
Computer-Based Technology and Caregiving of Older Adults

What's New, What's Next

Distributed By:



Developed By:



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Computer-Based Technology and Caregiving of Older Adults

What's New, What's Next

About This Guide

This guide is designed to provide you with information about the latest technologies that support the care of older adults, as well as the technologies on the horizon. The guide examines issues in implementing the technologies on a wider scale, and in dealing with those issues from a personal, social, ethical, financial and policy perspective. There is also a checklist of points to consider when choosing computer-based technology to assist in caregiving, and a reference section for more information.

Why This Guide is Necessary

Over the next few years, the need for caregiving for the older adult population will become acute. Americans are living longer, increasing their likelihood of developing chronic conditions such as congestive heart failure, diabetes, and chronic obstructive pulmonary disease. By the year 2030, when most of the baby boomers are in their 70s and 80s, the number of Medicare beneficiaries will double.

Who will provide care to these older adults? A recent AARP survey of disabled adults 50 years and older found that 86 percent receive most of their care from unpaid caregivers, including spouses, partners, and grown children. These caregivers assist in the activities of daily living (ADLs) such as dressing, bathing, feeding, and toileting. They also provide transportation to medical providers, help with medications, and perform physical therapy. For many caregivers, it is an all-consuming task.

Caregivers often must sacrifice their jobs, ties with other members of their families, and even their own health. Family caregivers need support in the form of finance, information, counseling, stress relief, and connection to health care providers. A number of organizations are testing various types of computer-based technologies to provide help to caregivers. These technologies include the World Wide Web and other Internet applications, video link-ups, robotics, and Global Information Systems.



Part One

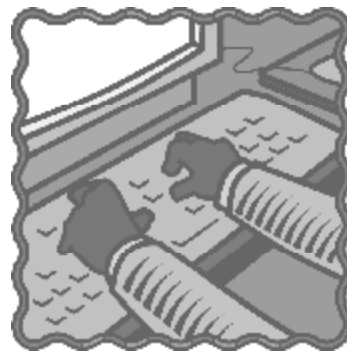
An Increased Need for Home-Based Care for Older Adults

In a recent AARP survey of disabled adults 50 and older, respondents said their two major concerns were the loss of independence and the loss of mobility. They overwhelmingly wanted to receive care in their homes as opposed to an institution, to choose who provided that care, and to manage the cost of the care themselves.

Bringing care to the homes of older adults via the Internet or other technology-based methods could help address a number of these problems. Since more than 85 percent of disabled adults ages 50 to 64 are already online, and almost half of all adults 65 and older are, this is becoming increasingly feasible.

The use of computer-based technologies is a promising tool for encouraging seniors to improve their health practices. Benefits include

better access to their health care providers, confidence that their conditions are being monitored, and the ability to keep track of provider appointments. Patients also can receive feedback on how their compliance with medication, exercise, and nutrition regimens is affecting their conditions.



Part Two

Technology Offers Support in the Caregiving of Older Adults

Computer-based technology can address a number of caregiving problems for older adults. These include:

- Providing quality information to family caregivers.
- Helping caregivers inform and educate additional family members, to engage them in the caregiving process as a “team effort.”
- Providing the caregiver with information on caregiving resources available from the local Area Agency on Aging and other members of the aging network in their communities.
- Providing health record information to medical personnel during an emergency or the time of care.
- Monitoring chronic conditions such as congestive heart failure, chronic obstructive pulmonary disease, and diabetes.
- Contacting emergency services automatically when an older adult is in distress.
- Monitoring the movement of older adults in the home to detect falls or wandering.
- Keeping the older adult visually connected with the health care provider or long-distance caregiver.
- Offering the caregiver and the older adult access to online support groups for specific chronic conditions and situations.

- Enabling the health care provider to furnish the older adult and caregiver with timely feedback on the status of chronic conditions.
- Providing health care information from a distance for those who are homebound or in rural areas.
- Reducing medical errors with the use of a bar-coding system, which would link patients, those who prescribe medications, and pharmacists.
- Controlling the overall cost of health care by reducing unnecessary trips to the hospital (particularly the emergency room).



