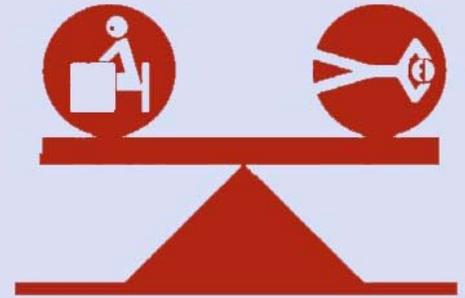


# POST POLIO PACER



*Conserving Strength and Energy through Pacing*

*January 2012— Madison, Wisconsin*

*Madison Area Post Polio Support Group Newsletter*

*MAPPSG formed in 1985 — This Is Our 27th Year!*

## Win with a Smile

By Kathleen Blair, Columnist

*Twenty-five years ago, before the consequences of polio (from 1955) returned to change my life, my husband became disabled and I became his primary caregiver for 17 years. After his death, I wrote about this experience and the lessons I had learned about care giving.*

*Since care giving is a subject close to the hearts of polio survivors and their families, and is often discussed in our Post Polio Support Group meetings, I decided to share one of my stories with you. ("Sam" is the name our granddaughter used to call her grandfather.)*



April presents her favorite photos of "Sam" at Carroll College.

I learned early in my care giving mission the importance of putting on a happy face, maintaining a positive attitude and consciously making smiling a habit. If I let myself feel worried and unhappy, my appear-

ance and demeanor showed my feelings and soon my grumpiness affected Sam. Then we were both worried and unhappy.

Stress and depression are debilitating. I realized that too much anxiety would adversely affect my health. I had to stay healthy enough to care for Sam, or we and our family would all suffer.

After attending a \*Zig Zigler seminar, I became attracted to his WIN philosophy. W-I-N is an acronym for doing **what's important now**. Although "I am a woman" and, therefore, had become adept at multi-tasking through the years of raising our seven children, I learned that at this stage of my life it was better to adopt the WIN attitude. I learned to prioritize and focus on one issue at a time.

I made daily "to do" lists with each task listed in order of importance, the most urgent ones noted at the top. It felt good to cross off each item as it was accomplished. When I could draw a line through each priority on the list by the end of the day, I had WON.

Many times the priorities as I saw them didn't mesh well with Sam's need for attention, and I recall sadly how I had to learn this lesson. My first priorities after coming home from work were always testing Sam's blood sugar, determining how much insulin he would need, and getting a healthy meal on the table. It was important that Sam eat the right foods on time. I would give him a cup of coffee to drink while I rushed around the kitchen preparing our dinner.

One evening Sam wanted to tell me something about his day. Unable to understand what he was saying, I said, "Wait until I get dinner on the table, Honey, and then we can talk."

When I finally sat down and said, “Okay, what did you want to tell me?” he looked at me, a blank expression on his face and said, “I forgot.”

This is how I learned that “**what’s important now**” was to drop what I was doing when Sam wanted to talk, and sit down in front of him so I could see his face which helped me to understand his slurred speech. When a thought came to him he needed to share it right now before it slipped away.

I still regret that I missed the story he had for me that day. After that incident my first priority after we both got home – him from day care and me from work – was to sit at the table and chat with him as he enjoyed his cup of coffee.

As year followed year sitting with Sam, holding his hand, listening and talking to him topped the WIN list almost every day. Somehow the tasks that went unfinished didn’t matter.

I felt I had to smile and make light of every situation, even the bad ones. No, I wasn’t trying to be a saint; I was surviving. I was helping Sam to survive.

I admit that in my humanness I often did not “win” or succeed in smiling through adversity – especially the many times Sam dropped his cup of coffee on our light-colored carpet, spilled sticky juice on the kitchen floor, or tipped over a bag of leaves on a windy autumn day making it necessary for me to rake and pick up those leaves a second time.

After Sam’s death, I was to remember and regret those times I had erupted over the stains on the carpet and the messes I had to clean up. When I shared these regrets with my grief counselor she wisely suggested I weigh those incidents against the 17 years I cared for Sam in our home, and then perhaps I could forgive myself.

