NATIONAL ASSOCIATION OF
CHRONIC DISEASE DIRECTORS
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ARTHRITIS

THE PUBLIC HEALTH CHALLENGE FOR STATES

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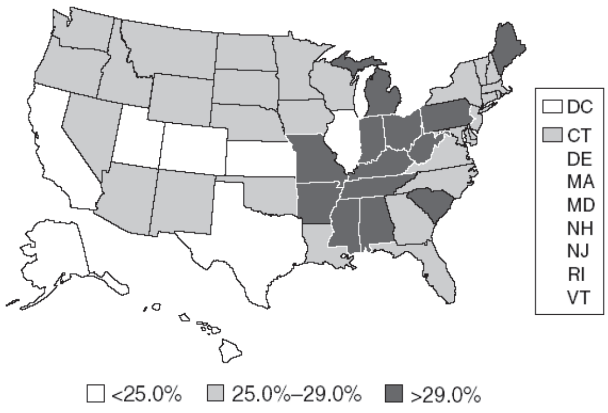
The Challenge of Arthritis

The challenge facing our states and communities is how best to address the burden of arthritis and improve the health of entire population groups. By using a population-based approach, building partnerships to implement effective interventions, and linking public health efforts with those of the clinical community, public health agencies CAN make a positive impact on the quality of life for people with arthritis.

Arthritis comprises over 100 different diseases and conditions. The most common are osteoarthritis, gout, rheumatoid arthritis, and fibromyalgia. Common symptoms include pain, aching, stiffness, and swelling in or around the joints. Some forms of arthritis, such as rheumatoid arthritis and lupus, can affect multiple organs and are associated with premature death.

- ***Nearly 1 in 5 adults in the U.S. reported a doctor had told them they had arthritis.*** In 2002, this accounted for 43 million Americans—making arthritis one of the nation's most common health problems. An additional 23 million Americans reported chronic joint symptoms that may be arthritis, but have yet to be told by a physician they have arthritis. In the next 25 years as the population ages, the number of adults with arthritis is expected to reach at least 67 million.

Figure 1. Percentage of Adults with Arthritis, 2004



- ***Arthritis causes over 9 thousand deaths each year***—and a disproportionate share are women and minorities.
- ***Arthritis is the number one cause of disability in the United States.*** More than 16 million citizens are limited in some way because of arthritis, causing undue hardship on not only the people who have arthritis but also their families and society. Arthritis limits daily activities for more than one in three people with doctor-diagnosed arthritis—and nearly a third of working age adults with doctor-diagnosed arthritis experience work limitations.
- Each year, ***750,000 hospitalizations and 36 million outpatient medical care visits occur because of arthritis.***
- Translating the human cost into dollars, in 1997 alone, ***arthritis cost our nation more than $86 billion.*** These figures are undoubtedly higher today, and will continue to increase dramatically without thoughtful and focused attention on this public health problem.

Interventions that work

The cure for arthritis has not yet been discovered. However, several interventions have been shown to be effective in preventing arthritis and alleviating the pain and disability that often accompany the disease.

Healthy lifestyles
Prior to 1990, people with arthritis were told by their physicians to rest their joints. Evidence now exists to show that *physical activity* is beneficial for most types of arthritis: it decreases pain, improves function, and delays disability. Research also suggests that maintaining a *healthy weight* reduces the risk of developing arthritis and may decrease disease progression. A loss of just 11 pounds can decrease the occurrence (incidence) of knee osteoarthritis. In addition, joint injury can lead to osteoarthritis. People who experience sports or occupational injuries or have jobs with repetitive motions like repeated knee bending have more osteoarthritis. Thus, *prevention of joint injuries* may help to reduce the risk of developing osteoarthritis.

Self management
Programs that teach people with arthritis to better manage their disease and optimize function can reduce both pain and health care costs. Self management education has been shown to reduce pain even 4 years after course participation. Less than 1 percent of Americans with arthritis who could benefit from such programs currently participate in them—clearly a missed opportunity for health care providers and persons with arthritis to improve health.

Education and appropriate management
Early diagnosis of arthritis and appropriate medical management are very important, especially for inflammatory types of arthritis. As an example, early targeted therapy for rheumatoid arthritis has been shown to decrease joint destruction and improve outcomes.