Part Three

Current Technologies

A number of computer-based technologies for use with older adults are now in place—some in widespread use, and others with limited but increasing availability. These include:

- Interactive web sites with health care information and support systems for specific conditions.
- Monitoring devices that enable the patient to send temperature, blood pressure, glucose levels, and other data to health care providers electronically.
- Computer and televisual set-ups to allow health care providers to conduct “virtual house calls” with older adult patients.
- Sensors that detect movement (such as falls) and various activities, enabling the unintrusive monitoring of patients in the home.
- Electronic health records that are easily available to health care providers and patients.
- Electronically linked systems that contact both emergency services and the patient’s physician in case of a medical emergency.
- Global Information Systems (GIS) that help municipalities figure out where older adults live, and then design “senior-friendly” neighborhoods with nearby health care, transportation, community centers, low-cost housing and shopping.



Part Four

Technologies in the Works

Numerous agencies and organizations are using computer-based technologies in the care of older adults—some on a very small experimental scale, and others already in place and operating.

The Atlanta Regional Commission

The Atlanta Regional Commission in Georgia is using a comprehensive database of services to match community-based health and social services with older adults. After first asking a client a series of over-the-telephone questions, the Commission mails the client a response with information tailored to the client's needs. The Commission is also providing its database to local hospitals and related agencies to reduce duplication of effort. Parts of the database are available to the general public through the Commission's web site. In addition to

the database applications, the Commission is using Global Information Systems via satellite (GIS) to help plan "senior-friendly" communities in the Atlanta area. GIS is used to determine where seniors are settling so that the city can make sure that public transportation, health care, low-cost housing, and other services are there to support "aging in place." www.atlreg.com (English and Spanish)

The U.S. Department of Veterans Affairs (VA) and the Veterans Health Administration (VHA)

The DVA and the VHA are testing a telemedicine system in Florida and Puerto Rico with 2,000 veterans. The program includes a home monitoring system that enables veterans to electronically send health information to their health care provider. The provider, often a nurse, can then provide the veteran with feedback and

advice. In addition to the telemonitors, the system includes video-phones, in-home messaging devices, and personal computers with interactive chat rooms. This monitoring system has significantly reduced the number of hospital visits of participating veterans pertaining to chronic conditions. It has increased patient compliance with medications, and patient satisfaction with care, and perceived quality of life.

The VHA also has converted all of its medical records to an electronic format, which allows for ready updating, electronic transmittal, and trend identification. www.va.gov

National Library of Medicine Web Sites

The National Library of Medicine (NLM) currently maintains several web sites designed to provide accurate health information to the consumer. MEDLINEplus (www.medlineplus.gov) (English and Spanish) has sections on health topics, medications, physicians, and medical terminology, and is easy to use and understand. Information on the site can be accessed through alphabetical menus as well as through

buttons and the search window. The new NLM site, Senior Health, contains information on aging-related health topics, remedies, and help for caregivers. www.nlm.nih.gov

Patient-Initiated Emergency Response System (PIERS)

The PIERS Project, developed at the Johns Hopkins University School of Medicine, provides rapid assistance to patients with heart disease. The system consists of a Personal Patient Module (PPM) that patients carry with them. The PPM contains past medical history, information on current medications, a baseline electrocardiogram, and the patient's cardiac risk factors. When the patient perceives cardiac distress, the PPM can take a new ECG and communicate that by telephone to a system server. If the server detects that the patient is experiencing an acute myocardial infarction, it automatically sends for emergency help. The server also connects the patient to a cardiac teleconsultant, who interviews the patient and determines next steps. www.hopkinsmedicine.org/lbd/otl/3949.html

Worker Interactive Networking (WIN) Project

The Worker Interactive Networking Project, operating out of the Hebrew Rehabilitation Center for the Aged in Boston, Mass., provides an Internet link between the home of the older adult and the workplace of the primary caregiver. The purpose of the project is to alleviate the stress and anxiety felt by many caregivers who feel torn between job and caregiving responsibilities. These individuals are able to receive information about their loved ones during the day, obtain professional advice, and participate in an online workers' support group.

