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Thank you to all the members who contributed their thoughts and experiences to make this issue a valuable resource.

We would also like to thank **Bristol-Myers Squibb**, **Genentech** and **Biogen IDEC** who helped fund this issue with unrestricted educational grants.

## Time for a change?

It's difficult to know when you might need a cane, walker, wheelchair, lift cushion, or other device to help you get around. A recent member-driven survey on the TMA Bulletin Board revealed that there isn't one "time" for everyone. A large part of this discrepancy comes from people being diagnosed at different stages in the disease, so some who responded to the online survey may have actually had symptoms longer than others when they were finally diagnosed. Age, health before myositis, and treatment success may have also been factors in this survey.

### So what did the survey tell us?

Canes were typically the first aids added to daily routines, with most who participated in the survey relying on a cane for at least outdoor walking within 3 to 4 years of diagnosis. Walkers soon followed, and wheelchairs, including power chairs and scooters, were added only when other methods failed to prevent falls or when the situation became too difficult for caregivers to help. Lift cushions, reachers, braces, and other equipment were also used.

Many other devices are available to help with daily tasks, taking some demands off both you and your caregiver. These

aids lessen frustration and make life easier. This *OutLook Extra* explores these options with your help. You have written to us and posted on the Bulletin Boards, and we have researched other ideas for you as well.

### How will you decide what to use and when?

From reading many emails, letters and posts, it is apparent that some gadgets and strategies work for some while not for others. As with the disease itself, each person is unique.

- Keep your own specific needs in mind. What is causing you trouble? What type of device or solution would solve these problems?
- Remember the saying "less is more." Sometimes, the basic product is all you need to help you out the most.
- Consider safety. Choose the product or strategy that will be both safe and effective.

Many of you have found ready-made products that work; and some of you have taken conventional products and modified them to fit your needs. We hope this *Extra* will introduce you to just the right tool or ignite your creativity to make your own!



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Dear Reader:

This is the second Products issue of *OutLook Extra* published by The Myositis Association. Last year's was very well received, and we think you will find this year's to be equally helpful. In fact, you will find within this issue an index from last year's issue so that you know what has already been covered and can refer back to last year's issue, if need be. If you need a copy of last year's issue, please let us know and we will gladly send it to you.

This second Products issue follows the theme of independence for the individual and that is what many of the products covered here are designed to do - to allow you to be self-sufficient and help relieve caregivers of some of the stress and strain.

We include an hour-by-hour approach to highlight products that can be used round-the-clock to help you support yourself.

Although caregivers are critical to enabling many of those with myositis to function daily, many of these products will enable you to be less dependent on others.

There is true ingenuity and creativity in the talents and adaptations our members have developed to produce these unique products. Share their success and revel in the ability of those with myositis to live creative, enriching lives in spite of the disease!

Fondly,

A handwritten signature in black ink, appearing to read 'Bob Goldberg', written in a cursive style.

Bob Goldberg  
Executive Director

*The opinions expressed in this newsletter are not necessarily those of The Myositis Association. We do not endorse any product or treatment we report. It is our intent to keep you informed. We ask that you always check any treatment with your physician. Copyright 2004 by TMA, Inc.*

## Clothes for all ages

There are a number of adaptive devices available for various reasons, but clothes don't readily come to mind when you think of making changes. Buying a few articles of clothing that make you feel more comfortable and confident may be just what the doctor ordered.

### ESPECIALLY FOR JM'ERS

#### Kid-tested, kid-approved clothing

For children taking prednisone, the weight gain tends to be drastic in a short period of time due to children taking relatively higher doses than adults with myositis. This weight typically comes off quickly once the dose is lowered, so parents don't want to spend a fortune on a new wardrobe. But it's important that your children feel confident and, depending on their age, in style as well.

Nikki Silver found an online catalog to suit the needs of her daughter when Morgan gained weight. *Hanna Anderson* offers stylish clothes with a good fit. "They have beautiful clothes and they all have an elastic waist," says Nikki. "What a blessing for us parents."

#### As told by you

Some of you have written in with your own suggestions on what types of clothes to buy when you've gained weight. Lauren Adelman, a teenager with JM, says to keep it simple. Stay away from form-fitting clothes, including pants that often cut tighter through the thighs. Stick with materials that have more "give" in them, like khaki or terry rather than denim. Lauren preferred cute short skirts with an over-blouse. "An over-blouse did not emphasize my bigger tummy as much," she says, "and was more comfortable."

She adds that buying too much at one time isn't the answer: "I never buy more than one to two pieces of

clothing at a time because my weight changed fairly quickly, especially initially."

These and other hints apply to both children and adults with myositis:

- Choose darker colors and patterns that compliment you; avoid patterns that are too busy.
- Go with flat-front pants rather than pleated pants.
- Wear V-neck shirts, which make your neck look longer.
- Buy clothes in a bigger size, but keep from getting too much bigger as this tends to make you look bigger.
- Replace top shirt buttons with Velcro, keeping the lower buttons closed while pulling the shirt over your head. The Velcro is easier to manage than fitting buttons through buttonholes.

### CLOTHES MADE WITH THE WHEELCHAIR USER IN MIND

For any of you confined to a wheelchair or seated for most of the day, there are plenty of styles created just for you. (See also Ms. Wheelchair Virginia, page 16.) Certain styles simply don't work if you're sitting all day. Pants with a higher waist in the front, for instance, may bunch up and become uncomfortable throughout the day. Choose material that is less restrictive – khaki, cotton or polyester over denim. Or buy pants made especially for you. USA Jeans offers jeans and slacks with a lower front and higher back, giving the look of a more even waist when seated (\$47.95); jeans from Rolli-Moden (\$99) incorporate special pockets and flannel lining; and



Finally It Fits has an array of wheelchair and standing pants (\$65) with Velcro closures and knee pockets to reach more easily.

Shirts and tops that come below the waist may get in the way, tug-

ging as you try to turn in your chair. Buy tops that come just below your waist and settle comfortably above your sitting point. Some companies make tops that are shorter in length and a bit wider at the bottom to allow for more flexibility.

Rolli-Moden even caters to the professional, designing complete suits for women and men, and sportcoats for men. They offer pre-knotted ties so you can "just zip and go!"

There are a variety of accessories at most specialty stores, from scarves and gloves to ponchos and leg covers. Visit them online or order their free catalogs to find what clothes work best for you.

*Editor's note: If you've found a way to alter the clothes already in your closets, let us know! Provide as many details as you can so others will be able to make their own modifications.*

### RESOURCES

**Finally It Fits:** 866-866-9740; [www.finallyitfits.com](http://www.finallyitfits.com); P.O. Box 24708, San Jose CA 95154; [info@finallyitfits.com](mailto:info@finallyitfits.com)

**Hanna Anderson:** 800-222-0544; [www.hannaAnderson.com](http://www.hannaAnderson.com); 1010 NW Flanders, Portland OR 97209;

**Rolli-Moden:** 800-707-2395; [www.rolli-moden.com](http://www.rolli-moden.com); 12225 World Trade Dr, Suite T, San Diego CA 92128

**USA Jeans:** 800-935-5170; [www.wheelchairjeans.com](http://www.wheelchairjeans.com); 9062 East 28th Street, Tulsa OK 74129; [Darlene@wheelchairjeans.com](mailto:Darlene@wheelchairjeans.com)



## MYOSITIS 24/7

It's a new world out there for people with disabilities, as assistive devices are improved and adapted to help them remain more independent. For every activity that's necessary throughout the day, there's an ingenious gadget, resource, machine or strategy that makes the task a little easier. While we know that most of our readers aren't able to afford the very high-end solutions, we've included them here along with some low-tech, low-cost items that are more familiar. We've also included products for different levels of disability – those relying on wheelchairs and other devices to get around as well as those who just need occasional assistance with specific tasks. (See "Everyday tips," page 6, for many of the less expensive and more temporary items and strategies.)

We hope the "hour by hour" format, and the costs associated with each item, will give our readers some ideas, and start them thinking about ways technology can compensate for some of the losses that accompany myositis. Thanks to the staff at *The Disabled Dealer* for developing the information on technology for daily tasks and the costs associated with them. We begin at midnight.

### Midnight

**Task:** Sleep

**Assistive device:** Alternating air mattress with electric pump, for those unable to move around unassisted, prevents pressure sores and adds to comfort. A higher-cost investment is a lateral turning bed and mattress combination with pump, motor and electronic controls to regulate the bed's tilt and turning frequency. Emergency communication can be provided by a bell, a switch with remote buzzer, a medical alert device, an auto-dial telephone, a voice-dialed cell phone, or an environmental control unit with built-in phone.

### **Cost:**

- Air mattress (\$60-\$200)
- Electric pump (\$250-\$400)
- Lateral turning bed and mattress combination (\$4,500-\$12,000)
- Bell (\$10)
- Buzzer (\$40)
- Medical alert device (\$30 per month)
- Auto-dial telephone (\$30)
- Voice-dial cell phone (\$100-\$300)
- Voice-activated phone (\$500-\$1,000)
- Environmental control unit with built-in phone (\$2,000-\$10,000)
- Second phone line to accommodate other needs (\$25 per month)

**Expert advice:** Seek guidance for expensive items, like the lateral turning bed and environmental control unit. Make sure to weigh the expense against realistic expectations of personal care needed to perform the same chores.

### 1 am

Can't sleep? Check the time and temperature by projecting it on the ceiling with a special clock. Some environmental control units can tune the radio to music of your choice, a late night talk show, or a favorite old movie.