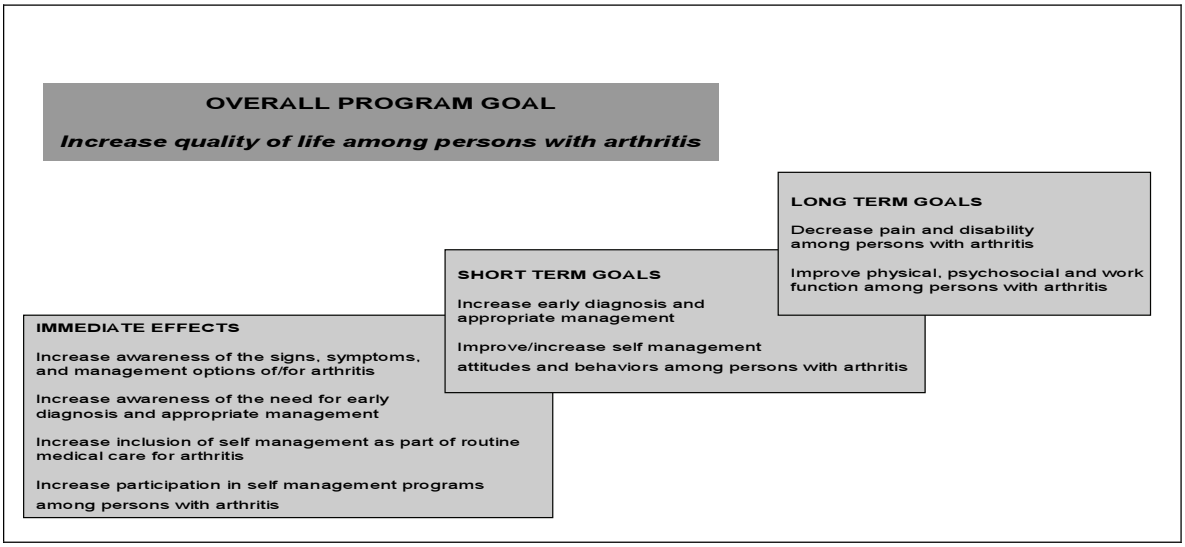
People with arthritis are:

- Older, more often female, and have a much poorer quality of life.
- Overweight or obese, which is associated with further progression of disease.
- Less physically active, which is associated with higher medical costs.
- Often hesitant to discuss their joint symptoms with their doctors, resulting in delayed diagnosis and greater progression of disease.
- Not receiving existing interventions, such as counseling to increase physical activity, achieving a healthy weight, and learning about and participating in self-management education.

The national framework for prevention

In recognition of the significant and growing impact of arthritis on the public's health, the Centers for Disease Control (CDC), the Association of State and Territorial Health Officials, and the Arthritis Foundation partnered with 90 other organizations to develop The *National Arthritis Action Plan: A Public Health Strategy*. This landmark plan recommends national, coordinated efforts to reduce pain and disability and improve the quality of life for people with arthritis.

Figure 2. Framework for Prevention



Delivering on a promise: the state role

Prior to the publication of the *National Arthritis Action Plan* in 1998, and the availability of cooperative agreement funding from CDC in 1999, only two states (Missouri and Ohio) had even a modest level of public health activity to address arthritis. Now, 36 state health departments have a basic level of public health infrastructure for arthritis efforts. These agencies play a unique role to play in preventing arthritis and its related disability.

Figure 3. States with Arthritis Programs, 2005

States develop and implement Arthritis Action Plans.
All but 5 states have developed and disseminated state arthritis plans, and almost half have posted the plans on their websites. These plans include an analysis of the burden of arthritis in the state and establish realistic objectives and strategies for reducing that burden. Worthy of note is the fact that health officers in 23 states have endorsed their respective states' plans, an indication of the credibility and potential power of these strategic documents. Most states anticipate updating or revising their plans at some point in the next five years.

OKLAHOMA's Arthritis Action Plan

When the Oklahoma Arthritis Network began its planning process in February 2000, it had no intention of producing an award-winning document. Its mission was far more elementary: to involve a broad spectrum of perspectives in setting goals and objectives for reducing the burden of arthritis in the State. Using an extensive mailing list, letters and press release were sent to over 100 individuals and organizations inviting their participation in the newly created arthritis Advisory Council. Attendance at monthly meetings was highly variable and inconsistent—ranging from 9 to 70. Marisa New, Program Director, recalls that "We found it challenging to bring people up to speed on arthritis quickly and get good input in meetings. It proved critical to have something to draw people in." The Action Plan fit the bill, serving as a reason for "people to come together with a defined task and purpose."

