”; Likes knowing his measures are available to providers in CPRS; Feels more secure that CC/HT Coordinator is helping him to monitor health status; Proud that he has not had to be hospitalized for CHF in past 18 months; Become active supporter of CC/HT-describing it to all the providers he encounters

Caregivers related the following positive outcomes: Getting regular medical care (B/P now controlled, involved in weight management group; Depression resolved; Makes time to go for walks and family activities; Feels confident in ability to continue in caregiver role; Feels that she is part of vet’s care team and more involved in his care; Feels that she has better knowledge of vet’s day-to-day status; Feels more knowledgeable about progression of chronic disease; Feels more knowledgeable about levels of care and long term planning; Feels that CC/HT Coordinator helps with anticipating her support needs; States less burden because she knows someone is helping her to monitor vet

Lessons Learned: CCHT is a valuable tool to support/educate the veteran (and caregiver) with multiple comorbidities. Although the caregiver was not the identified client for this program it is believed that CCHT has great promise for caregiver screening, support, and education as well as caregiver health maintenance promotion.

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The Caregiver Project

The project has made a significant impact on veterans and has increased the overall awareness of the healthcare providers. Ask for what you need...you just may get it!

The complexities of treating veterans were often compounded by the limitations of the caregivers. The need for a culturally enriched network of support and education was not available at the medical center. The “**Caregiver Project**” was developed to address this need and to increase patient satisfaction.

Major components of the project:

- Weekly group respite for caregivers included structured activities for veterans
- Improving socialization and treatment compliance.
- Eliminating barriers to treatment with patient and caregiver focused plans of care.
- Support /Empowerment of caregivers. Access to resources and entitlements.
- Educating caregivers and health care providers
- Incorporating technology and healthy lifestyles.

Specific Diagnosis/Population Served: The group respite component is primarily for veterans with mild to moderate Alzheimer’s Disease and other dementia related disorders. The Caregivers Project has a complementary relationship with the various programs in the medical center establishing a flexible continuum of care.

Resources needed included: Organizational support, fund raising, use of in-kind resources e.g. program space, staffing, caregiver team and volunteers. Age and diagnosis specific programming and educational materials are also required.

Outcomes : To date the “**Caregiver Project**” has made a significant impact on the veterans at the medical center and has increased the overall awareness of the health care providers. Veterans/Caregivers satisfaction surveyed (number of patients for fiscal 2005) 99% reported improved patient and caregiver satisfaction, as well as treatment relationships.

Lessons Learned:

Critical : Transportation, Access to healthcare, Team building. Patients/ Caregivers are appreciative of the increased healthcare benefit, home and community supports. Potential for replication and expansion. This project can delay/avoid the cost of nursing home placements.

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Caregiver Support Group plus Group for Veterans with Dementia

Survey results show less isolation and education about resources and others experiences can help with caring for progressive decline.

Couples attend a support group and bring two lunches, one for each of them. Veterans meet in a separate room to do recreational activities while caregivers meet to discuss issues and problems and get support. Meetings are once a month .

Specific Diagnosis/Population Served: Dementia

Resources Needed: Two social workers to facilitate women's group and a recreational therapist for the men's group.

Outcomes: Questionnaires have been sent several times since the group's inception. Surveys show less isolation, education about resources and other's experiences helps with caring for progressive decline.

Lessons Learned: Administrative support is important to get the commitment of resources for this program.

Wives have requested this double group because they like to go as a couple where they do not feel embarrassed by their husbands' behaviors.

For More Information Contact:

Susan Bass, VAPAHCS - (650) 493-5000 x65246

CONNECT Project: Testing the effectiveness of telephone support for dementia caregivers

Attendance is good as telephone support groups are more easily attended and anonymity helps caregivers to be open.

CONNECT is a three-year, VA Health Sciences Research & Development funded study of a randomized clinical trial of telephone support groups for dementia caregivers, which began in October 2004.