### 5:30 am

**Task:** Wake up and exercise

**Assistive device:** Personal care aid

**Cost:** \$5-\$20 per hour

### 6 am

**Task:** Morning bathroom care

**Assistive device:** Use a shower chair next to the hospital bed; a sling with a ceiling motor lift and overhead rail to transfer; or a Hoyer lift. You can also use a ceiling track from the bed to the bathroom instead of a shower chair. A renovated bathroom has a special floor with center drain, waterproof tile walls, long flexible

shower hose and accessible wash basin; or a roll-in shower stall might replace an existing tub. An electronic faucet makes bathing easier and saves hot water.

### **Cost:**

- Shower chair (\$600-\$1,400)
- Hospital bed (\$1,000-\$2,000)
- Sling (\$200-\$300)
- Ceiling motor lift (\$1,800)
- Ceiling track (\$1,500-\$3,000)
- Overhead rail (\$500 then \$100 per foot)
- Hoyer lift (\$900-\$2,500)
- Renovated bathroom as described (\$3,000-\$7,000)
- Roll-in shower stall (\$1,200-\$2,500)
- No-touch faucet (\$550)

### 7 am

**Task:** Dress

**Assistive device:** Special clothing (see pages 3 and 16)

**Cost:** Depending upon the clothes you choose, up to two or three times the cost of conventional clothing; alternatively, there are many ways to modify what you already have in your closets.

### 7:30 am

**Task:** Settle in chair or wheelchair

**Assistive device:** Transfer into a powered wheelchair. Features like a motor-operated tilt, elevating legs, and reclining back may be essential. If you are leaving an upstairs bedroom, you'll need a vertical or angled platform lift or an elevator.

**Expert advice:** If you are unable to reposition yourself during the day, take some time to make sure your original position is comfortable.

### **Cost:**

- Power wheelchair (\$2,000-\$5,000)
- Motor-operated tilt (\$1,000)
- Elevating legs (\$500-\$1,000)
- Reclining back (\$1,500-\$2,500)

Platform lift (\$17,000-\$22,000)

Elevator (\$28,000-\$36,000)

### 7:50 am

**Task:** Eat breakfast; prepare for work or school day

**Assistive device:** You may find eating breakfast more comfortable with a utensil holder or arm fulcrum assist. A cape coat is easier to put on than a conventional coat. An automated door opener will help if the wheelchair user is alone at home. Thresholds up to three inches can be ramped with modular ramping. Steps will require either a ramp or a lift. Choose a custom-made ramp of pressure-treated wood or a modular metal ramp. A vertical platform lift may be a good choice if the height is more than about 30 inches or the space for a ramp is limited.

#### **Cost:**

Utensil holder (\$12)

Arm fulcrum assist (\$300)

Cape coat (\$60-\$100)

Automated door opener (\$1,000-\$2,500)

Modular ramping (\$50 per inch of height)

Custom-made wood ramp (\$125 per inch of height installed)

Modular metal ramp (\$120 per inch of height; \$1,500-\$1,800 per platform; \$500-\$1,000 installation)

Vertical platform lift (\$1,500 per foot of height installed)

### 8:00 am

**Task:** Go to work or school

**Assistive device:** Many cities now have public transportation provided by vans that are specially equipped for wheelchair users. If you're getting around with a cane or walker, most cars can accommodate you. If you're taking public transportation and need some assistance from canes, braces or a walker, you may want to explore "flex-time," coming in well before or after the rush hour, and

leaving at a slower time for traffic. If you are in a wheelchair, you'll need special accommodations.

#### **Cost:**

Wheelchair van driven by carpool (\$35,000-\$50,000 for the van)

Specially-equipped vehicle (\$60,000-\$80,000)

Wheelchair taxi service (\$50 plus \$2.50 per mile each way)

### 8:30 am

**Task:** On the job

**Assistive device:** Whether you're working at home, or are in an office, you'll need a large, flat table, about 42" x 60", with non-interfering legs, whether custom built or from a catalog. It must be of proper height for knees and of sufficient depth for computer display and elevated legs. On top must be workspace and telephone, and if needed, answering device, computer keyboard, display screen and printer, fax and copier. A motorized set of shelves is useful, and an automatic door opener may be necessary unless there is a great deal of traffic at doorways. A level IV Environmental Control Unit, wireless and activated by a voice or keypad, would be a powerful aid in many computer-dependent job situations, like teaching, writing, surveying, engineering, design, scheduling, etc.

#### **Cost:**

Table (custom) (\$500-\$2,000)

Table (stock) (\$600-\$2,500)

Motorized shelves (\$1,500)

Automatic door opener (\$1,500-\$2,500)

Level IV ECU (\$5,000-\$10,000)

### Noon

**Task:** Lunch; relief from wheelchair pressure

**Assistive device:** Many wheelchair users find it simplest to bring a lunch. Eating at your desk allows time to change your position, offering relief

from possible pressure sores and other discomfort. Wheelchairs offer tilt and recline features so you can shift your position.

#### **Cost:**

Wheelchair tilt feature (\$1,000)

Power reclining back (\$1,500-\$2,000)

### 5:30 pm

**Task:** Leave for home

**Assistive device:** The options are the same as getting to work (see 8:00 am). In cold weather, use the cape coat (see 7:50 am).

### 6:00 pm

**Task:** Dinner

**Assistive device:** You'll need a table with plenty of leg room. A universal cuff holds regular forks and spoons. If you're dining out, ask for large pieces of food to be cut in the kitchen, or order meals like stir-fry, stews, salads and pastas that are served in bite-size pieces.

#### **Cost:**

Universal cuff (\$12)

### 7:30 pm until bedtime

**Task:** In for the night

**Assistive device:** Once you're in bed, whether with the help of an aid or transfer, you can use your computer for bill-paying, working, email, games, reading, studying or writing if you have an environmental control unit that includes mouse control. The voice-activated control will allow you to make adjustments to the bed positioning, change television channels, adjust volume, make phone calls, dial a radio station, set the thermostat and turn out the lights. To watch television from a reclining position, try prism glasses.

#### **Cost:**

Prism glasses (\$80)

ECU (\$5,000-\$10,000)



## He said, she said: your everyday tips

### Get a grip on jars and bottles

“To more easily open new bottled products: Punch a very small hole through the cap or lid. Such hole will immediately allow equalization of the vacuum (gravity weight force of air), which holds such lids so tightly. If you are concerned about leaving the hole in the lid open then just place a piece of scotch tape over the hole to reseal the jar. Another useful idea for easier opening of jars is to wear rubber gloves such as those thin medical gloves that are so inexpensive and available in stores. Wearing a glove on each hand will make it much easier to hold both the jar and the lid for easier turning to open and close all containers. These ideas do really help persons with weakening hands like me.” John/IBM

### Grabbers

“I use ‘Gophers’ available from Dr. Leonard for \$9.95 for the first one and \$7.95 for additional. I have four around the house and will buy a couple more to put in my vehicles. I can pick up a dime laying flat on the floor. My wife likes them also (she is healthy!)” GMill (Bulletin Board)

“I too use ‘the gopher.’ Great in the garage when I drop something. Only one problem: the little nut at the end of the rubber tip comes off, and is a ‘bugger’ to find. REMEDY: I replaced the original nuts with ‘lock tight’ nuts (the ones that have plastic inside the nuts), and the problem seems to have been corrected.” John/IBM

“I found one at WalMart made by Invacare for \$9.93. It is 22 inches long and will stand in the basket of my walker so I have it near all the time. It has a pistol action handle which is easy to squeeze and rubber suction cups on the end. I used it to take items out of the dryer, to pick up pieces of ice that I dropped, and to

retrieve shoes from the back of the closet. This is going to be a very handy tool.” Dorris/IBM

“A very useful product I couldn’t be without is the AliMed Grabber – long handle. It can assist in picking things up from the floor or nearby. It has a magnet at the tip. I have seen other grabbers but this is better made than most.” Mikki/IBM

### Praise for elbow canes

“I have IBM and up to 2 years ago had many falls even though I used a cane. I have read your summary of equipment showing different handles, etc. Well, on my last fall (2 years ago) I broke an ankle and after the surgery and during physiotherapy in the hospital I noticed a patient using an ‘elbow cane.’ Thought I’d try it. WHAT A DIFFERENCE! Not a fall since.” Ted/IBM

### Rubbing out your itchy scalp

“I have been using Head and Shoulders soothing lotion for my itchy scalp. I found it at Target. It has reduced my itching by about 60%. I hope it can help others. I can at least sleep at night now.” Tootwhistle (BB)

“I wash my hair with Paul Mitchell Tee Tree shampoo and conditioner. I only wash my hair every other day so my scalp doesn’t dry out too much. Make sure you wear hats (rain or shine) so your scalp isn’t exposed to the sun! You can get the shampoo at any super WalMart that has a salon or the beauty stores in the malls.” Tricia/DM

### Bathing basics

“Spray in hair conditioner that you don’t have to rinse out – this was a life or at least hair saver after knee surgery, when taking a shower exhausted me, even using a chair.” Linda/PM

### Papi-Lift

“I recommend a look at ‘PAPI-LIFT.’ This is a Canadian product that is very helpful for anyone needing assistance getting up from chairs, etc. A call to 1-800-889-5295 will get full information and photos. I have IBM and have one of these and suggest that everyone with IBM consider this bathroom assistant. It is not inexpensive but mine is priceless to me.” Ernest/IBM