I also remembered my elder sister’s admonition, “Kathleen, if you ever let yourself feel guilty, when this is over I’m really going to yell at you!” *After growing up as her little sister, I surely didn’t want to be yelled at again.*

A clinic social worker interviewed me privately dur-

ing one of Sam’s doctor appointments. She asked me to look over a list of symptoms of depression saying, “You must be feeling some of these.”

I reviewed the list and nothing popped out at me. Perhaps I did have a niggling of some of those symptoms creeping into my subconscious, but I was probably suppressing them with my practiced positive attitude. I couldn’t let weakness on my part impact the life Sam and I shared. After all, forty years earlier I had promised, “In sickness and in health until death.”

*“My grace is sufficient for you, for power is made perfect in weakness.” (2 Corinthians 12:9)*

I believe that in my weakness, God was making me strong. He was making Sam strong as well. We were winning.

*\*Zig Zigler - a popular Christian motivational speaker.*

**F.Y.I.—Welcome HOME**-House of Modification Examples has a **new mailing address**: 4280 W. Hawthorne Dr., West Bend, WI 53090.

Welcome HOME is a Bed & Breakfast in a House Of wheelchair-friendly Modification Examples located just 30 minutes north of Milwaukee, WI in the Village of Newburg .

**More information is available by:**  
**Phone: 262-675-2525**  
**E-mail: welcomehome@hnet.net**  
**Website: www.welcomehomebb.com/**

**Golden Rule of Post Polio Syndrome**

**"If something you do causes you fatigue, weakness or pain, you shouldn't be doing it!"**

## Home Care

*On July 9, 2011, Russell King, Executive Director of Wisconsin Homecare Organization, presented information that those present suggested be included in the Pacer. The article, attributed to Wisconsin Homecare Organization, is being presented in three sections, with part 1 in the October 2011 issue and part 3 in the April 2012 issue.*

### Who Pays for Home Care Services?

Home care services can be paid for directly by the patient and his or her family members or through a variety of public and private sources. Hospice care generally is provided regardless of the patient's and/or family's ability to pay. Public third-party payors include Medicare, Medicaid, the Older Americans Act, the Veterans Administration, and Social Services block grant programs. Some community organizations, such as local chapters of the American Cancer Society, the Alzheimer's Association, and the National Easter Seal Society, also provide funding to help pay for home care services. Private third-party payors include commercial health insurance companies, managed care organizations, CHAMPUS, and workers' compensation.

#### Self-pay

Home care services that fail to meet the criteria of third-party payors must be paid for "out of pocket" by the patient or other party. The patient and home care provider negotiate the fees.

#### Public Third-party Payors

**Medicare:** Most Americans older than 65 are eligible for the federal Medicare program. If an individual is homebound, under a physician's care, and requires medically necessary skilled nursing or therapy services, he or she may be eligible for services provided by a Medicare-certified home health agency. Depending on the patient's condition, Medicare may pay for intermittent skilled nursing; physical, occupational, and speech therapies; medical social work; HCA services; and medical equipment and supplies. The referring physician must authorize and periodically review the patient's plan of care. With the exception of hospice care, the services the patient receives must be intermittent or part time and provided through a Medicare-certified home health agency for reimbursement.

Hospice services are available to individuals who are terminally ill and have a life expectancy of six months or less; there is no requirement for the patient to be home-

bound or in need of skilled nursing care. A physician's certification is required to qualify an individual for the Medicare Hospice Benefit. The physician also must recertify the individual at the beginning of each six-month benefit period. In turn, the patient is required to sign a statement indicating that he or she understands the nature of the illness and of hospice care. By signing this statement, the patient surrenders his or her rights to other Medicare benefits related to terminal illness.