The telephone support groups of one trained group leader and 5 to 6 caregivers meet twice a month for the first two months and monthly thereafter for one year. Content for the first five sessions includes basic information on dementia, legal and financial issues relating to caregiving, safety hazards in the home, caregiver health and healthy lifestyle, communication, and problem solving. A caregiver notebook provides information on topics including behavior and stress pamphlets that focus on caregiver stress and coping skills and activities of daily living (ADLs) of dementia care recipients. Calls are semi-structured with education, coping skills and cognitive restructuring and support components, guided by a trained professional group leader. Each session includes a short signal breath relaxation exercise, caregiver updates, a review of strategies from the preceding session's topic, and the group leader's presentation on one of the specific behavior management or stress and coping educational topics. The last half of each session includes discussion and practice by the group of a signal breath relaxation exercise.

Specific Diagnosis/Population Served: Dementia caregivers who are either veterans receiving care at the Memphis VA Medical Center or providing care to such a veteran

Resources Needed: Information for caregivers for each topic presented, conference calling or VANTS capabilities, group leader

Outcomes: Data on caregiver general well-being, caregiver distress about care recipient behaviors, and costs will be available after September 2007.

Lessons Learned: Some other options for groups would include holding them more often than once a month, organizing groups by type (early dementia, bereaved, etc.), an open group format with date specific topics, and increasing time to 1.5 hours.

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INNOVATIVE CAREGIVER PRACTICES

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Development and Validation of the C.A.R.E. Tool (Caregiver Assessment)

A validated assessment tool to understand caregivers' aspirations, realities and expectations (C.A.R.E.).

This tool increases worker understanding of many aspects of caregiving and enables them to identify key caregiver concerns rapidly and to go beyond their understanding of caregivers as 'burdened' to identifying the contributing factors and the impacts of the subjective and objective reality of caregiving, which is essential if an appropriate service plan is to be put into place.

Outcomes: A validated assessment tool to understand caregivers' aspirations, realities and expectations (C.A.R.E.)

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Electronic Resource Guide for VA Caregivers

Organized, electronic resources enable caregivers to quickly and efficiently find access to community and national resources.

A searchable online database was developed to contribute to VA and community resource needs of both informal family and professional caregivers. Resources can be accessed through entering keywords into the database. The resource guide may be found on the VA Intranet at: <http://10.181.1.92/v22caregiverRD/list.cfm>. The product is currently only available internally to VA staff. The guide has in excess of 150 resources records that include caregiver resources within VA and the community. There are a number of very good private businesses that support caregivers, however this site is limited to government and recognized organizational support systems and does not maintain linkages to private or local endeavors.

Specific Population Served: Caregivers/VA Staff who support Caregivers

Outcomes: In approximately 6 months there have been over 900 visitors to the Intranet site.

Lessons Learned: Web based resources can be time consuming to track and maintain.

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Establishing Social Work Liaisons with Community Agencies to Better Serve Veterans and Caregivers

Social Work Staff were encouraged to make monthly visits to selected community agencies to build and maintain effective relationships between them and the VA.

It was the expectation of the Chief of Social Work that each staff social worker partner with a community agency, and serve as that agency's liaison with the Cincinnati VA. Social work staff were encouraged to make monthly visits to that agency to talk about eligibility, access, services provided, etc. They were also asked to raise and address issues that might result in better coordination between VA and that agency. As a regular agenda item at monthly staff meetings, social workers reported back so colleagues could remain current on happenings in the community that might impact VA's ability to make appropriate referrals of our patients and their families.

Specific Diagnosis/Population Served: The agencies that social workers paired with included disease specific organizations involving AIDs, Hepatitis C, cancer, mental illness, stroke and heart disease. Staff also worked with Social Security Administration, the Area Agency on Aging and Adult Protective Services.

Resources Needed: Social work staff needed protected time to make these visits and coverage when they were out of the facility.

Outcomes (if any): 1) Improved visibility of VA in the community. Many organizations increased their understanding of VA eligibility criteria and services 2) Many veterans/families reported greater ease in accessing community resources as agencies were better educated about VA services 3) Better relationships were formed between VA social work staff and community organizations. Staff developed personal contacts that were utilized to facilitate referrals. 4) The partnerships resulted in the development of a large pool of potential presenters for Social Work in-services and conferences that were often made available to all VAMC clinical staff.