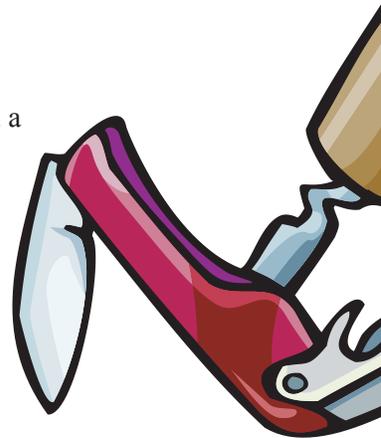
“Papi-Lift. This is a device that fits right over an existing toilet or commode. Rechargeable battery operated. It allows independence getting on or off the toilet. Well-built and definitely worth the money.” Mikki/IBM

### Cleaning without the fuss

“One of the most helpful items I have found is the Black & Decker Scum Buster. It works great for cleaning the bathroom, patio furniture, etc., and they now have several new accessory brushes and pads. The only downfall is that you really need to purchase the stronger VersaPak Gold batteries. The ones that come with it (silver) just don’t hold the charge.” Tricia/DM

### Movies delivered right to your door

Try NetFlix at [www.netflix.com](http://www.netflix.com) to watch all the movies you want without running out to the video store. For a monthly fee, you choose up to five movies at a time. Turn in your wish list to NetFlix, and they’ll send



## Gadgets for myositis

By Sr. Teresa Meza, FSP

*Editor's note: Thanks to Sr. Teresa for sending in this list of products that have helped her throughout her days with dermatomyositis:*

I have muscle weakness and lesions from dermatomyositis, as well as vasculitis and Raynaud's on my hands. My main problem is with my hands, which makes it very hard to do simple things such as to use gloves or mittens in the bitter cold weather, turn a key to get into my office, open a soda can or bottle, or simply put on my socks or stockings in the morning.

The following are a few practical gadgets that make my everyday dealing with this disease a little easier in order to be a little more independent. I have found some things through catalogs and on the Internet; others I have made myself or had someone make for me.

**Hand muffs with fur inside:** It is painful for me to put on gloves or mittens. You'll find fleece hand muffs and hand warmers at most sports stores in the hunting section or at [www.heatfactory.com](http://www.heatfactory.com). (Though some products use animal fur, there are plenty of animal-friendly products available to keep you warm. See Resources for items made with faux fur or fleece.)

**Pen/poker on a cord:** Using a regular pen on a cord that can be found in most stores, I took a rubber fingertip, cut it a little, and taped it on the end of the pen. With a string, you can carry this around your neck so it is always handy, especially for pushing elevator buttons or opening things that require using your fingertips.

**Flat screwdriver:** This is very handy for opening boxes or letters

that you normally have to pull open with your fingers.

**La Cross Tweezers:** Tweezers are useful for any little things you would normally use your fingernails to pick up. I have found that La Cross tweezers are easier to squeeze, and they even have a model that is very easy to hold. These can be found at most drug stores or Walmart.

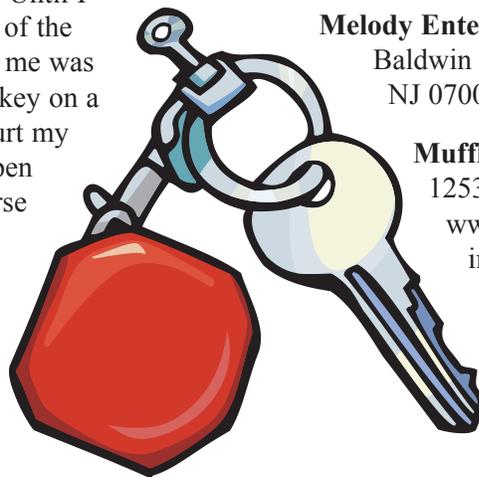
**Easi Grip Tweezers:** I have one of these that I use for everything, from opening pill wrappers to candy wrappers.

**Long-nosed pliers:** These are great for pulling harder wrappers or boxes apart. They can be found at any hardware or hobby store.

**Toothbrush handle:** Your dental hygienist/dentist probably has a supply of these that he/she could give you. If not, you can make one for yourself out of the handle foams described below.

**Handle foam (color coded):** These foam handles will fit cutlery, toothbrushes, pens, pencils, tools, window handles...anything you can think of that hurts or bothers your hands to hold. You can probably find these in a pharmacy that carries special handicap equipment or at The Wright Stuff.

**EZ Key Turner:** Until I got this item, one of the hardest things for me was trying to turn the key on a door. I used to hurt my hands trying to open my door. Of course I could ask someone to help me, but it feels good to be a little independent! (The Wright Stuff)



**Easi Grip Scissors:** When your fingers are swollen and have limited flexibility, regular scissors are hard to handle. These Easi Grip Scissors are great. I found some nice ones that are easy to use at a Joanne Fabrics store or you could try to get something similar at The Wright Stuff.

**Table Finger Nail Clipper:** This is very handy for cutting your own fingernails without having to handle the clippers too much. It is easy to make – have a friend or spouse make it for you. Cut a piece of wood that is about 3/4 inch thick, 4 inches long and 2 1/2 inches wide, then sand it to make it real smooth. Take a fingernail clipper or a toenail clipper (I prefer the larger one), and attach them to the wood piece. Both clippers have a hole on the top where you can screw it down and put two screws on the other side to keep it steady (screws have to go in slanted so the head of the screw will hold it down). Or you can use a thin wire to hold down the opposite end.

These are only a few things that have helped me deal with my slow DM recovery. I hope some of these will be helpful to someone else.

### RESOURCES:

**Sheepskin Fashions:** 973-743-5858; [www.sheepskinfashions.com](http://www.sheepskinfashions.com)

**Melody Enterprises:** 224  
Baldwin Street, Bloomfield  
NJ 07003

**Muffle-up (UK):** 44 0  
1253-822-392;  
[www.muffle-up.com](http://www.muffle-up.com);  
[info@muffle-up.com](mailto:info@muffle-up.com)

**The Wright Stuff:**  
877-750-0376;  
[www.thewrightstuff.com](http://www.thewrightstuff.com)



## Adapt to your child's changing needs

When you think of adaptive equipment, you probably picture canes, walkers and wheelchairs. There are many other devices, both big and small, available to make life easier for anyone in need of an extra boost. The products and strategies included here are by no means all of those available, but they give you some ideas for adjusting to the daily challenges of juvenile myositis (JM).

Check with your child's physician or therapist to find out what your child needs and what you can do to minimize the use of adaptive equipment. Using these devices unnecessarily can have a negative impact on your child, as he or she isn't allowed to become naturally independent. There's a fine line between pushing too hard and giving in too easily, and your child's therapist will help you determine the right path.

Even when you decide your child does require some help, deciding what to use depends on your child's specific disease stage, size, needs, and more. And many devices you use will only be temporary. Families have shared some devices and strategies that have helped them along their JM journeys.

### MOVE AROUND TOWN

In a disease flare, your child may have trouble walking, especially distances. Your own health is extremely important, too, so be sure to think of yourself when considering whether a cane, wheelchair or other walking device would help.

#### A helping hand

Walkers and four-legged canes help with balance and allow your child to remain fairly independent while maintaining as much strength as possible. Though your JM child may feel self-conscious using devices uncommon to most children, one JM'er found a way to adapt them to

her own needs: "She put stickers on the walker so it would be dressed up." With a little creativity, any of these devices can become kid-friendly.

#### When to use wheelchairs

JM children don't often need wheelchairs for an extended period of time, so consider renting from the local hospital or rehabilitation center. Usually, the basic model is sufficient. You can arrange cushions, neck collars, headrests and pillows to keep your child more comfortable.

If your child will need the wheelchair for a longer time, buy one that will grow with your child. You'll find models with tilting backs and softer padding for more comfort. Ask your hospital or rehab center for their recommendations.

Many places, like malls and grocery stores, have carts, wheelchairs or strollers to use, either free of charge or for a small fee. For younger children, strollers or wagons are fun and prevent fatigue. Older children, who no longer fit properly in standard strollers, may be concerned about using a wheelchair because of how it "looks," but there are still options.

#### Strollers for your child's growing needs

If your child is too big for a standard child's stroller, Shari Hume suggests a "special needs stroller." One model is the **Maclaren Major Special Needs Stroller** (available online at [www.Adaptivemall.com](http://www.Adaptivemall.com), \$500 – \$700). There are also several additions helpful for JM children, including a sunshade and different pads. This stroller folds up like a typical umbrella-type stroller, measuring 10 x 10 x 44 inches without the footrest when folded. "We were considering buying a wheelchair for times when Parker is too fatigued to walk," says Shari, "but this is a much more attractive

alternative and doesn't have the same stigma attached to it." The 7-inch tires allow you to push with ease, and the front wheels swivel for easier handling. The Maclaren Stroller holds up to 140 pounds and includes a five-point harness system if you need to buckle your child in the seat. The web site offers help in choosing the right size.

A less expensive option is the **Pogon Buggy Stroller** (\$300+). This model holds up to 125 pounds and has several extras like a carrying bag and footrest. The **Convaid Metro Stroller** (\$450 – \$860) offers seat widths of 12, 14, 16 and 18 inches, with therapists available to help you choose the right size for your child. Depending on the size, the Metro Stroller holds children from 5 to 11 years up to adults at 250 pounds.

### AVOID THE MORNING RUSH

Mornings are hectic times for most families, with children getting ready for school and parents preparing for work. If your JM child has trouble with certain daily tasks, this adds on to the time it takes to get everyone ready. To avoid too much rushing around, get up a little earlier to account for the extra tasks you'll need to take care of as a parent. There are a variety of other products and strategies that can help, too.

#### Start your day off right

Eating is awkward and frustrating if finger and grip strength is weaker than normal. Several items are available to help:

- **Wide-handled forks, spoons and knives** improve grip. You can buy these already made or add foam or layers of duct tape to widen the handles.
- **Cutlery of different shapes** make scooping, spearing or cutting food



easier and help your child eat without your help.