Over the next 18 months, a small group of "regulars" served as chairs of workgroups and formed a Steering Committee to guide plan development. They used the National Arthritis Action Plan as their model, adapting its components to the State's unique circumstances and issues. Carefully selected Plan Review Consultants—individuals highly influential in the public health community such as the Vice President of Blue Cross/Blue Shield and noted physicians—commented on the draft and lent it credibility. Finally, the plan was officially signed by the Commissioner of Health, shared with the Governor and a host of other stakeholders, and published in 2001 as the *Oklahoma Arthritis Plan, A Public Health Strategy: Maximizing Ability, Minimizing Disability in All Communities*.

One esteemed Review Consultant, Edward Brandt, Jr., MD, PhD, former DHHS Assistant Secretary of Health , deemed the Plan "ambitious but good!" Brandt also serves as Chair of a Oklahoma's Turning Point initiative, a national effort sponsored by the W.K. Kellogg and Robert Wood Johnson Foundations to strengthen public health infrastructures by engaging diverse groups in identifying and influencing the determinants of health. These two concurrent statewide initiatives proved fortuitous, reinforcing compatible philosophies and momentum toward similar goals.

By all counts, the Arthritis Plan has served the State well. It is a living document which, according to New, "has helped us stay on track, provides a framework to report progress and a way to fit everything in. It also serves as a common frame of reference." The Steering Committee envisioned the Plan with a 5-year horizon, so are now meeting to review goals, objectives and strategies. Their investment is evidenced by their willingness to "commit to strategies they'll take the lead on, and prepare work plans for implementation." They want to use what they've learned over the past few years to add to the Plan's usefulness and "make the idealistic more realistic." They are also committed to inviting and nurturing closer relationships with heads of organizations representing major minority populations—something they feel was lacking with the initial process.

Their enthusiasm is further bolstered by a recent and highly unexpected honor: the naming of Oklahoma's Plan, in 2005, as a "Notable Government Document" by the American Library Association's Government Documents Roundtable and a committee from the Journal of Government Information. This prestigious annual award publicizes the diversity of information that can be found in outstanding local, national and international government publications. In the Governor's Commendation recognizing the Department of Health's efforts in deserving this award, he stated: "We congratulate you on the creation of the Oklahoma Arthritis Action Plan and the work your agency is leading to maximize the quality of life for our citizens affected by arthritis and other rheumatic diseases."

States implement proven arthritis interventions in collaboration with the Arthritis Foundation and community partners.
States have focused on three evidence-based interventions: the Arthritis Foundation Self-Help Program, the Arthritis Foundation Exercise Program, and the Arthritis Foundation Aquatic Program.

> ***The Arthritis Foundation Self-Help Program*** is designed to help persons with arthritis learn and practice the different skills needed to build their own individualized self-management program, and gain the confidence to carry it out. Also conducted as a group program, the 6-week course complements the professional services provided by a health care team and is led by trained volunteers, many of whom have arthritis. It consists of weekly 2-hour sessions on such topics as: the latest pain management techniques, managing fatigue and stress, purposes and effective use of medications, finding solutions to problems caused by arthritis, dealing with anger, fear, frustration and depression, the role of nutrition in arthritis management, communicating with family and friends, and forming partnerships with the health care team. On average, participants report a 20% decrease in pain, and a 40% decrease in physician visits, even 4 years after course participation.
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> ***The Arthritis Foundation Exercise Program*** is a group recreational exercise program designed specifically for people with arthritis. Using 72 gentle activities performed sitting, standing, or on the floor, trained instructors cover a variety of range-of-motion and endurance-building movements, relaxation techniques, and health education topics. Classes meet 2-3 times each week, and all of the exercises can be modified to meet participants' needs. Demonstrated benefits include reduced pain and stiffness, improved functional ability, decreased depression, and increased confidence in one's ability to exercise.
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> ***The Arthritis Foundation Aquatic Program*** is a water exercise program that allows people with arthritis and related conditions to exercise without putting undue strain on their joints and muscles. Trained instructors lead exercises to improve flexibility, joint range of motion, endurance, strength, and daily function. After a series of classes (2-3 times per week for one hour), participants report significant decreases in pain and stiffness.