Lessons Learned: It helped to have this expectation written in the social workers performance plan as this served to highlight its' importance as a high priority

For More information Contact:

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Good Neighbor Program

Recruitment and retention of volunteers is critical!

Matches VA volunteers with veterans in the veterans home/nursing home (place of residence) as a friendly visitor program.

Specific Diagnosis/Population Served: Veterans at their place of residence

Resources Needed: VA volunteers/eligible veterans

Outcomes (if any): Improved quality of life for veterans; increased volunteer opportunities and satisfaction with volunteering for the volunteer(s).

Lessons Learned: Recruitment/retention of volunteers is critical. Veterans and volunteers both benefit from the Program

For More Information Contact:

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The Great Game Plan

(Glucose Reduction through Education and Assessment Technology; Goals Accountability Monitoring and Effectiveness: Prevention through a Lifestyle of Activity and Nutrition)

Empowering patients and challenging them to make small steps in lifestyle changes is very important!

The purpose of the GREAT GAME PLAN is to assess the clinical effectiveness of a nurse-run telehealth initiative, using Health Buddy® software and hardware to assist veterans at risk for diabetes to effect positive lifestyle changes. Another purpose is to demonstrate an improved cost/benefits ratio for the GREAT GAME PLAN protocol compared to conventional approaches to pre-diabetes management. Both research and empirical data reveal that individuals successful in making lifestyle modifications have typically required intensive healthcare resources and support from dietitians, physicians, and others.

Specific Diagnosis/Population Served: Patients with pre-diabetes/metabolic syndrome

Resources Needed: The resources needed for the GREAT GAME PLAN include 1.0 RN, 0.5 Administrative, 2 personal computers, one laptop computer, and health buddies for each patient. Also provided are digital weight scales, digital blood pressure monitors, and tape measures. Educational brochures and a personal educational regimen are given in one face to face meeting. The coordinator teaches patients/caregivers about diabetes and making lifestyle changes. Diet instruction is given with emphasis on portion control, the role of sugar and carbohydrates in the diet and exercise for a healthy lifestyle. Teaching patients that a 5-7% weight loss and 150 minutes of exercise a week can decrease developing diabetes by 58% or more.

Outcomes: During the initial 6 months of enrollment the first 105 patients have shown an average weight loss of 10.14 pounds, a decrease in BMI of 1.769 and a decrease of waist measurement of 2.25 inches. There have been weight losses of up to 80 pounds and waist measurement decreases of up to 7 inches. There have been triglyceride levels dropping, one that went down over 700 points within 6 months. (As the television advertisements report in fine print these may not be representative of all the patients but some results have been amazing!!)

Lessons Learned: EVERY patient and caregiver should be given 100% of the best education possible. Super stars early on appeared uninterested, almost hostile when education was given. Most important in the role is instilling inspiration for change.

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Group: “I never thought I would have to make those decisions”

Time and education are needed to orient providers and case managers about new processes to support clinical guidelines that have been developed.

Reason for group title: Caregivers repeatedly said "I never thought I would have to make those decisions". It was therefore decided to offer a group with the title "Decisions Group".

Action: A flyer was developed and inserted in the packet which is given to patients and families on admission. "Many family members have expressed their concerns and anxiety about decisions they have to make for their family members.

A monthly group for families to share the issues about which they are concerned, included:

- "I never thought I would have to make medical decisions"
- Financial decisions - e.g. "should I apply for medicaid?"
- Caregiver decisions - "how do I take care of myself?"
- Other issues of concern

Population served: Caregivers who are feeling overwhelmed and want to clarify decisions they need to make.

Outcomes: Caregiver issues are addressed, resource information is shared, and they feel supported.

Lessons Learned: Although information is included in admission packet, caregivers need to be individually contacted to invite them to the group. This can be done at the time of the initial psychosocial assessment.

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Improving access to dementia education: A collaboration between VA and the Alzheimers Association

It is important to gain institutional buy-in for using a new community resource that supports veterans and their caregivers.