■ **Non-slip mats or plates with suction**

**cups** on the bottom keep the plate from moving while your child is cutting or scooping food.

■ **Food bumpers** can be put on the plate to give your child a surface to push food against when she needs to concentrate on scooping, spearing or cutting.

■ **Cups with a textured surface** rather than a smooth surface prevent slipping.

### Dressing and daily hygiene

Even a simple task like brushing their teeth holds challenges for some JM children. Colby, a young boy with JM, uses a **Sonic toothbrush** as recommended by his doctor to help with bleeding gums from cyclosporine. The wider handle is also easier to grasp, and the battery-operated movement reduces the effort needed to brush.

Getting dressed creates another dilemma. Physical therapists recommend you choose **looser**

**clothing** as well as clothes and shoes with **elastic or Velcro fasteners**.

(See “Clothes for all ages”, page 3, for more detailed options.) Trouble holding their arms up, especially for an extended period, is a common complaint for JM children. One young JM child used a **reacher** and **long shoehorn** to help herself: “She thought they were neat because she was fascinated with gidgets, gadgets



and gizmos,” says one family member. “She also wanted to do things for herself and not have to wait for someone to help her.” She still uses the reacher to get things from the top closet shelf, even though she no longer needs it for lower items. **Long-handled hairbrushes** keep children from reaching as far to brush their hair.

### FIND A WAY TO PLAY

Playtime is essential for children, no matter what age. It may be difficult for them to participate in certain activities, like bike riding or contact sports. Find hobbies and interests that are compatible with the stage of your child’s JM. Puzzles, crafts, coloring books, computer games, and other activities will hold your child’s interest and give him or her a creative outlet. There are products to help children keep playing – holders to make playing cards easier (even for your younger children who haven’t experienced a change in mobility), easy-grip scissors, and slant boards for better positioning. (See page 15 for more on arts and crafts.)

For those who enjoy physical activities – and whose activities haven’t been restricted – try a therapy bike. “[The bike] had three wheels, a large safe seat with a seatbelt, and a big basket for her stuff,” says one JM caregiver. “She loved it because she had never been able to balance a bicycle and wanted to ride around the park with her sister.” This gave her the freedom she needed to play, but it also gave her family peace of mind that she was safe.



## HELP YOUR CHILDREN HELP THEMSELVES

It’s impossible to create a list of items every child will need over the course of the illness. Some will get by with few or no devices, while others need extra help for a longer period. Each child’s needs change over time, too.

So how do you decide what to use and when? Therapists are available to develop a plan that can help you and your child with daily activities. Here are some things to consider:

■ **Keep safety in mind.** Keep a non-slip mat in the tub or shower to prevent falls. Determine what areas may create extra hurdles for your child.

■ **Make your child aware.** Talk about how they can help themselves. Be sure your child understands the need to rest so they won’t burn out. Discuss how they might get around certain obstacles on their own.

■ **Focus on strengths.** It’s important to interact with others, but soccer, bicycling and climbing may be out for a while. Try less strenuous activities - board and computer games, or arts and crafts - then invite others to come over and join in the fun.

■ **Encourage independence.** Therapists recommend using the least restrictive device possible. All parents want to help their children succeed without frustration. When children do things on their own, the rewards are immeasurable.

■ **When in doubt, talk to others.** Use TMA’s online Bulletin Board and email listserv for JM families to hear how others have handled certain situations. Though each child is different, other families are an invaluable resource.

## Beyond medicines: strategies for JM families

### More on skin protection

Skin sensitivity is a common concern for JMers, and sun protection products and strategies are a mainstay in JM households. “We had sun protective film put on all of our household windows,” says Suzanne Printz. “Prior to this, we kept curtains drawn and the house was dark and dismal. The window screening gives us peace of mind that Abby is ‘safe’ against the UV rays while at home.” The sun’s harmful UV rays reach you through windows, on cloudy days, and in other seemingly unlikely conditions.

For more variety, families buy products with UV protection in the material – parasols and umbrellas, canopies, clothing, and hats. Donna Anderson appealed to her son’s school to place light filters on the fluorescent bulbs in Colby’s classroom. These filters can move with Colby as he changes classes from year to year. She has also looked into an Ex Officio Buzz Off® outfit – clothes with UPF 30+ and an insect shield. These are a bit pricey but worth the expense to protect her son.

### Setting up your own web diary

“My husband set up a web site for our son,” says Condie Ward, “which was a therapeutic activity for him and led to many connections for getting and sharing information.”

Ralph Becker initiated “Julia’s JDMS Diary” when she was first diagnosed with juvenile dermatomyositis, sparking a number of other online diaries and journals. Most families new to JM find Ralph and Julia’s information online and soak up the detailed entries on treatments, side effects, emotional aspects, and more. Both Ralph and Julia graciously provide their email

addresses for others to contact them directly.

### A more personal approach

“I have created a photo journal for Quinn,” says his mom, Karen. “I have photographed the process of the home health visits and the doctor visits. I am in the process of creating a scrapbook for him – something to look back at later when he is in remission.”

If your children are young, they may not remember much about their experience with JM. Because this was a major event in their lives, some children would like to know more. Having a pictures-and-words diary helps you as you retell the stories to them. Several parents have commented that they wish they had kept a journal to remember all of the medicines and their side effects. You may think you’ll never forget, but most parents have told us that their memories of treatment details have faded over time.

### Teaching them to take responsibility

“He reads the food labels for fat and sodium content because he knows that ‘low sodium and low fat are best,’” says Karen. Quinn also helps his home health nurse, Theresa, take inventory of his medicine cart and mix his medicines. Having a

sense of control helps him deal with the different treatments and adjustments that accompany JM.

For the same reason, it’s best to allow children to

choose meals among the healthful options available. Children won’t dread the food limitations each meal

since they’ve decided on their own menus. Since lower sodium and lower fat are better in general, your family can enjoy healthier meals, too.



### HERE WE GO AGAIN...

Sometimes it's not equipment or medical supplies you need but distraction. Your child endures needle pricks, pokes and prods, and after a while, this routine gets old. Candy and other sweet treats only work for so long.

So what can you do to help your child get through these long treatments and doctors' appointments?

- Read a book. Find a chapter book that'll keep your child interested so she'll look forward to what will happen next.
- Create. Arts and crafts are a great diversion. Use this time to make gifts for friends and family or to just dabble in different things.
- Watch a video. It may be the same video time and time again, but as long as the story holds your child's attention, it has done its job.
- Have a party. If your child has home health nurses to administer IVs at home, invite one or two of his close friends over for some quiet activities during the treatment.
- Talk on the phone. Does your child have a special friend or family member out of town? Let this be the time to call on someone she doesn't talk to very often.

There are many activities you can find if you use your imagination!



# Companions serve the disabled in surprising ways

By GREG GLASSNER

*Editor's note: We've been following with interest the use of dogs to help people with disabilities other than blindness. Thanks to Greg Glassner, Managing Editor of The Madison Eagle for his article on a man and his companion dog.*

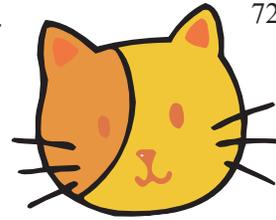
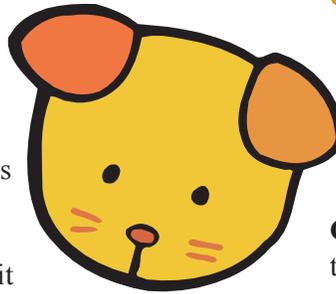
Kevin Seale is a gregarious man who spent 25 years of his life working outdoors. Six years ago, he was diagnosed with Multiple Sclerosis. Seale now spends much of his time at home, jetting around the house and deck on an electric scooter. It has been quite an adjustment, but one made more bearable by his new companion, an assistance dog named Shamrock. Shamrock is an 87-pound, 2 1/2-year-old "Labradoodle" (part standard poodle, part labrador with a father who was a golden retriever). Shamrock has an even disposition, shaggy hair and a friendly, almost human face.

So named because he was born close to St. Patrick's Day, Shamrock is a highly-trained companion for people with disabilities – a graduate of Manassas-based Blue Ridge Assistance Dogs, Inc. Shamrock can pick up items Seale drops, turn the lights on and off, pull a wheelchair, open heavy doors, push elevator buttons, carry items in a backpack and accomplish other tasks that Seale finds difficult, even impossible.

In the final stages of his education, Shamrock trained with Seale to cement the bond between them and to iron out key commands. "The dog actually has to bond to me. I had him since the third day of training together. We commuted together to Manassas."

"He's a tremendous help to me," said Seale, who is home alone on weekdays. "If I tipped over or fell out of my scooter, he's trained to get

help by going to a neighbor's house." Other tasks Shamrock has mastered are fetching the phone when it rings and taking things out of the refrigerator. "We keep the things I'll need on the lower shelf," Seale said. A sixth sense even tells Shamrock when Seale's diabetes is out of control.