Over the past 5 years, more than 2,200 leaders were trained to deliver these courses. These newly trained leaders joined an already large force of experienced leaders to conduct over 4,000 courses. Senior centers, health care facilities, and assisted living centers are the most common sites used. Faith-based organization sites are used about one-third of the time.

NEW YORK's Interventions

To Mari Brick, Director of New York's Arthritis Program, implementing interventions is a matter of following leads and building bridges. Initially in 2002, she approached her primary partner, NY State Office for the Aging, and together they selected four Area Agencies for Aging (AAA) with the potential capacity to conduct 6-week Arthritis Foundation (AF) Self-Help courses. The geographically dispersed sites each received $1750 and were required to partner with the local AF chapter or branch.

In 2003, the Program branched out to other not-for-profit organizations through its Advisory Council. Five awards (each $1750) were made, including two AAAs (one representing an Indian tribe), a hospital rehabilitation department, and a rural health network representing the northern area near the Canadian border. The following year, the Program moved from sole source funding to competitive awards. The NY Disability and Health Program contributed additional funding for the expansion and helped develop the Request For Applications (RFA). Eligible agencies included AAA, any not-for-profit organization interested in arthritis, and independent living centers. Three $4,000 awards resulted, focused on two of the evidence-based interventions: the Arthritis Foundation Self-Help Program and the Arthritis Foundation Exercise Program. In the upcoming funding cycle, hopes are to continue to fund at least three Independent Living Centers.

Because higher "reach" numbers are so important, Brick targets "systems to get the most bang from the buck," e.g., the large Rural Health Network Hospital System rather then individual agencies. She thinks about how to partner with networks or systems to reach large numbers and underserved populations (such as American Indians and Hispanics), helps new partners think "outside the box," and tries to be consistently available for technical assistance and not "leave them on their own." She begs to differ with the perception that 6 weeks is too long to devote to a Self-Help Course, that people are too busy; her experience is quite the contrary: they want more self help groups—not less.

Results? For the 2-year period of 2002-2003, 37 sites delivered 43 Arthritis Foundation Self-Help courses to 606 new participants; and, since March 2003, a total of 112 leaders have been trained. The majority of participants were 65-74 years old, female, and living with osteoarthritis. Pre and post evaluation of the intervention demonstrated positive outcomes, most notably in the use of disease management techniques.

Brick attributes success to:

- Working closely with other chronic disease programs, particularly those connected organizationally in the same bureau. This includes sharing an epidemiologist with the Disability and Health Program. "We are so used to working in our silos."
- Having a stakeholder in the State Office for the Aging.
- Preparing an information packet for potential partners, answering basic questions (e.g., what is the Self-Help Program, how effective is it, what is expected of partners, how much time will it take).
- Involving the AF chapter in all critical meetings with partners.
- Always thinking about "what's in it for the partner, especially in terms of sustainability."
- Striving to train leaders who are "tied to a facility" since they will be more likely to follow through and have their employers' support.

States promote *Physical Activity: The Arthritis Pain Reliever*.
Media campaigns to promote health messages are useful in reaching broad segments of the population. The ***Physical Activity: The Arthritis Pain Reliever*** health communications campaign, designed exclusively by CDC for use by state arthritis programs and their partners, has been shown to:

- Raise awareness of physical activity as a way to manage arthritis pain and increase function.
- Increase understanding of how to use physical activity (types and duration) to ease arthritis symptoms and prevent further disability.
- Enhance the confidence of persons with arthritis in their ability to be physically active.
- Increase trial physical activity behaviors.

Thirty states have conducted communication campaigns; most of them used *Physical Activity: The Arthritis Pain Reliever*.

WISCONSIN's Media Campaign

The Wisconsin Arthritis Program conducted its first successful media campaign in Milwaukee, from July 11-August 8, 2004. Using carryover funds from its 2002 CDC grant, the Program hired a well-known marketing firm and recruited a small Campaign Advisory Committee. Early on, they agreed to target Milwaukee's 220,400 African Americans, comprising 37% of the city's population. Jointly, they analyzed census data to narrow down the geographic target area for the campaign.