Primary care providers or social workers explain the value of being connected to the Alzheimer's Association for information and support. A form with Release of Information and privacy safeguards is filled out with the caregiver's name and phone number. It is faxed to Alzheimer's Association Living with Memory Loss Program. A clinical social worker then contacts the family and answers questions. The primary care provider is notified of this contact.

Specific Diagnosis/Population Served:

Patients and families with a diagnosis of dementia- early, middle, or late stages

Outcomes (if any):

This is a new project and data is being studied to see if getting information about Alzheimer's disease and behavior will affect numbers of calls for Same Day Clinic or visits to the Emergency Room by reviewing the charts. The next review is in process.

Lessons Learned:

It can be difficult to get institutional buy in for using a new resource. This resource is very simple but not often used across settings unless encouraged.

For More Information Contact:

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Interventions that Decrease Caregiver Burden

Educated caregivers have decreased care burdens.

The North Texas (Dallas) Home Based Primary Care (HBPC) team focused on identifying and supporting caregivers to enable caregivers to maximize their role(s) while maintaining an appropriate balance in their personal lives. Caregiver workshops were organized to educate caregivers and to assess and measure caregiver burden.

Specific Diagnosis/Population Served: The program started with dementia patients. It was later expanded to include patients with diabetes, hypertension, congestive heart failure, and cancer, as well as Home Based Primary Care, residential and community caregivers.

Outcomes:

- The rate of emergency room visits by dementia patients decreased by 20% over a year initially. As of 9-06 the rate is 0 visits.
- Caregiver panic calls have decreased in the dementia population.
- Of those who attended workshops, caregiver burden decreased proportionally and caregivers felt relaxed and appreciated
- Caregivers indicated that the lack of appreciation from their loved ones (patients, family and their community) was their most frequent complaint.

Lessons Learned:

- Caregivers had an increased understanding of their role
- Staff wanted to continue the workshops. They better understood the caregiver's role and how to meaningfully support caregivers
- Educated caregivers had decreased care burdens
- Patient's quality of life increased with a consistent caregiver
- Decreased caregiver burden resulted in decreased hospitalization and reduced emergency room visits
- The workshops were an excellent way to get community resources disseminated.
- Caregivers want appreciation and support groups
- Caregivers want respite services/HHA and community referrals.

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The Many Faces of the Caregiver: In Their Own Words.

It was key to the project to illustrate mortality and fragility and how all individuals benefit from strength and service.

Caregivers were given an opportunity to share their experiences with each other, as well as with those who coordinate and fund the VA programs they utilize. It was the intention to illustrate the great worth of caregiver contributions and the importance of supporting them in any way possible. The focus was on acknowledging that veterans were once young and strong and served their country. It was key to the project to illustrate mortality and fragility and how all individuals benefit from strength and service.

Specific Diagnosis/Population Served: Veterans, Caregivers, VA Employees

Resources Needed: Written input from caregivers, photos of veterans while serving in the military and current photos with caregivers and family.

Outcomes (if any): There was an overwhelming response to the photographs and the non-scripted narratives. To be able to visualize the veteran in his prime and then see where life had taken him and how he was being cared for now, was truly humbling for many. The caregivers were each given a copy of the book and they, too, were humbled by the experiences of each other. Hopefully, the impact of VA programs that assist the caregiver, were again seen for their great importance. The necessity of their continued availability was recognized.

Lessons Learned: It was learned that VA can and does make a difference. The process reinforced the notion that when something is placed before an individual, that person has power to take ownership. The needs of one person can be met swiftly or not at all. Sometimes, it may just depend on who answers a phone call. Future endeavors would include more caregiver stories.

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Technical support was appreciated and is acknowledged from:
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VAMC Syracuse, NY: Susan Beth George
Alissa Moore

National VA Staff Survey: Perception of Caregiver Services and Resources in VA and Community

“Caregivers need some kind of guide on how to take care of our patients, what to expect and who to call...they need to know VA is there for them as they support our veterans” Quote from survey.