## SOURCES:

**Blue Ridge Assistance Dogs, Inc.:**  
www.blueridgeassistancedogs.org;  
8600 Smith Lane, Manassas VA  
20112; 703-369-5878

**Canine Assistants:** www.canineassistants.org; 3160 Francis Road, Alpharetta GA 30004; 800-771-7221; info@canineassistants.org

**Canine Companions for Independence:**  
www.caninecompanions.org;  
P.O. Box 446, Santa Rosa CA  
95402-0446; 800-572-2275



Almost as important as the physical assistance Shamrock provides is the companionship. "I'm here by myself basically eight to ten hours a day. I can talk to him and he doesn't talk back," Seale said. Seale first realized he had a health problem in 1996. "I couldn't walk a course and keep up with a group," he said. In 1997, at age 45, Seale was diagnosed with MS. A big change in his lifestyle followed. "I lost the use of my legs, one at a time. I can tell my hand what to do and it did it. I can look at my leg all day long and it doesn't move," he said. He and his wife Maggie started looking for an assistance dog about two years ago, found a program nearby through the Internet, and waited for about a year. Seale entered into training with Lydia Wade Driver, who runs Blue Ridge Assistance Dogs, Inc.

The dogs begin when they are puppies, cared for by special puppy trainers who work with the dogs until they are ready for advanced training. For Seale, training included a shopping trip together with Shamrock at a nearby mall. For him, Seale said, the companionship is as important as the assistance.

## PETS FOR HEALTH

If you have pets, you've already experienced their uncanny ability to sense how you're feeling and react to it. Whether it's a dog nuzzling against you or a cat purring on your lap, pets create a sense of calm that brings about health benefits for you as well.

Mayo Clinic documents this important relationship in a recent e-newsletter. Research shows that caring for pets lowers blood pressure and decreases the likelihood that you'll feel depressed and lonely.

Do you have the time, space, money and physical ability to care for a cat, dog or other pet? If so, reap the benefits of companionship and better health.

## Ingenious solutions keep gardens growing

No activity combines our connection with the earth with our need to create as well as gardening. TMA members have found ways to stay in the garden, overcoming weak muscles and limited mobility with ingenuity and determination.

Dorris Norris, known by many as the “Flower Nanny,” has some suggestions for myositis patients who want to keep their hands in the dirt. Dorris finds that she has a better grip using hand tools with thicker (fat) handles. Something true in all gardens is that it’s always easier to pull weeds or dig with a trowel when the soil is wet. Other hints from Dorris:

- I have a rolling garden stool that I sit on; I can still get off it by putting my hands on either side and pushing up. It is hard, but I am determined to do it as long as possible.

- I load everything I might need in a yard cart: plants, tools, gloves, phone, etc. This saves me going back to the house to get things I need; when I finish, I load everything in the cart for the trip back to the house.

- I walk with my cane in one hand and pull the cart with the other hand. I take one step at a time, pull the cart a little ways, give the stool a shove with my foot, and repeat the process until I get to my flower garden.

- I go out very early in the morning, about 7:00 am, and try to limit myself to working about an hour; then I come in and rest on the bed for an hour. Before IBM, I worked in my yard all morning on many days; I could always see something else I

wanted to do. Now, I don’t work outside in the heat of the day because it makes me weaker. I don’t garden at all in July, August and September, because we have such hot, humid days here (Dorris lives in Mississippi). I have to let the weeds grow during those months. There is something very therapeutic about pulling weeds, setting plants and watching them grow.

### Gardening your own way

The University of Missouri has a wonderful web site devoted to gardening for people with various types of disabilities at <http://outreach.missouri.edu>. Jeremy Diener, who collected most of the information for the site, believes that gardening can be a very good activity for people with disabilities, as long as they give some consideration to their own special needs. Here are some of Dr. Diener’s suggestions, used with his permission:

- Try raised beds. Raised beds provide an excellent option if there’s space and mobility to allow you to care for these beautiful garden plots. Each raised garden bed will be different depending upon the needs and desires of the individual gardener. As a general rule, though, all raised bed gardens should be easily accessible and fit aesthetically into the surroundings.

- Use garden pathways. Pathways through your garden are important, especially if you have disabilities. Garden pathways can be made out of almost any material, depending upon who will be using the pathways most often. Whatever the material, paths should be firm, level and smooth, and the grade should not exceed a 5 percent rise in elevation. Paths should

be of an accessible width for someone in a wheelchair or using the assistance of a walker to easily turn around, and there should be a clear beginning and end. You’ll need to use appropriate edging to indicate the borders of your path, and you’ll want to use textured surfaces for better traction if you are not in a wheelchair. As an extra safety precaution, Diener recommends that you use contrasting colors and textures to increase visibility of your pathway and install garden lights to aid in visibility. It’s a great idea to place seating areas along your pathway for rest breaks.

- Be kind to your body. Diener advises people with muscle or joint weakness and pain to warm up joints before beginning to garden, and do some light stretching to reduce soreness later on; to keep tools and watering sources near the garden to cut down on extra steps and conserve energy; to garden at times when you feel the strongest; and to use proper tools (see next page) and keep them in good condition. For those with weak upper-body muscles, he advises

you to use the largest muscle group possible to complete a task. For example, when carrying a bag of tools, place the bag on your forearm and let the large muscles of your arm do the work

instead of carrying it with your hand. You should use a stool or knee pad when working on or near the ground to protect your knees, wear gloves to protect your hands, and change positions frequently to avoid becoming stiff.

- Choose the proper tools. Using the right tool is a vital part of successful gardening. Whatever style of tool you choose, try to find tools with



a depression or ridge in the handle for your thumb to rest on, as this will keep your hand in the proper alignment. Use tools with longer handles to cut down on the need to bend over or kneel, keep tools sharp and in good condition to conserve energy, and use the lightest weight tool possible to complete tasks.



### SOME HOMEMADE MODIFICATIONS MAY HELP

Modifying your own garden tools may be the cheapest way to have custom tools. Almost anything can become an adapted tool. Diener gives some suggestions, but invites you to use your imagination to find more ways:

- Use a length of PVC pipe and a funnel to plant larger seeds.
- Place small seeds in a spice jar and sprinkle them onto the garden.
- Use baseball tape wound around the handle of your tool to create a larger surface area to grip. (Duct tape or any sporting grip tape will provide this thickness as well.)
- Create a PVC pipe handle by heating an appropriate length and diameter piece of PVC pipe to 235 degrees in the oven. **\*\*BE CAREFUL: the PVC will be hot!\*\*** Slide the pipe onto the handle of your tool and gently squeeze to create a firm grip.
- Purchase bicycle grips and slide onto the ends of tool handles.
- Use foam pieces to enlarge the size of the handles on tools.

## Discover your creative side

Though most people don't spend the time they'd like on arts, crafts and other hobbies, these activities provide an invaluable outlet to relieve stress, frustration and other negative feelings. If myositis has reduced your ability to continue working on the hobbies you've enjoyed in the past, you can discover new interests or find ways to adapt your current hobbies to account for any loss of weakness or mobility.

### Arts and crafts for kids

Children have a strong need for arts and crafts in their lives as a way of expressing themselves, especially for younger children who can't yet put their feelings into words. Some of the smaller supplies used in certain crafts, though, are tough to hold or to put in place. Even holding crayons, markers and paintbrushes is an exasperating task for some.

What you choose is an important part of your child's therapy as well. "Be creative in your activities to include stretching and range-of-motion," says Dr. Lisa Rider (NIEHS, NIH), answering a question on exercise. "Do something fun, like painting, as a method of stretching." One young JM boy participates in art therapy as a means of getting in touch with his deeper feelings.

Art supplies are often adapted for little hands; these items are also helpful for those with limited grip and mobility. Some to consider:

**Paintbrushes** [i.e. Crayola So Big Brush, [www.crayola.com](http://www.crayola.com), or Beginner Paintbrush Set, [www.alextoys.com](http://www.alextoys.com) or [www.specialkidszone.com](http://www.specialkidszone.com)]

### Large-size crayons and markers

[i.e. Chubbi Stumps crayons, [www.kaplanco.com](http://www.kaplanco.com)]

### Sponges or sponge-tipped painters

**Finger paints or finger brushes** [brushes at [www.specialkidszone.com](http://www.specialkidszone.com)]

### Art easels or slant boards

[[www.specialkidszone.com](http://www.specialkidszone.com)]

Many of these items are available at larger discount or department stores, while others are only sold at specialty stores like Zany Brainy, Imagination Station, Imaginarium, Alex Toys, and through Internet sites. Remember, it's always possible to modify what you already have to fit your needs. With paintbrushes, for instance, thicken the grip with foam.

### Doing what you love

"I do a little handquilting as a small business," says Mary, who suffers from DM. "It usually takes me about four months to do a bed-size quilt. The physical therapist said not to do repetitive motion tasks for more than 20 minutes. I am having a hard time accepting that my quilting days may be over."

From this Bulletin Board post came a host of responses, encouraging Mary to find new outlets or to keep experimenting with her quilting. For many of you, your bodies will let you know when

you've done enough. So how can you continue doing what you love to do? If you crochet, for instance, Access to Recreation offers a Crochet Aid. Through a series of Velcro bands and rings, this gadget helps



## More than making do: building a house that works

By Harris Teller

*Editor's note: Harris Teller was planning the home of his dreams when he hit a snag. With some positive thinking and good help, Harris now lives in this dream home. Here's his story in his own words:*

This saga starts with disappointment, frustration and anger. Briefly, I was expecting my new manufactured home in 30 days. The design was perfect for my needs, the price was in the “ballpark” and I had found an adult community I liked. A phone call brought months of planning and anticipation to a halt...the manufacturer cancelled the order. As I was in the mobile home park at the time, I asked if there was possibly something for sale that might meet my needs. Enter the sow's ear.

Initially, the only good thing that could be said about the manufactured home in Space #8 was that it had a very long ramp that made for easy access. It had been vacant for over a year. Further, it was old and tired looking. Small and narrow were the key words – small kitchen, small bathroom, small bedrooms, a narrow hall, narrow doors throughout, and, oddly enough, large closets. Against the advice of family and friends I began to investigate the feasibility of transforming this neglected place into the serviceable “home of my dreams.” I had spent considerable time planning a safe and efficient living space for someone in a wheelchair living alone. All I needed to do was apply that concept to #8.