*[www.hebrewrehab.org/
curnews_detail.cfm?ID=40](http://www.hebrewrehab.org/curnews_detail.cfm?ID=40)*



Part Five

Technologies on the Horizon

Nursebot

The University of Pittsburgh School of Nursing, Carnegie Mellon University, and the University of Michigan are collaborating to produce the Nursebot. This mobile robotic device helps older adults with their daily routines by connecting them with family and health care providers with an informational touch-screen; helping them to get around their homes; transporting small objects; and reminding them to adhere to their health regimens. www.cs.cmu.edu/~nursebot

Sensor-Based Monitoring System

The Medical Automation Research Center (MARC) at the University of Virginia is developing a system that monitors the functional abilities of older adults from a distance. The system includes unobtrusive sensors placed in the home that detect

movement and pressure; software for collecting and interpreting the data; and hardware to transmit the information to the older adult's health service provider. The sensors help to establish the normal pattern of the adult's activities of daily living, so that aberrations due to sickness or accidents can be transmitted immediately to the service provider. The goal of the system is to enable disabled older adults to remain in their own homes. <http://marc.med.virginia.edu>

Intel's Assistance for Alzheimer's Patients Program

In collaboration with groups such as the American Association of Homes and Services for the Aging and the Alzheimer's Association, Intel is testing a number of technologies to support the care of older adults in the home. One of these is designed to help early-stage Alzheimer's patients to eat and

drink as well as identify the location of the individual in the home.

www.alsuccess.com/hotnews/37h25103519.html

Online Support Group for Parkinson's Disease Patients

The Wellness Community and the University of California at San Francisco are collaborating to test online support groups for caregivers of Parkinson's disease patients. Preliminary results from the test show significant reductions in caregiver depression and hopelessness. www.twc-chat.org

Internet-Based Dementia Caregivers Support System

The Scripps Gerontology Center has tested the assistive value of Internet monitoring technology with 19 caregivers of dementia patients. The test consisted of monitoring the use of the technology through wired cameras and wireless sensors over a 24-week period. The goals of the monitoring system were to help the caregiver reduce stress, connect with support systems, and keep the patient safe.

www.scripps.muohio.edu/scripps/general/Links.html

CARE (Collecting ADLs for Remote Evaluation) System

The Assistive Technology Research Center (ATRC) of the National Rehabilitation Hospital is testing a system to evaluate the functional status of patients in their homes through the use of switches attached to moving parts in the home (drawers, faucets, light switches, etc.). The ATRC plans to use the data collected from the switches to establish how well the patient is conducting his or her activities of daily living throughout the rehabilitation process. www.atnrc.org/index.html



Part Six

Key Issues in Using Technology to Care for Older Adults

While computer-based technology can be a huge asset in the care of older adults, a number of issues must be addressed before the technology moves to wider use and acceptance. Such issues include:

Privacy

Electronic health records, physical examinations using remote video cameras, sensing devices, and web-based support groups and chat rooms all have the potential of revealing information about an older adult that he or she may not want shared with those who have no right to it. In the future, confidential information should be encrypted so the patient will know who has access to personal health information. It will also be important that the patient gives permission before any potentially invasive technologies become part of the care.

Patient Safety

The mission of the Patient Safety Institute (www.ptsafety.org), a nonprofit national medical information exchange network, is facilitating care coordination by providing ready, yet secure, access to a patient's health information. The goal of this centralized system is to reduce medical error by providing the most accurate patient health information to various care providers at the time of care. The Institute has tested its system on a city-wide scale, and is now moving to state-wide implementation in Delaware.

Equitable Access

New technologies will be costly, so financial support systems should be developed to ensure access for those who cannot afford them. This will be an issue for policy makers—another facet of the nation's "digital divide" problem.

Research Agenda

For computer-based caregiving technologies to become more accepted and widespread, researchers will need to establish the efficacy of such technologies. The Agency for Healthcare Research and Quality, the Robert Wood Johnson Foundation, the Intel Corporation, the Centers for Medicare and Medicaid Services, the Department of Veterans Affairs, the National Cancer Institute, the National Library of Medicine, the National Rehabilitation Hospital, and a number of universities are all supporting or conducting research on the use of computer-based technologies and caregiving. It will be important for the general public to be informed about the results of such research so that they, and their health care providers, can make reasonable and intelligent choices about the use of such technologies in home health care.