In March 2006 a national survey was electronically administered to VA staff with the intent of assessing staff perception of need and available caregiver services within VA and the community. The 39-item survey gathered information on perception of availability of services/resources, education, psychosocial needs as well as impressions and recommendations of those staff who work with caregivers. The survey also collected data about innovative caregiver programs and practices within VA communities with the intent of contributing to this “innovative practice” guide.

Specific Population: Care Coordination, Home Telehealth, Home Based Primary Care and Social Work

Outcomes : Responses were received from 271 individuals in the following categories: 63% social work, 24% nursing staff, 2% physicians, 5% other. Of these 271 individuals, 34% indicated they worked with caregivers 0-25% time; 32% worked with caregivers 26-50% of the time, 20% worked with caregivers 51-75% of the time, and 14% worked with caregivers 76% of their time or greater. Top five responses for most needed services in VA and the community included 1) transportation; 2) communication with medical staff; 3) medication management education; 4) individual emotional support and 5) assistance with personal care (bathing and grooming). Detailed survey results are posted at http://vaww.survey.va.gov/surveys/H6P44V/H6P44V_0001.html or can be found on the VISN 22 Care Coordination Home Telehealth Intranet website at http://vaww1.va.gov/V22_CCHT/ “caregiver support” or by viewing the summary document “VA Staff Caregiver Survey Power Point”

Lessons Learned: Staff who work with VA caregivers are essential for their professional insight to barriers and facilitators of caregiver access and knowledge of important resources and interventions for development of caregiver programs.

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On-Line Community Resource Directory

It is believed that more staff members were making more referrals as a result of having easier access to community resource information.

An electronic directory of community resources commonly used by the Cincinnati VA Social Work staff was created and made readily available to clinicians throughout the medical center and in the Community Based Outpatient Clinics. Any staff member could access it by clicking on a desktop icon.

Specific Diagnosis/Population Served: All Medical Center staff in need of locating appropriate community resources and services for veterans and their caregivers

Resources Needed: Staff with the interest, knowledge and time to develop and regularly update such a directory

Outcomes (if any): Calls and trips down to the Social Work office by staff seeking information about available resources decreased. Though not measured, it is believed that more staff were making more referrals as a result of having easier access to community resource information.

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Partners in Dementia Care 1997-2003

Leadership effort is needed to sustain interagency relationships and prevent erosion of changed practice and procedures.

An innovative partnership between five VA Medical Centers in VA Healthcare Network Upstate NY and four local Alzheimer's Association Chapters was formed.

Employed were case finding, early identification, co-care management between agencies and family caregiver information and support.

There was also a strong emphasis on staff training to :

- increase awareness of dementia and the Partners in Dementia Care model
- familiarize VA and AA/RD staff with each others' practices and procedures
- Ongoing operational learning and adjustments to best practice exemplars
- Inter-agency coordination of activities

Specific Diagnosis/Population Served: Patients with Dementia and their Caregivers

Outcomes:

53% increase in dementia diagnoses over pre-study practices

AA/RD Chapters enrolled their clients who are vets in VA

53% of providers used proscribed dementia assessment tools

57% of vets and/or families used AA/RD Chapter resources

Caregivers reported having enough information on at least 2/3 of the issues they had to address

93% reported sufficient help with daily living tasks

85% reported enough help with family concerns

59% reported providers discussed treatment options

Lessons Learned:

- Model was successful during the demonstration period and produced practice and procedure change
- Leadership effort is need to sustain interagency relationships and prevent erosion of changed practice and procedures
- Administrative and clinical champions are essential components to implement the model and designated points of contacts are needed at both agencies

- Flexibility must be maintained to make necessary adjustments to tailor the model for clinic and agency settings

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Rapid Relaxation using Mantram Repetition for Family Caregivers of Veterans

Research on mantram repetition has demonstrated usefulness in decreasing stress, anxiety and anger and increasing quality of life and spiritual well-being in patients, healthcare workers, and adults with HIV/AIDS.