### Finding the right help

First, I had to locate a contractor who specialized in manufactured homes. Second, he had to be a contractor who could be sensitive to the special needs of the disabled and very conversant with ADA regulations. This was not as easy as it sounds. Finally, I found

a contractor who fit my requirements – except they had never ADA retrofitted a manufactured home completely. We agreed on a feasibility study by their staff. The designer and I felt that the key was a space large enough for a complete ADA bathroom.

By incorporating the laundry space from the kitchen area, taking space from what would be the spare bedroom and removing the water heater, more than enough room was found. The retrofit was indeed possible.

### Trading spaces

The final design of the bathroom included a large roll-in shower, a raised toilet, an over/under laundry unit, an elfa® basket unit in lieu of a cabinet, a wall-mounted medicine cabinet, various accessible shelves and storage space.

(Note: The elfa® system allows you to design your own drawer styles, including sizes, using ventilated covered steel baskets that can be mounted in closets or free-standing systems.) In the center was more than the five-foot diameter required by ADA. One important feature of the bathroom is that in addition the usual grab bars, both the large towel rack and the shower curtain rod are secure grab bars as well.

Next the kitchen was designed. In order to make room in what had been a very narrow kitchen, the inside wall was moved several feet into the grand room. The counters, including the stovetop, are all at the height necessary for easy use by a person in a wheelchair. Again elfa® basket units

were used in lieu of cabinets and drawers. The basket units can be pulled out with just one finger or with a hook attached to a dole. The oven is a combination microwave/convection. The design also incorporates a movable island for additional storage and workspace.

The dining area is at the end of the kitchen; it will seat three others besides myself comfortably. I was able to use the china cabinet and dining table from my old house by careful space planning. A large window was installed at the end of the area to create a link with the outside. On the wall between the kitchen and the dining area, we attached a small drop-

leaf table that I use when I eat alone. It also acts as a desk.

The grand room serves two major purposes. One end is my office and the other end, my family room. The room was made to appear larger by removing the glass doors to the closed-in porch.

This porch has become the main entry and the library/museum. With the main entry door open, one can sit and read and feel as if they are in a tropical garden. Plants line the ramp on both sides right up to the door.

The windows of the master bedroom also open on to the ramp area. This and the solar tube give the room a feeling of being outdoors. The dresser uses the elfa® basket units and the closet area has pull-down clothes poles that pull down easily for removing garments and retract almost by themselves.

The hallway between the bathroom and the bedrooms is extra wide



## The tailored kitchen

As baby boomers plan ahead for the future, many are looking at the concepts of universal design, and that interest applies to kitchen design as well. That's not only because everyone foresees a time when it will become harder to cook, but because many have become comfortable entertaining in the kitchen, with guests and family helping, and would like to include guests who are disabled or frail or parents who may visit for extended periods of time.

### Thinking ahead: a kitchen with your needs in mind

The kitchen that seems so efficient to you may look like an obstacle course to even an experienced cook in a wheelchair. Making meals and cleaning up is really a series of tasks requiring many stages that flow almost instinctively and involve appliances, plumbing, fixtures, storage, ingredients and tools.

If you or a relative spend part of your time in a wheelchair - or anticipate that you will - it's wise to think carefully about your kitchen needs. If you're looking at homes that claim universal design, you may be surprised at the wide variations in the kitchens you see: some are suitable; some are not.

If you're building your own home, experts advise that you go carefully through the steps it will take you to store, find, prepare and cook food. By analyzing the steps carefully, you'll end up with a kitchen that is truly workable for you.

If you live alone, the kitchen layout should respond to

your capabilities. If you live with a partner who is not in a wheelchair, the design should fill the needs of both



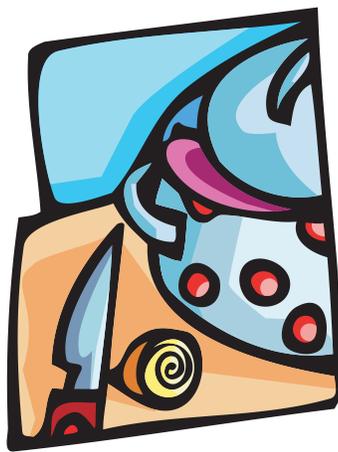
people. This requires a slightly different approach to the design. If you never do any cooking, you may not want to alter the kitchen at all. But if you do, some crucial planning will help you continue with this most nurturing and creative of household chores.

### Planning your efficient workspace

Everyone is familiar with the "kitchen triangle," the three work centers that define the work of any kitchen. They are the stove and oven; the refrigerator and freezer; and the sink, disposal, and dishwasher. These centers should be set up to follow the natural sequence of work for food preparation and cleanup.

For example, food is usually removed from the refrigerator or cupboard, washed at the sink, and then prepared at a work counter. Then it's placed in a pan or pot and put on the stove or in the oven. When the meal has been served, the cleanup has its own pattern: dishes are scraped and rinsed at the sink, then put in the dishwasher. When it's time to unload the dishwasher, the dishes and utensils are put in the cupboards and drawers. It really doesn't matter whether these chores are done in a right-hand or left-hand flow, but you may feel more comfortable with one or another.

A number of different arrangements are workable, including U-shaped, L-shaped, and galley kitchens. The U-shaped kitchen often provides the best efficiency for a wheelchair user because the countertop is more continuous. For these cooks, the galley-



style kitchen is the most difficult to use. Work spaces on the counters near each of the work centers is particularly important for people in wheelchairs, since those with impaired mobility often set their tools or ingredients down as they reposition themselves at the next work center.

As a general guide, the refrigerator and freezer should have at least a one and one-half foot wide countertop next to the opening side of the unit; the sink and dishwasher should have at least three feet of counter to the right and two feet to the left (assuming a right-handed user); the stove and oven should have two feet of countertop on each side.

As a rule, you should work for a minimum of ten feet of countertop in any kitchen. In some kitchen arrangements, part of the workspace can be supplied by a table. Proper kitchen design puts few obstacles in the flow of work. For cooks with impaired mobility, the countertop should be as continuous as possible to link the workstations with level surfaces. If the kitchen is to serve the needs of several users (for example, a spouse or other family member), the proper height for the countertop should be carefully considered. A standard counter height is 36". (In Europe, most counters are slightly higher, at 37".)

As a general rule, work surfaces should be higher when users are performing close work that requires precise actions. On the other hand, tasks requiring more physical strength, like rolling dough or mixing ingredients are easier to do on a lower countertop. For most people in a standing position, the standard kitchen-counter height is a reasonable compromise between these levels. Many people who use wheelchairs or walkers elsewhere are comfortable without them

## Dress yourself in style:

### Ms. Wheelchair Virginia shares her tips for wheelchair users

Pam Coble Clark's accomplishments speak for themselves and have nothing to do with the fact that she's in a wheelchair. Pam – Ms. Wheelchair Virginia – has a doctorate and works as an administrator at a state community college. Her determination and optimistic spirit enabled her to move from being a primary grade school teacher to a high-level administrator. They've also influenced and inspired her long struggle to find meaning and vision in her life after a motorcycle accident left her in a ditch by the side of a road with her spine broken in several places, bones shattered, ribs cracked and her whole body torn and bruised.

As a professional person and a woman of pride and strength, Pam's goal was not only to succeed academically and professionally but to present herself as positively as possible. "I've always taken a great deal of pride in my appearance," Pam said. "I think now it's even more important." She's well aware that when she meets people now, they may have preconceptions about people in wheelchairs – stereotypes she can perhaps change with her own brand of style, personality, and grooming.

With a serious physical therapy regimen every day, Pam may someday leave her wheelchair: until then, she's determined to have a physical presence that will reflect the most positive things about her. After receiving her doctorate, she was approached by Ms. Wheelchair Virginia organizers with information about this competition. They heard about her from Miss Virginia, who had met Pam in a professional educator's group and believed Pam would be a wonderful advocate for wheelchair users. "I really investigated this," Pam said. "I called and questioned them several times. Finally, I became convinced that I

could have a positive role here and entered." Pam won the title and is now in the running for Ms. Wheelchair America.

#### Looking good, feeling good

There's no question that looking their best gives everyone – wheelchair users and walking people; men and women – a real boost and promotes positive interactions with other people. Pam found it very important before her accident, and this didn't change afterwards.

"I was barely conscious, in pain and still hospitalized when the people from my spa showed," she said. They washed her hair, polished her nails and toenails, and rubbed her skin with lotion. "That was the most loving, helpful thing anyone could have done," she said. "It did wonders for my morale." Pam has a dream of someday opening her own spa, one that would cater to people with disabilities, with comfortable shampoo stations, various lifts, massage tables, and manicuring areas set up so that anyone with a disability could be comfortable.

Pam had a full, energetic life before her accident. She bred and rode horses, taught school, modeled and rode motorcycles. She had been an accomplished gymnast and loved athletics of all kinds. She learned a lot of what there is to know about disappointment and courage after the catastrophic wreck. "I never questioned why," she said. "I've always known that things just happen, and they happen to everyone." She learned even more after she became Ms. Wheelchair Virginia. "I'd stayed

mostly with my old friends, walking people," she said. "After the pageant, I began to know more people in wheelchairs and my eyes were opened again. There's so much pain, worry and fear. I'm convinced I can do something to make a difference for them."