Provider Acceptance

There has been some noted health care provider resistance to using computer-based technology for caregiving. Health care providers need training to implement “telehealth” and

other technologies effectively. Often, however, they are not given either the training or the time to adjust to the new systems that some health care payers require them to use. In addition, the use of telehealth technology can increase the provider’s workload, since more patients can be seen in the same amount of time. Yet payments to providers may not increase to reflect the heavier workload.

Standardization

Numerous companies, organizations and agencies are developing a variety of computer-based technologies for home caregiving. At this time, however, there is no standard set of specifications in place for the hardware and software used in these applications. Such standards will need to be established before there can be widespread use of the technologies in both home and professional health care settings.

Part Seven

Considerations in Selecting Computer-Based Technology

- What is the problem you are trying to solve with the technology?
- Are there reliable sources of information about computer-based technology used to care for older adults with the problem?
- What are the advantages and disadvantages in using the technology?
- Is the older adult a willing partner in the use of the technology?
- How much does the technology cost?
- Is the cost a one-time-only expenditure or will there be further costs for service?
- Will insurance cover all or part of the cost of the technology?
- How does the primary care physician fit into the support systems for the technology?
- Is the older adult's home (or other care facility) properly outfitted for the technology? For instance, does it have an Internet connection?
- What agency, if any, has certified that the technology you are considering is effective and safe to use?
- Does the technology protect the privacy of the older adult?
- Is a training program available for the older adults and/or caregiver in order to assure proper use of the technology?
- Is there a reliable "help source" to assist in resolving any operational problems that may occur in using the technology at home?

Part Eight

References and Contact Information

Government Web Sites

Agency for Healthcare Research and Quality (AHRQ). www.ahrq.gov. Provides caregivers with information on health conditions/diseases, health plans, prescriptions, prevention and wellness, and healthcare for older adults. *English and Spanish.*

Centers for Disease Control and Prevention (CDC). www.cdc.gov. CDC serves as the lead national agency for developing and applying disease prevention and control, environmental health, and health promotion and education activities designed to improve the health of the people of the United States. Provides the caregiver with preventative health information and items of immediate concern, such as the flu. *English and Spanish.*

Centers for Medicare and Medicaid Services (CMS). www.cms.gov or www.medicare.gov. Provides detailed information on Medicare and Medicaid services, as well as a nursing home quality initiative for communities called “Nursing Home

Compare” located at www.medicare.gov/nhcompare/home.asp. Nursing Home Compare provides a Nursing Home Checklist to aid in making decisions regarding level of quality, inspection result information, staff information, and general facts about individual nursing homes. *English, Spanish and Chinese.*

Department of Health and Human Services (DHHS). www.dhhs.gov. Comprehensive source on health information, diseases and conditions, safety and wellness, aging, as well as a resource locator.

Eldercare Locator (AoA). www.eldercare.gov. Eldercare Locator is a nationwide service that helps older adults and their caregivers find local area services that are provided to seniors. Users simply enter their state and ZIP code, and the Eldercare Locator will link to information, referral services, and their state and area agencies on aging. These programs help families identify appropriate services in the area where they or their family member resides.

FirstGov. *www.FirstGov.com.* Official portal to all U.S. Government websites.

Food and Drug Administration (FDA). *www.fda.gov.* Provides a wide range of information on food and drug regulations for consumers, health care patients, and health care professionals. *English and Spanish.*

Healthfinder. *www.Healthfinder.gov.* Carefully selected information from health info web sites from government agencies, clearinghouses, nonprofits, and universities, including A to Z in the areas of prevention and wellness, diseases and conditions, plus medical dictionaries, a medical encyclopedia, journals and more. Also provides information about doctors, dentists, public clinics, hospitals, long-term care, nursing homes, health insurance, prescriptions, health fraud, Medicare, Medicaid, and medical privacy. *English and Spanish.*

Medline Plus (National Library of Medicine). *www.medlineplus.gov.* Provides up-to-date information on health topics, drug information, a medical encyclopedia, dictionary, news, and directory for those who need information about health care. *English and Spanish.*

National Institute on Aging. *www.nia.nih.gov/health.* Provides a resource directory for older adults, including a database of state and national organizations and agencies. Patient or caregiver may search by subject area or by name of organization.