**Medicaid:** Administered by the states, Medicaid is a joint federal-state medical assistance program for low-income individuals. Each state has its own set of eligibility requirements; however, states are only mandated to provide home health services to individuals who receive federally assisted income maintenance payments, such as Social Security Income and Aid to Families with Dependent Children (AFDC), and individuals who are "categorically needy." Categorically needy recipients include certain aged, blind, and/or disabled individuals who have incomes that are too high to qualify for mandatory coverage but below federal poverty levels. Individuals younger than 21 who meet income and resources requirements for AFDC, yet otherwise are ineligible for AFDC, also qualify as categorically needy. Under federal Medicaid rules, coverage of home health services must include part-time nursing, HCA services, and medical supplies and equipment. At the state's option, Medicaid also may cover audiology; physical, occupational, and speech therapies; and medical social services. Hospice is a Medicaid-covered benefit in 38 states. The Medicaid hospice benefit covers the same range of services that Medicare does.

**Older Americans Act (OAA):** Enacted by Congress in 1965, the OAA provides federal funds for state and local social service programs that enable frail and disabled older individuals to remain independent in their communities. This funding covers HCA, personal care, chore, escort, meal delivery, and shopping services for individuals with the greatest social and financial need who are 60 years of age and older. Increasingly, individuals who can afford to pay for some of these services are being asked to contribute in proportion to their income. Individuals often request the services they need through an Area Agency on Aging, which will provide them directly or in cooperation with local organizations.

**Veterans Administration:** Veterans who are at least 50% disabled due to a service-related condition are eligible for home health care coverage provided by the Veterans Administration (VA). A physician must authorize these services, which must be delivered through the VA's network of hospital-based home care units. The VA does not cover nonmedical services provided by HCAs.

**Social Services Block Grant Programs:** Each year, states receive federal social services block grants for state-identified service needs. The government allocates these funds on the basis of the state's population and within a federal limit. Portions of the funding often are directed into programs providing HCA and homemaker or chore worker services. Individuals should contact their state health departments and local offices on aging for additional information.

**Community Organizations:** Some community organizations, along with state and local governments, provide funds for home health and supportive care. Depending on an individual's eligibility and financial circumstances, these organizations may pay for all or a portion of the needed services. Hospital discharge planners, social workers, local offices on aging, and the United Way are excellent sources for information about community resources.

### Private Third-party Payors

**Commercial Health Insurance Companies:** Commercial health insurance policies typically cover some home care services for acute needs, but benefits for long-term services vary from plan to plan. Commercial insurers, including Blue Cross and Blue Shield and others, generally pay for skilled professional home care services with a cost-sharing provision. Such policies occasionally cover personal care services. Most commercial and private insurance plans will cover comprehensive hospice services, including nursing, social work, therapies, personal care, medications, and medical supplies and equipment. Cost-sharing varies with individual policies, but often is not required.

Individuals sometimes find it necessary to purchase Medigap insurance or long-term care insurance policies, for additional home care coverage.

Medigap insurance is designed to bridge some of the gaps in Medicare coverage. Some Medigap policies offer at-home recovery benefits, which pay for some personal care services when the policyholder is receiving Medicare-covered skilled home health services. The policyholder's physician must order this personal care in conjunction with the skilled services. Home care coverage in Medigap policies is not designed to cover extended long-term care. This type of coverage is most helpful to individuals recovering from acute illness, injuries, or surgery.

Long-term care insurance primarily was intended to protect individuals from the catastrophic expense of a lengthy stay in a nursing home. However, as the public

need and preference for home care has grown, private long-term care insurance policies have expanded their coverage of personal care, companionship, and other in-home services. Considerable care should be taken in selecting a long-term care insurance policy, as home care benefits vary greatly among plans. Consumers should be aware of limitations on coverage, such as prior hospitalization requirements, and pre-existing condition exclusions. Some policies may only pay for services that are already covered by Medicare.

**Managed Care Organizations:** Managed care organizations (MCOs) and other group health plans sometimes include coverage for home care services. MCOs contracting with Medicare must provide the full range of Medicare-covered home health services available in a particular geographic area. Medicare beneficiaries who are enrolled with an MCO may elect their hospice benefit from the hospice of their choice. These organizations only pay for services that are pre-approved.

**CHAMPUS:** On a cost-shared basis the Civilian Health and Medical Program of the Uniformed Services (CHAMPUS) covers skilled nursing care and other professional medical home care services for dependents of active military personnel and military retirees and their dependents and survivors. CHAMPUS offers a comprehensive hospice benefit to its terminally ill beneficiaries, which covers nursing, social work and counseling services, therapies, personal care, medications, and medical supplies and equipment.