#### Pam's creative ways

Pam's regimen is not for everyone. Some of her tips are just "Pam things," as she says. She's willing to take whatever time it takes to try to look her absolute best – in her case three hours some days, less on others. She delights in nail polish, jewelry, sequins, furs and three-inch heels. She completes her physical therapy religiously, five days a week, and includes time in a standing box as well as stretching and strengthening exercises. She's able to use her arms, so the makeup and hair styling are not the problems they might be for some people with myositis. She has many good ideas, won from personal experience:

■ Keep it simple. Pam used to wash her hair every day and wear it many different ways. Now, she washes it every three days, pulling it away from her face on the second and third days.

■ Find what works and stick with it. Dressing is difficult when you can't leave your chair. Pam has found yoga pants at Victoria's Secret that slip on. She wears the black pants (size extra small, extra long) almost every day. "I found that nothing worked better," she said, "so now I just provide variety with my tops." The black is to hide marks that come from dirt getting on her wheels, then her hands. Pam finds tops she likes – sweaters, tube tops and tops with spaghetti straps – and buys some in every color.



Pam Coble Clark

“This has worked so well that my sister (not in a wheelchair) now does it, too,” she said. “Once you have a certain style that works, why not just make it your style and vary it with color?”

■ Buy tops that end at the waist. For obvious reasons, wheelchair users don't want things hanging out and bunching up. Pam wears leather jackets that fit snugly at the waist. When she's out in bitterly cold weather, she brings blankets to cover her legs.

■ Keep changing temperatures in mind. Pam knows she can't always move out of a draft or away from a sunny window, so she tries to buy tops that have matching cover-ups.

■ Pay attention to your teeth. A nice smile goes a long way towards the first impression you make. Pam found out from her dentist that store-bought whitening strips are just as effective as expensive treatments from a dentist.

■ Buy pants a little longer than you used to. Pam needs extra long pants because of her three-inch heels, but she also has found that pants that will always be seen from a sitting position should be longer. “Maybe this is just a ‘Pam thing’,” she said, “but I like for my pants to meet my shoes with no gap in between.”

■ Take the time. “If it's important for you to look presentable and together, you can find the time,” she said.



## We want to hear from you!

Have you found some items you just can't live without? Share them with us to include in the 2005 Products Issue of *OutLook Extra*. We certainly can't put this resource together without your tips, so help us help others with myositis! Write, email or call with your ideas.

## In the market for a wheelchair? Start with a mouse

*Editor's note: We wrote at length about choosing a wheelchair in the first Products issue of the OutLook Extra. Request a copy for more information on which type of chair may be right for you. Meanwhile, a few pointers for shopping online:*

■ Why should I start with an online search? Finding a wheelchair by searching the Internet is a good way to research and compare what types of wheelchairs are available. Online shopping is easier for most people with a disability than in-store comparison shopping in the event that there is no wheelchair convenient to you.

■ What should I look for? Don't pick something immediately from the first site you visit. You may be surprised at how many choices you actually have. The best web sites give you advice on how to have someone properly measure you for comfort and safety. Be aware that accessories are important: wheelchairs can be ordered with specific upholstery; features like different types of armrests and seat-backs; and helpful additions like batteries, baskets, weather canopies and a host of others. Some online mer-

chants sell used wheelchairs, considerably cheaper than new ones.

■ What other factors should I consider besides price? Price should never be your only consideration. Find out if the wheelchair will be financed or if the site has a low price guarantee. Ask how long it will take to ship the wheelchair and if it is possible to have shipping expedited. Ask about warranties, return policies, and service contracts. Find out your options for checking the status of an order, tracking delivery, toll-free numbers, email help, and other online tools.

■ How else can I gather information? It always pays to ask your friends, family and disabled associates for their experiences with specific wheelchair models. The Myositis Association's bulletin board, for example, will lead you to personal referrals. Also check to see if any of the wheelchair manufacturers or models has earned the endorsement of any legitimate, third party rating entity.



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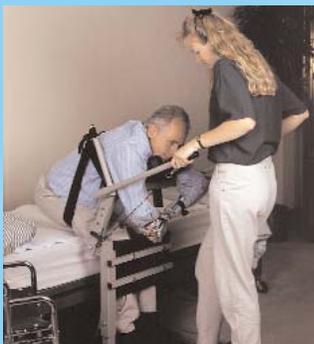
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## Everday tips,

continued from page 6

movies to you postage-free (within the U.S.) as they're available. Once you finish, return the movies to them, again postage-free.

### A good night's rest

"The problem is not being strong enough to turn over in bed nor being able to slide over the bottom sheet to help those efforts. Many people have solved it with silk or satin sheets. That would not work for me. When sitting down on or getting up from the side of the bed my condition is such that I would be in great peril of sliding off onto the floor. My question is does anybody have any experience with some kind of cotton sheet tightly woven and hard finished?" Jack/IBM

"What has helped me the most are polished cotton sheets with a thread count exceeding 300 tpi [threads per inch]. I love the 800 thread count sheets the best, but paying over \$100 per sheet is too much for me." Jim/IBM

"Would this work? Sew a panel of a piece of satin (go to a fabric store) down the middle of your sheet. This might help you to turn over in bed but not slide out of bed since the satin is not on the side." Julia

"Sheets made from pima cotton are smoother. KMart (in my area) is the only place I know of that has them." Dorris/IBM

### The debate on braces

"I have discussed the use of braces with both my physiatrist (an MD) and my PT. Both have advised against braces, at least for now. I have successfully used a walker and have only fallen once in 1 1/2 years – that was when I bent over and leaned on something which moved. I now use a grabber to minimize the need to bend. I know that we are individuals and

that no one device works for all." Richard/IBM

"I have ankle braces on both legs and they keep my foot from dropping so that I don't catch my toe and fall. The only trouble I find is going down a ramp they have a tendency to push you forward as your ankle can't bend and therefore I back down any surface that has an incline. They are a bit heavy but I can not get around well without them. A bit warm in the summer but they help me. I have used them for about 7 years. I also have full braces but choose not to use them." Bob/IBM

"I have been using Otto Bock walk-on AFOs ([www.ottobockus.com/products/op\\_walkon.asp](http://www.ottobockus.com/products/op_walkon.asp)) for my foot drop, and they are great. They are carbon fiber and consist of nothing but a sole piece and a side-attached post that runs around your ankle and up behind your calf to just below the knee, where it is stabilized with a Velcro strap. There is no joint, but the fiber has enough flexibility to adjust to inclines. They only weigh a few ounces, and except under the Velcro strap, they don't enclose anything, so no sweating discomfort. They are so slim that you can stuff them into any shoe. Before I developed serious upper-leg weakness a few months ago, I'd do 6 to 8 mile hikes on uneven terrain with no problems." Burkhard

## Building a house,

continued from page 14

and has carpeting attached three feet up the wall. All of the interior doors are "pocket" doors.

### Safety first

Additional safety features include:

- All exterior doors are equipped with "Quik Release" deadbolts.

- The home is fully alarmed – burglar, smoke and medical emergency.

- There is a Knox box, which contains a house key outside the front door for the paramedics.

- There are speakerphones in every room of the house, including the bathroom.

### The final touches

The outside has been made an extension of the living space. I can breakfast outside on nice days or curl up in my chair on rainy days surrounded by relaxing foliage. No matter where I am on my property, I am never more than a few seconds away from anywhere else. My extra wide wheelchair is easily accommodated in all the rooms and spaces.

I am pleased that I have been able to create a safe, attractive, and efficient environment out of approximately 800 square feet while recreating much of the feeling of my previous 3000-square-foot home.



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### Southern California

Anaheim (800) 879-4844  
 Riverside (800) 226-9765  
 San Diego (800) 736-4872  
 S. Luis Obispo (800) 879-4872  
 Palm Desert (800) 226-9765

### Northern California

Hayward (800) 824-8400  
 Modesto (800) 817-1417  
 Sacramento (800) 793-1195  
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## Creative side,

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those with limited dexterity. With a little creativity, you may be able to craft your own tool to help with sewing, crocheting, needlework, knitting, and other activities.

Painting was a natural choice for Mike Shirk, whose wife is a watercolorist (see *Staying in the game* from the June 2003 *OutLook*). "I've taken classes and workshops, joined art organizations, entered local competitions and am having more fun than I did before I was diagnosed!" Mike says. Dagmar Slaven chose to create origami "Wings of Hope" when prompted by her TMA Keep In Touch support group leader to come up with a fundraising idea. "I look at the action of paper folding as some sort of therapy, mental as well as physical," she says, "but I am very much aware that it cannot reverse the damage that is already there. I look at it more as some sort of 'carpe diem' approach, make the most of things while I am still able to do them." (Dagmar would love to share the plans for her "Wings of Hope" with others. Contact TMA if you're interested.)

You'll find classes at your local community college or centers teaching a variety of things – painting, photography, scrapbooking, and more. Find something you think you'd enjoy, then go for it!

## RESOURCES:

### Access to Recreation:

[www.accesstr.com](http://www.accesstr.com); 8 Sandra Court, Newbury Park CA 91320-4302; 800-634-4351 [Click on "Aids for Daily Living" to view the Crochet Aid]

### Achievement Products, Inc.:

[www.specialkidszone.com](http://www.specialkidszone.com); P.O. Box 9033, Canton OH 44711; 800-373-4699

**Assistive Tech:** [www.assistivetech.net](http://www.assistivetech.net)

**Alex Toys:** [www.alextoys.com](http://www.alextoys.com)

**Crayola:** [www.crayola.com](http://www.crayola.com)

**Kaplan:** [www.kaplanco.com](http://www.kaplanco.com); P.O. Box 609, Lewisville NC 27023-0609; 800-334-2014



## Tailored kitchen,

continued from page 14

in a kitchen, where there is always something to lean on. For a person who must be seated in a wheelchair, however, the standard height may not be workable at all. To solve this problem, the entire kitchen counter can be lowered to 34" except at the dishwasher. This is a little difficult for ambulatory cooks, so another approach is to lower specific sections of countertop, like a countertop workspace, the sink or a cook top. While this solves some problems, it makes the intersections of the different countertops awkward to use, so these changes should be well thought out. A more sophisticated and costly alternative is an electrically operated,

adjustable-height countertop that's raised or lowered to accommodate each user.