The kickoff event epitomized the philosophy of community involvement that permeated this campaign. Held at a local mall in conjunction with a monthly health program for mall walkers, the event started with a formal proclamation from the Mayor naming kickoff day as *Arthritis Pain Relief Day*. Walkers were treated to continental breakfast and bone density testing compliments of Covenant Healthcare, a nonprofit regional health care system. Arthritis program staff distributed pedometers imprinted with the campaign slogan (*Physical Activity. The Arthritis Pain Reliever*), campaign brochures, and AF information.

Over the next month, the marketing firm arranged radio spots on four African American radio stations, three radio talk show interviews, three news releases, ads in three African American newspapers, and a television interview on the local NBC affiliate. As part of a "package deal" negotiated with the purchase of radio spots, the marketing firm arranged for the campaign to be a sponsor of the annual United Negro College Fund (UNCF) Walk/Run. The campaign was mentioned in radio spots advertising the UNCF event and invited to have an arthritis display at the event.. In addition, campaign brochures and pedometers were stuffed in the "goodie bags" distributed to the first 50 walkers at the finish line.

To compliment these efforts, the Program distributed posters and brochures in churches and local businesses throughout the 3-square-mile target area; and in libraries, community centers, and medical clinics on Milwaukee's north side. Student interns also organized walking clubs at five African American churches, where pedometers and the AF "Walk with Ease" book were disseminated.

The campaign cost about $20,000, with the majority allocated to the marketing firm contract, radio time, printing, and pedometers. For this modest investment, the campaign yielded:

- 283,312 radio media impressions
- 376,000 print media impressions
- 137 campaign posters and over 2,000 campaign brochures distributed
- Over 300 pedometers distributed

Fran Parker, Arthritis Program Director, attributes much of the campaign's success to a good long-standing working relationship with the marketing firm. She offers these words of wisdom for other states contemplating media campaigns:

- Begin planning at least 3-4 months before the campaign kickoff.
- Don't assume others view arthritis as a high priority; "you must make the case."
- Select 1-2 primary partners and invest sufficient time to cultivate relationships.
- Include health department logos on all campaign materials
- Develop written agreements regarding local community and health agencies' roles and commitments and, to the extent possible, offer funding to "compensate for their time."
- Augment paid staff with college students and other volunteers.

A second campaign was conducted in May 2005 in the smaller city of Beloit, with a third campaign planned for June 2006 in the northern Wisconsin community of Rhinelander.

States collect, analyze and disseminate surveillance data on the burden of arthritis.
In 2001, all 50 states and the District of Columbia used the Behavioral Risk Factor Surveillance System (BRFSS) to measure how many people with arthritis live in their state. Many states also used data from BRFSS and other surveys to identify populations at risk or to design and evaluate interventions.

UTAH's Surveillance

The Utah Arthritis Program in the Utah Department of Health has a long tradition of conducting and using surveillance data to focus program priorities, improve program outcomes, and increase participation in evidence-based arthritis self-management programs. Surveillance efforts of the Utah Arthritis Program are guided by an overriding philosophy: "Don't measure anything unless it will increase reach and participation in programs—it's all about delivery of programs."

With its first CDC grant in 2000, Utah began using the Behavioral Risk Factor Surveillance System (BRFSS) to define the burden of arthritis in the State and identify populations at greatest risk. Early data suggested women age 45-64 as the "group to target." Reinforcing this finding were national data from the AF and CDC suggesting that a mere 1% of women in this age group had taken advantage of available evidence-based interventions.

But, says program manager Richard Bullough, Ph.D., "we wanted to know why in Utah." So using a survey, focus groups and phone interviews of women, physicians, and leaders of the Arthritis Foundation Self-Help Program, they discovered very low participation among consumers and providers in Self-Help courses. They also learned how women get their information about arthritis and other diseases, how they prefer to receive this information, and what physicians know about Self-Help courses and their referral practices. This information was used to design interventions, with remarkable results. From a baseline of no evidence-based programs in 1999, Utah now has nearly 1,500 participants per quarter in Arthritis Foundation Exercise, Self-Help, and Aquatic Programs—an astounding increase in just 5 years.