National Institutes of Health (NIH). *www.nih.gov.* Provides an overview of NIH health resources, clinical trials, health hotlines, MEDLINEplus, and drug information, as well as the 27 departments, including National Cancer Institute, National Heart, Lung, and Blood Institute, and National Library of Medicine. *English and Spanish.*

NIH SeniorHealth.gov. *www.nihseniorhealth.gov.* This web site is organized by health topic and currently includes information on Alzheimer's disease, exercise for older adults, and caregiving. Within each topic there are sections containing general background information, open-captioned videos, short quizzes, and answers to frequently asked questions (FAQs). High contrast text, text enlargement, and speaking website all available.

Social Security Administration. *www.ssa.gov.* Plan your retirement, calculate your benefits, apply for retirement or disability benefits online, and other information. *In 16 languages.*

U.S. Administration on Aging (AoA).

www.aoa.gov. The Administration on Aging is the official federal agency dedicated to the delivery of supportive home and community-based services to older individuals and their caregivers. The AoA website has a special section on family caregiving. *In nine languages.*

U.S. Department of Education.

www.ed.gov or www.disabilityinfo.gov. This site provides access to disability-related information and programs available across the government on numerous subjects, including civil rights, education, employment, housing, health, income support, technology, transportation, and community life. *English and Spanish.*

U.S. Department of Veterans Affairs (VA).

www.va.gov or www.myhealthvet.va.gov. My HealtheVet provides one-stop shopping for VA benefits, special programs, health information and services. Also provides a commercial health education library to provide up-to-date information about medications and conditions, tools to measure health status, a prescription checker, and the latest in health news. In the future, users will be able to reorder VA prescriptions, view appointments, maintain their own personal health logs, and review their VA health information online. *English and Spanish.*

Caregiving Information Organization Web Sites

Family Caregiver Alliance.

www.caregiver.org. FCA is the lead agency in California's system of Caregiver Resource Centers. FCA provides support and help to family caregivers, and champions their cause through education, services, research and advocacy. Services are specific to California, although information can be accessed nationally.

Foundation for Accountability (Robert Wood Johnson Foundation).

www.CompareYourCare.org. Uses interactive tools to help a patient gauge the quality of care and information a physician is providing by comparing it to the norm of other doctors.

Merck Institute of Aging and Health (MIAH).

www.miahonline.org. Merck is dedicated to improving the health and independence of older adults around the world by communicating vital health information; educating the public and health professionals; and encouraging health research in the aging field. HealthCompass (www.healthcompass.org), a joint project with the American Federation for Aging Research and MIAH, is a self-study program designed to help consumers make well-informed health and lifestyle choices, by learning ways to find and evaluate information and research

findings on health and aging.

National Alliance for Caregiving.

www.caregiving.org. The National Alliance for Caregiving provides support to family caregivers and the professionals who help them. The web site helps family caregivers learn about information, videos, pamphlets, etc. that have been reviewed and approved as providing solid information.

National Association for Homecare and Hospice.

www.nahc.org. This organization for home healthcare agency providers allows family caregivers to use the Internet to access a list of member agencies across the country.

National Caucus and Center on Black Aged, Inc.

www.ncba-aged.org. Dedicated to improving the quality of life for elderly African American and low-income minorities. Provides aging resources, programs and services, and publications.

National Council on the Aging.

www.ncoa.org. NCOA is the nation's first association of organizations and professionals dedicated to promoting the dignity, self-determination, well-being, and contributions of older persons. Includes BenefitsCheckUp, found at *www.benefitscheckup.org*, which helps people over the age of 55 find federal, state, and local public and private programs that may pay for some of their

medical care costs, including prescriptions.

National Family Caregivers Association.

www.nfcacares.org. The National Family Caregivers Association (NFCA) is a grassroots organization created to educate, support, empower and advocate for the millions of Americans who care for chronically ill, aged, or disabled loved ones. NFCA is the only constituency organization that reaches across the boundaries of different diagnoses, different relationships and different life stages to address the common needs and concerns of all family caregivers. NFCA serves as a public voice for family caregivers to the press, to Congress and to the general public. NFCA offers publications, information, referral services, caregiver support, and advocacy.