## Tweaking the small stuff

When the cook's in a wheelchair, many small adjustments can make a big difference. For instance, one handicapped cook I know has all the controls at the front of the stove, so she doesn't have to reach across a hot burner to turn the stove down or up, or to turn the oven on. She's also used only under-counter storage, with pots, measuring cups and ingredients on shelves with lazy susans, and she's got a number of stations around the kitchen where she can set a heavy or hot pan or pot down without reaching up. Get to know not only the design but the kitchen gadgets that are helpful, and you and your family will benefit from the independence and satisfaction that comes from a creative kitchen.



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## RESOURCES

### JM-specific products and strategies:

**Adaptive Mall:** 1-800-371-2778  
www.Adaptivemall.com;  
info@adaptivemall.com; Bergeron  
Health Care, 15 Second Street,  
Dolgeville NY 13329

**Baby Jogger Company:** 1-800-  
241-1848; www.babyjogger.com  
(click on "Special Needs");  
sales@babyjogger.com or trosen-  
burg@babyjogger.com  
(International); 1907 South 14th  
Street, Union Gap WA 98903

**HealthCheck Systems, Inc.:** 1-  
888-337-4684 or 718-339-6212;  
www.healthchecksystems.com  
(click on "Baby Care Products"  
then "Baby Jogger...");  
sales@healthchecksystems.com;  
P.O. Box 230215, Brooklyn NY  
11223;

**Recreational Equipment, Inc.  
(REI):** 1-800-426-4840 (US and  
Canada) or 253-891-2500  
(International); www.rei.com; REI,  
Sumner WA 98352-0001 [Ex  
Officio Buzz Off® Clothing]

### General:

**Access to Recreation:** 1-800-634-  
4351; www.AccessTR.com; 8  
Sandra Court, Newbury Park CA  
91320-4302

**Achievement Products, Inc.:** 1-  
800-373-4699; www.specialkid-  
szone.com; P.O. Box 9033, Canton  
OH 44711

**Disability Products:** 1-800-688-  
6794;  
www.disabilityproducts.com; 5447  
East Elmwood Street, Mesa AZ  
85205

**Dr. Leonard's:** 1-800-455-1918;  
www.drleonards.com; P.O. Box  
7821, Edison NJ 08818-7821

**Dynamic Living:** www.dynamic-  
living.com; 428 Hayden Station  
Road, Windsor CT 06095-1302;

**Knox-Box Rapid Entry System:**  
1-800-552-5669;  
www.knoxbox.com; 17672  
Armstrong Avenue, Irvine CA  
92614.

**Maddak, Inc.:** 973-628-7600; 661  
Route 23 South, Wayne NJ 07470

**Maxi-Aids, Inc.:** 1-800-522-6294  
(to order) or 631-752-0521 (for  
information);  
www.MaxiAids.com; 42 Executive  
Blvd., Farmingdale NY 11735

**Rolli-Moden:** 1-800-707-2395;  
www.rolli-moden.com; 12225  
World Trade Drive, Suite T, San  
Diego CA 92128

**Sammons Preston Rolyan:**  
www.sammonspreston.com; 4  
Sammons Court, Bolingbrook IL  
60440

**The Container Store** (elfa shelv-  
ing system): 1-888-266-8246;  
www.containerstore.com

**Wisdom King:** 1-877-931-9693;  
www.wisdomking.com; 2410  
Cades Way, Unit B, Vista CA  
92081

## TMA is a resource, too

### Online support

The Myositis Association's web site is filled with useful information, links and stories. Check [www.myositis.org](http://www.myositis.org) for:

- TMA equipment exchange (Marketplace). Whether you have something to sell or need a particular device, this exchange allows you to find a suitable buyer or just the right item.
- Bulletin boards (Community Forum). Stay in contact with others by posting what helps you deal with the daily challenges of myositis - both physically and emotionally - and reading about other people's strategies.
- Clinical trials (Resources). Learn what clinical trials are currently recruiting patients and healthy volunteers, and find ones for which you may be eligible to enroll.
- Community events (Events). Locate what's happening near you, or download TMA's campaign manual to help you organize your own event to raise funds and awareness.
- Research. Learn about the latest research related to myositis. Read about the research being funded by TMA, and find links to other sites with valuable research information.
- Newsroom. Learn about recent legislation that may impact those with myositis and how you can convince federal and state legislators to act on your behalf.

### Personal touch

If you don't have Internet access, or just need a hand, all members of TMA's staff are available by phone, mail and email. Do you want to participate in the equipment exchange but can't get online? Or find out what clinical trials might affect you? We're here to help.



## 2003 Products Issue OutLook Extra

*TMA's first Products issue of OutLook Extra brought a host of responses from you. And many new members and friends contributed to this issue, making this second edition as full of useful ideas as the first.*

*For those who haven't already flipped through the 2003 Extra, here's what it included:*

**The search is on: But why start now?** Consider aids to help with daily living before they become an absolute necessity.

**Need a lift? Decide whether you should drive or push.** The advantages of manual versus power wheelchairs

**Wheelchair users have more choices than ever before.** How to find what you need, from big to small options.

**Buying and using your scooter or power chair.** Selecting a scooter or power chair that's right for you.

**Staying on the road:** Questions and answers. Getting into and out of cars with your wheelchair.

**What about walkers and canes?** Options available for these long- or short-term aids.

**A couple of classic common-sense solutions:** The Moench Buttonhook and Half-Step. Two commonly requested do-it-yourself modifications.

**Helpful hints: Members share their ideas.** Contributions from

TMA members - their own devices and strategies.

**Relief from dry skin.** Recommendations for combating this pesky component, especially of dermatomyositis.

**Tried and tested ideas for bed and bath.** Exploring smaller to larger products available for the bedroom and bathroom.

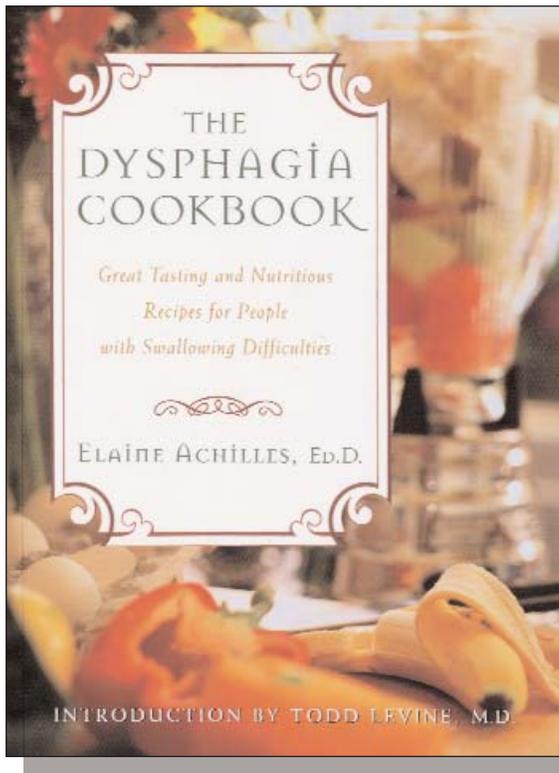
**Finding funding for your needs.** Programs available to provide funding, or assistance in locating appropriate programs to help.

**Resources.** Listing of resources for general information, do-it-yourself solutions, dry skin relief, sun-protective products, emergency alert systems, wheelchairs, and more.



### Immune Globulin Services Provided In Patients' Homes

**IgG America** is a national specialty pharmacy organization that provides immune globulin services in the home setting. IgG America can arrange services during the day, evening, and/or weekend. Not only is it more convenient than having infusions in a physician's office or outpatient center, it is usually less expensive. Services provided include immune globulin, supplies, pump/IV pole, and nursing services required to administer the immune globulin. The nurse stays the entire duration of the treatment and follows a comprehensive administration protocol. If you would like more information on IgG America's services or would like to inquire if your health insurance would cover home immune globulin treatments, please call (toll free) 1-877-674-9700 or visit our website at [www.iggamerica.com](http://www.iggamerica.com).



## The Dysphagia Cookbook

The Dysphagia Cookbook offers a wide range of recipes for those with swallowing problems. In his foreword, Todd Levine, MD, Director of the Neurophysiology Department at Good Samaritan Hospital in Arizona, and one of the experts on TMA's medical panel for the 2004 Annual Conference, breaks down the act of swallowing and some of the conditions that may lead to swallowing troubles.

Tips for preparing and serving food, general recommendations for swallowing, information on food consistency, handy tools and foods to have on hand, and suggestions for traveling and eating out supplement the recipes. The author marks each recipe with S (soft), G (ground/shredded/sliced) or P (pureed) to help you decide which recipes are most appropriate depending on the severity of your swallowing difficulties.

Recipes include vegetable dishes, fish and meats, breakfast dishes, soups, salads, sauces, desserts and fruits, and drinks.

**Now available in TMA's marketplace at [www.myositis.org](http://www.myositis.org).  
Order your copy of The Dysphagia Cookbook for just \$14.95.**



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