An 8-week (90 minutes/week) family caregiver training was provided on rapid relaxation using mantram repetition—a psycho-spiritual technique for stress reduction. In Sanskrit mantram means “to cross the mind” or rise above ruminating, obsessive thoughts. Silently repeating a mantram (or mantra)—a word or phrase with spiritual meaning—throughout the day is an ancient practice adapted for modern times to promote a sense of calm and well-being. Repeating a mantram enables a person to re-focus attention and create “pause-time” that allows for more thoughtful, intentional behavior. Unlike other meditative/relaxation techniques, mantram repetition can be practiced anytime even while engaged in other activities, making it easily integrated into a caregiver’s demanding schedule.

Specific Diagnosis/Population Served: Family caregivers of veterans with Alzheimer’s Disease or other debilitating illnesses.

Resources Needed: (a) Instructors who are familiar with mantram repetition and can teach it to others. [The team is developing “train the trainer” materials.] (b) Course manual, (c) One of the following books: *The Mantram Handbook* (2001) or *Strength for the Storm: Creating Calm in Difficult Times* (2005) by Eknath Easwaran (www.easwaran.org).

Outcomes: Caregivers experienced decreases in perceived stress and increases in mindfulness attention awareness.

Lessons Learned: The mantram course for caregivers was feasible, acceptable, and effective for lowering perceived stress. Not all caregivers were comfortable with the

spiritual aspect of the program. It was found to be helpful to explain that all cultures and spiritual traditions have a form of mantram repetition and participants could choose their own mantrams. Further explained was the program's assumption that human beings are spiritual with inner resources that can be tapped when the mind is calmed by repeating a mantram.

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Spirituality Support Group in Reducing Professional Caregiver Burden for Terminally Ill

Nurturing and supportive interventions enable the staff to integrate skills and work toward an understanding of their own feelings as well as improving the care of people with severe medical illness.

The challenges of working with medically complex persons with inadequate networks of social support, and multiple stresses and losses may be daunting to even the most seasoned of caregivers. Nursing home caregivers are often overwhelmed by the despair and sorrow encountered in the daily care of the severely ill patients. Nurturing and supportive interventions enable the staff to integrate skills and work toward an understanding of their own feelings as well as improving the care of people with severe medical illness. Numerous studies have found that spirituality provides effective coping mechanisms for patients and caregivers.

A monthly multidisciplinary forum is held where staff caregivers reflect on important psychosocial and spiritual issues faced by patients, gain insight and receive support from fellow staff members. Through an examination of caregiver narratives of their patients' experiences, the role of the health care provider, particularly in regard to challenging fear, is reviewed.

Specific Diagnosis/Population Served: Multidisciplinary professional caregivers

Outcomes: This group of providers reported 1) taking a vital clinical role as encouragers of patients' spiritual resources, 2) A vital role of their personal spiritual needs 3) Ability to foster growth and meaningful relationships with veterans facing end of life.

Lessons Learned: Health care professionals need to understand and address the psychosocial and spiritual difficulties of caring for patients facing terminal illness in order to provide good care.

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Spousal Caregiving as Couples Age: Readjustment to Living with Spinal Cord Injury

This practice model focuses on spouses as caregivers and a system's intervention that has been used effectively with late life couples.

This practice model focuses on spouses as caregivers and a system's intervention model that has been used effectively with late life couples. The model has 2 main goals: (1) to reconfigure the couple system so that it can function more effectively under new stressors and (2) to develop better caregiving, including the expanded utilization of support services, allowing the caregiver to take better care of him or herself.

The intervention is a 3 stage model. In the first stage, the clinician meets with the couple together and listens to their illness story. In the second stage, the clinician takes a more active and directive role, helping the couple utilize the material they have shared for the purpose of healing and restorative action. The goal of the third stage is to help the couple compensate for the usual imbalance in a relationship where one partner is the caregiver and the other the care receiver.

Greenberg, S., Penzo J., Stacey, M. (2001). Spousal caregiving: In sickness and in health. *Journal of Gerontological Social Work*, 35 (4), 69-82.

Specific Diagnosis/Population Served: Though the original abstract focused on the caregivers of veterans with spinal cord injury, the model is applicable to any aging couple where the care recipient has a chronic illness.

Outcomes:

1. Improved emotional and physical health of the caregiver.
2. Better caregiving through improved communication between the partners and the expanded uses of support systems to maintain the well-being of the caregiver.