National Health Council (NHC).

www.nationalhealthcouncil.org. Includes 115 organizations representing many areas of healthcare. Web site has telephone numbers and links to information on specific conditions such as Alzheimer's disease, heart disease, lung disease, stroke, and cancer.

National Hispanic Council on Aging.

www.nhcoa.org. Identifies resource programs to aid the Hispanic community in elderly caregiving. *English and Spanish.*

Pfizer, Inc. Older Adult Health Information. www.pfizer.com/do/mn_health_older.html. Provides facts about caring for older adults, information about chronic diseases and health maintenance tips. There is also a survey for older adults to assess if they are at risk for declining health, as well as online health glossaries. *English and Spanish.*

Visiting Nurse Associations of America. www.vnaa.org. Visiting Nurses Association of America promotes community-based home healthcare. Family caregivers can contact them to find their local Visiting Nurse Association.

Advocacy Web Sites

AARP. www.aarp.org. Anyone over the age of 50 can join AARP for only \$12.50 per year, and membership includes your spouse or partner, free. Provides discount information, tips for healthy living, retirement planning, and more. *English and Spanish.*

Medicare Rights Center. www.medicarerights.org. The Center provides hotlines for direct services, education/training, policy briefs, and a list of discount drug programs. The web site also has a list of phone numbers for each state's State Health Insurance Assistance Program (SHIP).

National Committee to Preserve Social Security and Medicare. www.ncpssm.org. Serves as an advocate for the landmark federal programs of Social Security and Medicare and for all Americans who seek a healthy, productive and secure retirement.

References

Gibson, M. J. (April 2003). *Beyond 50.03: A report to the nation on independent living and disability.* AARP.

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For more information on SPRY's current projects and publications, please visit www.spry.org.

About the SPRY Foundation

The SPRY (Setting Priorities for Retirement Years) Foundation, founded in 1991, is a national, independent, non-profit organization that conducts research and education to help all people age successfully. The SPRY Foundation focuses on translating primary research into applied settings, particularly those applicable at the community level. SPRY focuses on four interrelated areas:



wellness and physical health, mental health, financial security, and intellectual connectivity. SPRY has emphasized the development of

computer and internet-based, multigenerational and educational learning strategies to help people access quality information so they can maintain independence and pursue a high quality of life. In carrying out its activities, SPRY seeks to operate in partnership with other private organizations and government agencies. As an outcome, SPRY develops information and strategies that have national implications. SPRY's vision is to help re-shape society's view of aging, and recognize that as all people age, they have rights, benefits, abilities, and responsibilities.

Disclaimer

This guide does not offer medical advice and nothing contained in the guide is intended to be professional advice for medical diagnosis or treatment.

SPRY has developed the guide in order to provide resources for older adults and their caregivers who use the World Wide Web (the Web) to find information on computer-based technology and caregiving for older adults. This guide includes examples of Web sites from the federal government, non-profit organizations, private organizations, and educational institutions. The SPRY Foundation's reference to these sites is not an endorsement of the sites and implies no association with these sites or their operators. Further, SPRY is not responsible for the content of these sites, and does not make any representation that they will continue to be maintained as they are on the date of the publication, or that they will be updated to include advances in medical knowledge.

SPRY assumes no responsibility for how users use the information provided in this guide, or on any Web site that is referenced by this guide. The use of third-party Web sites is at the user's own risk and subject to the terms and conditions of use for such sites. SPRY cannot assure that the information that is available through these Web sites is exhaustive or complete on every subject or that it will necessarily include all of the most recent information available on a particular topic, or that the site will be suitable for a particular individual or for a particular purpose.

Individuals should always seek the advice of a health care provider prior to starting any new treatment, and to obtain information that is specific to their condition. Likewise, individuals should never delay, ignore, or fail to seek medical advice based on information obtained through any Web site.

About This Publication

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 - National Institute on Aging

 - Office of Research on Women's Health

 - National Institute of Nursing Research

 - National Cancer Institute

 - National Institute of Diabetes and Digestive and Kidney Diseases

 - National Institute of Arthritis and Musculoskeletal and Skin Diseases

 - National Heart, Lung and Blood Institute

 - National Library of Medicine

- Agency for Healthcare Research and Quality

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