In addition, the State has a reliable surveillance system producing sound data with which to continually evaluate and improve services. With honed knowledge of which data sources are most fruitful, areas of programmatic weakness can be more accurately identified and corresponding adjustments promptly instituted. For example, by focusing on women age 45-64, the program was missing the opportunity to target and involve seniors over 65 years of age. Thus, they initiated a senior center intervention for both Arthritis Foundation Self-Help and Exercise Programs, which is now fully implemented and self-sustaining.

Bullough attributes Utah's success to its capacity (staffing and funding). "We were lucky with the level of funding that we received from CDC." The Program also prides itself on "not viewing work as our work" but, rather, the result of close collaboration with the AF and others. As an example, Bullough notes that often when the Utah AF prepares a grant application or materials for advocates and education, it uses "arthritis prevalence, risk and cost data provided by our program"—and most of their grant applications have been funded. Also, Program partners help refine program priorities, develop state arthritis plans, and evaluate the effectiveness and impact of the program.

One of Utah's greatest challenges is "staying focused and only doing things that make a difference." How to meet this challenge?

- Follow CDC guidelines on what data to capture and what to avoid.
- Develop a close working relationship with your CDC program representative.
- Fill gaps in local data by asking other states if they have used qualitative data. "Don't reproduce. The odds are pretty good that the information's out there."
- Find partners within and outside of the health department. "We don't do this as often or as well as we should."

States initiate and strengthen partnerships with the Arthritis Foundation and other community agencies to reach underserved or minority community or population groups.
All state health agencies have established partnerships with their respective Arthritis Foundation chapters. Other common types of partners include universities, state programs, local community programs, private and nonprofit organizations, and coalitions. Most arthritis programs have also set up ongoing advisory councils, providing a mechanism to develop priorities for public health activities addressing arthritis. Councils play a variety of roles, with the most important revolving around planning and setting priorities, offering advice and resources for implementation, and expanding their collective "reach."

ALABAMA's Partnerships

Since its inception in 1999, the Alabama Arthritis Control Program has been "into" partnerships. For Linda Austin, Program Manager, collaboration with partners is both a practical matter ("we have so little money") and an effective way to do business ("people will believe their own more than a newcomer coming in"). This is particularly important in a rural state like Alabama.

Through its partnerships, the Program aims to increase its "reach" by identifying partners with systems that serve similar target populations. As a prime example, the Program's partnership with the Alabama Department of Senior Services (ADSS) brought together two agencies that shared a common target population (seniors) and a common focus (physical activity). Jointly, they developed a video to explain, demonstrate, and provide witnesses from the Arthritis Foundation Self-Help, Exercise, and Aquatic Programs. The video was initially distributed to 350 nutrition centers in the ADSS network—immediately generating strong interest in an exercise program for seniors. The leadership of ADSS responded by designating an exercise program coordinator, arranging for nutrition coordinators to become trained leaders, and incorporating these new responsibilities into staff work plans. A leaders' manual and streamlined reporting process followed—all contributing to the conversion of nutrition coordinators into effective and vocal advocates for the Arthritis Foundation Exercise Program.

Another partner, the Alabama Cooperative Extension Service, focuses on nutrition and physical activity for rural and underserved populations. They are in the process of incorporating the Arthritis Foundation Exercise Program into their activities and 11 cooperative extension agents that cover the State have been trained as leaders.

Other key partners include the AF, the University of Alabama (UAB), rural hospitals, and the Selma Housing Authority's Opportunities for Well Living (OWLS). The results of these partnerships in terms of course delivery is remarkable; since 2000, there have been:

- 82 Arthritis Foundation Self-Help Program classes delivered by 133 trained leaders, with 674 participants completing two-thirds of the classes; and 871 attending one time
- 163 Arthritis Foundation Exercise Program courses delivered by 207 trained leaders, with 1,360 participants completing two-thirds of their classes and 1,731 attending one time.

Austin admits that these accomplishments have not been easy. "Success is hard work, keepin' on keepin' on." She credits patience, persistence, and a good sense of humor—and offers a few tips:

- "Keep an open mind" and constantly enlist people wherever you are; don't dismiss anyone as a potential partner.
- Create situations that are "win-wins" for both partners.
- Develop compatible goals and objectives, and address at least part of what the partner needs. Recognize that arthritis may not be "high on their radar screen."
- "Court" the partner and nurture the relationship with "sales calls."
- Be "bending and accommodating;" accept and work with all types of personalities, beliefs and traditions.

For more information, contact your state health department:

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