Lessons Learned:

- 1). Model has been successful with short term as well as long term work with couples in both inpatient and outpatient settings; 2) Model can be adapted to meet the needs of each couple served; 3) The key to successfully utilizing this intervention is meeting the couple together.

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Well, Come Home! Who Cares for the Caregiver?

Caring takes time and funding.

Providers refer to Home Health for several levels of care in the home- from skilled nursing for wounds, teaching, and medication management to infusion services or Hospice, Adult Day Health or unskilled homemaker/respite care. Some providers are clear on what exactly the home health provider should do, when and how often. Those who are not fluent in the language of home care are assisted by Community Health Nurse Coordinators (CHNC) and Home Health Case Managers (HHCM). CHNCs receive a referral and assess for inclusion in one or more of the several skilled and unskilled programs and then pass this information to the agency. In home health there are cases that are not accepted due to the lack of a "willing and able caregiver" for the patient. "Willing and Able" caregivers are defined by Medicare Guidelines as caregivers who accept the responsibility of providing unskilled care at home. Often this care spans from managing ongoing medication, wound care, catheterizations, range of motion, exercises etc. Unwilling and unable refer to those caregivers who refuse the role of providing clinical care and are deemed so as not able due to their own physical or emotional limitations or not willing at all to be responsible for the provision of unskilled care in the home. It is critical to listen and do careful assessments of each unique caregiver and their situation to determine how to be most helpful.

Specific Diagnosis/Population Served: Caregivers of Veterans receiving Care Coordination/Home Telehealth with Interactive Video and Text Messaging Devices

Outcomes (if any): Significant (100%) increase in caregiver knowledge of VA and community based resources

Lessons Learned: The following factors should be considered if you decide to introduce this practice at your site: 1) Resources for caregivers of non-service connected or low service connected veterans may be more limited 2) The program had a limited ability to record, measure and monitor caregiver interface with current coding and funding systems 3) The demand for homemaker, adult day health and other services may be greater than the resources available to provide the level of assistance that some veterans and caregivers require

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Wellness Day for Caregivers

92% of caregivers in this study look forward to the annual event and 77% incorporated information learned into their daily lives.

Provide a stress free day for caregivers including support by staff and other caregivers, educational sessions, lunch and relaxation via spa services (massage, facial, pedicure, or manicure).

Specific Diagnosis/Population Served: Caregivers of Veterans enrolled in the Spinal Cord Injury/Disorder Clinic, including ALS and MS in addition to spinal cord injured.

Resources Needed: Conference room at the VAMC for morning sessions. Voluntary Service for coffee and treats, local Spa School to provide the services at a discounted rate, financial support to pay for spa services, guest speakers and/or materials distributed to caregivers. Our state PVA office supports this endeavor.

Outcomes: Our first caregiver event, in May 2003 was preceded by an inquiry form to assess the feasibility of a one-day caregiver wellness event. Four of five who completed the Caregiver Stress Index at both pre-test and post-test showed a decrease in their overall stress scores. All nine caregivers choose a massage as one of their two spa choices, and all agreed that this was a wonderful day of pampering, a day to enjoy with little responsibilities, a day of good times with others, and asking if "this was going to be a weekly, or monthly event?". It was a yearly event and in 2005 the team decided to evaluate the Caregivers Event. Twenty-seven caregivers participated in this event for the past three years (all were female caregivers). A questionnaire was mailed and an 88% return rate was accomplished. An overwhelming 92% looked forward to this event and 77% have incorporated information learned in their daily life.

Lessons Learned:

- Do not cram too many activities into the day.
- Contact your local School of Beauty and request a discount (wonderful learning opportunity for the students in dealing with caregivers).
- Lunch was catered (arranged by the facility) and served at the spa.
- Majority of caregivers chose a massage and facial. The need for "touch" seemed to play an important role (as compared to the pedicure/manicure).
- It was learned that the majority of the caregivers preferred fun/laughter activities over the educational activities.
- Be prepared for anything; cancellations, transportation to and from the spa, etc
- Getting these caregivers together is a very rewarding experience.

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