**Workers' Compensation:** Any individual requiring medically necessary home care services as a result of injury on the job is eligible to receive coverage through workers' compensation.

### How Do I Find Home Care?

Finding the home care provider best suited for your needs requires research, but it is time well spent. Important factors include the quality of care, availability of needed services, personnel training and expertise, and coverage provided by the payor. Before starting a search, it is important to determine which types of services you need. You may wish to consult with your physician, a hospital discharge planner, or a social service organization, such as an Area Office on Aging, for assistance in evaluating your needs. Once you've completed this assessment, you will be able to identify the type of home care provider most appropriate to assist you.

Fortunately most communities have a variety of providers to choose from. Your physician or hospital discharge

planner can help you locate home care providers in your area. Contact your state's departments of health, aging, and social services to obtain a list of licensed agencies. In addition, most state home care and hospice associations maintain directories of existing home care organizations and can assist you in identifying an appropriate provider.

Home care providers also are listed in the yellow pages under "home care," "hospice," or "nurses." If your community has information and referral services available through an Area Agency on Aging or a local chapter of the United Way, check with them. Your place of religious worship may also have information about local home care providers.

**Online agency locator:**

<http://www.nahcagencylocator.com/>

Part 3 "What are my rights as a patient?" will appear in the April 2012 issue.

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**In Memoriam**

**Walter Borner**, a long time member of the Madison Area PP Support Group, died on January 10, 2012 at age 77. He contracted polio at age 9 resulting in paralysis of both legs. His resolve and 9 months of therapy at the Sheltering Arms Hospital in the Twin Cities restored his ability to walk. His dreams for the future led him to UW-Milwaukee, where he met and later married his devoted wife of 53 years, Kathy. After completing a degree in physics, he began his 35 year career at GTE North.



Retirement allowed him to discover new joys in life, such as doing genealogy research, biking and attending a number of Elderhostels with his wife, Kathy, Tuesday coffee with GTE retirees and babysitting the grandchildren. He was a Packer and Brewer Fan as well as attending his grandchildren's baseball games, concerts and performances. Walt was a long-time

member of Lake Edge United Church of Christ and served his church community in many capacities.

He was a man of great strength and purpose, maintaining his wit and determination despite living with dementia and declining health for the past few years.

He is survived by his wife, Kathy, 3 children and 6 grandchildren. Our condolences to his family.

*This information above was excerpted from the Wisconsin State Journal, Wednesday, January 11, 2012.*

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**Post-Polio Thoughts**

**Nancy Baldwin Carter, B.A., M. Ed. Psych, Omaha, Nebraska (n.carter@cox.net)**

**CLOSE ENCOUNTERS OF THE POST-POLIO KIND**

It's not as if we polio survivors never run into a glitch or two in a day. Let's face it—dealing with the unexpected has become part of everyone's routine. Developing the finesse to do that smoothly and successfully—well, that may be a different matter.

Consider Alice, a former nurse with serious arm weakness. Alice just returned home from two weeks at a rehab center where she was evaluated by a PT, an OT, and her personal physician, all of whom concluded that she needs a power chair.

Congestive heart failure and weakness in her legs make it difficult for Alice to walk around the house, and she finds it impossible to be independent when it comes to such things as getting to the bathroom. She needs the power chair.

So the rehab center folks contact a power chair supplier and arrange for them to meet with Alice to work out the details for finding the right chair.

Meantime, Alice (now home and renting a power chair) engages a home health agency to provide the PT her doctor orders. And herein lies the problem.

The PT, seeing Alice only once, decides he will be a miracle worker, says he'll have her up and walking in no time, and puts the kibosh on the power chair.

Without consulting anyone, he calls the power chair outlet, switches them to his own questionable evaluation of Alice’s condition, and declares that only a manual chair is indicated for our weak-armed Alice. Trouble ensues.

Time for Alice to jump into action.

We all have options. We do not have to sit passively and watch others take over our lives. This doesn’t require shouting angrily in indignation, loudly stirring the pot with wild demands or accusations. A calm, quiet, “I’m in charge here,” will do.

Alice could:

1. Start by firing the PT (if not the home health agency) & hire one that will honor the perfectly acceptable existing evaluations already attained. Check the qualifications of workers sent by any agency & be clear on job descriptions. Everyone must understand that our health care decisions are up to us—we do not casually hand over our authority to every individual who stumbles into the picture.
2. Speak up. If we have already been through a certain process and have no intention of doing it again, we have merely to say so. If someone insists on our participation when we know this to be wrong for us, we refuse. The word “NO” comes to mind. And if this is more than we can handle, then we’d best find ourselves a “NO-man” to carry along with us to utter the word.
3. Work with experts. For instance, see an assistive technology professional to get exactly the fit and the kind of chair needed. Don’t settle for anything less. Discover what works for us. Don’t allow a salesman with extra scooters in his inventory to decide that would make a better purchase than the chair we want. Who knows our bodies better than we do?

Of course it isn’t just Alice. Lots of people need to realize it’s OK to act on the courage of their convictions. You know how it is. Jack makes an appointment with his doctor. When he arrives at the office, he learns he will be seen by a nurse only. Fine, if that’s what he wants. If not, he needs to say so. Firmly, but calmly, he must insist a pinch-hitter is not acceptable. Next time he can avoid this situation by confirming this when calling to get on the schedule. Nothin’ to it.

Easy enough—no whining or complaining. We simply gather up our polio pluck and make our lives work for us. What could be better than that!

*Nancy Baldwin Carter, B.A., M. Ed. Psych, from Omaha, Nebraska, is a polio survivor, a writer, and is founder and former director of Nebraska Polio Survivors Association.*

Source: Post-Polio Health International ([www.post-polio.org](http://www.post-polio.org))

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### Many thanks to my post polio friends

In October a gorgeous yellow begonia plant sent by the Planning Committee arrived a few days after I returned home following left hip replacement surgery. What a surprise! It literally glowed and is still blossoming. I plan to cut it back and see if it will bloom again in the spring or fall. Thanks again to you all.



And then at the November meeting, another gift--a large (for tea or coffee) cup with 2 identical large autumn floral arrangements on the outside side and “Give Thanks With a grateful heart” on the inside, and a bottle of “Sensual Amber” shower gel cradled in an amber leaf shaped dish suitable for a variety of fruit or chips.

Thank you all for the thoughtful and unexpected gifts. I do “give thanks with a grateful heart” for all of you, for what you do for each other, for articles and topic suggestions, helping label the Pacer for mailing and for your smiling faces around the tables at the Monona Garden Family Restaurant.

*Marcia Holman*

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Do you have suggestions for speakers, topics, books to read and discuss, etc.? Call or e-mail (see e-mail list) one of the people listed above to suggest program topics or speakers, volunteer to organize one meeting program, share your knowledge (or find an expert) about becoming a non-profit organization or volunteer your talents (financial, organizing, etc.) as a committee member.

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To get your Pacer in color on line, set your email program to always accept messages from wghmch@chorus.net

**Names in bold are new to the list or have an address change.** To add your name and/or up-date your e-mail address to this list, notify Marcia Holman at: wghmch@chorus.net

**POST POLIO PACER is a quarterly newsletter published in January, April, July & October for polio survivors, the Madison Area Post Polio Support Group, health care professionals and interested persons to share information and to promote friendships. Articles in this newsletter are for information; medical advice is always necessary.**

**Please request permission from the editor to reprint articles from the Post Polio Pacer.**

*Disclaimer: The opinions expressed in this publication are those of the individual writers and do not imply endorsement by Easter Seals Wisconsin or the Madison Area Post Polio Support Group.*





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**Monona Garden Family Restaurant**  
6501 Bridge Rd., Monona  
Noon to 2:30

**NO MEETING IN JANUARY**

**Saturday, March 10, 2012**

**Open Discussion**

**“What Do You Do to Keep  
Your Body, Mind and Spirit Active?”**

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