

## Innovative from the start

It wasn't long after Betty Curry founded the Myositis Association of America (TMA's former name) that resourceful patients began sending in ideas and products they'd found helpful in getting through their days with myositis. In the June 1995 *OutLook*, instructions were published for the "half-step," an ingenious device that allows patients to lift their feet only half as high while climbing stairs. After years of refinement and widespread duplication, the half-step was featured in the first *OutLook Extra*, published in 2003. Other suggestions followed, and soon the exchange of ideas, whether on the bulletin boards or in the *OutLooks*, became a big part of how TMA members encourage and support each other. It's impossible to exaggerate the importance of this generosity.

Some devices and gadgets are too hard to describe in words - you just have to see them. That's why we are inviting you to bring items that solve a challenge you face in your day-to-day life to the conference in Cleveland. If it's a commercial product that has proven especially useful, that's welcome, too. Whether it's a chair you've rebuilt for comfort, a tiny tool you've adapted, or a product you've purchased that is especially useful, there will be a place to display it and a time for sharing at the conference. If possible, bring written instructions and diagrams. Drop us a line at [tma@myositis.org](mailto:tma@myositis.org) to let us know what you're bringing and how much space you'll require.



We would like to thank **Genentech** and **Biogen Idec** who funded this issue in part with an unrestricted educational grant.

## What do you do during the day? Strategies for keeping your mind active

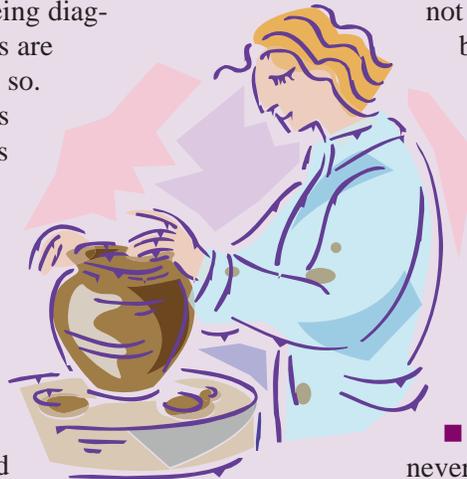
Some people with myositis continue to work either full or part time after being diagnosed; others are unable to do so. The Myositis Association's online message boards give people a chance to learn how other myositis patients have handled particular situations. Recently, one string of posts discussed ways to replace the mental stimulation they miss when they are no longer in the workforce.

Anna, whose mother suffers from PM, asked for some advice: "I was wondering how those of you who cannot work spend your time to prevent boredom and restlessness." As with the disease itself, every answer was different, shedding new light on how to get through the day with a sense of satisfaction and accomplishment.

"I am a word whomp girl myself," wrote Kim (JM). "Pogo.com has a bunch of games to play." Kim also takes classes at her local college for a chance to interact with students. Joce (PM) was given an instruction book on learning to speak Spanish: "Mine will come in extra handy when I go for my IVIg for four hours." Two bulletin board

regulars suggested delving deeper into your family history. Why not look into filling the branches on your family tree? "It might cost you some postage at Christmas time sending cards to fourth cousins and the like," said Charlie (IBM), "but it sure is fun and never ends!"

More suggestions:



■ **Drawing.** "If I had never become ill," wrote Tubby (DM), "I would have never discovered the joy of sketching and then learning to paint." She feels that drawing has helped keep her mind sharp, especially on those days she struggles to get out of bed.

■ **Reading.** Find a good book, newspaper or magazine, and get busy reading, suggested Joyce (PM). Crossword puzzles and similar word games found in most newspapers and magazines are especially challenging and invigorating.

■ **Bird watching.** Use Peterson Field Guides specifically for birds found in your area to pass the time, said Joyce. She finds bird watching an interesting and relaxing endeavor.

■ **Scrapbooking.** "It helps me sort through pictures, make memories for my kids, and feel a sense of

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Dear Reader,

This is the third year that TMA has produced a Special Issue of *The Outlook* focused on products that are useful to those with myositis. I think you will again find a wealth of information within, especially practical adaptations to meet your special needs.

What is truly gratifying is that many of the suggestions come from our members and readers of *The Outlook*. One of TMA's members, Ann Navan (IBM), who died earlier this year, frequently used TMA's online bulletin boards to share information about products she found useful. And like many members, she went out of her way to privately communicate with other members to see that they found products that could help them. Her spirit and enthusiasm for sharing information with others will be sorely missed.

If you have ideas about products that you want others to know of, please let us know by emailing us at [TMA@myositis.org](mailto:TMA@myositis.org) or calling our toll-free number: 800-821-7356.

Sharing information and helping each other cope is what TMA and its members are all about.

I hope you enjoy this Special Issue and find it helpful.

Sincerely,

A handwritten signature in black ink, appearing to read "Bob Goldberg".

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 2005 by TMA, Inc.*

## Strategies, from cover

accomplishment when a page is done," said Jackie (DM).

■ **Yoga.** Many community centers offer modified classes, where participants can perform the moves while sitting in a chair or can otherwise alter the moves to their abilities. "I think the mental aspects of yoga [are] great," said Barb (PM).

■ **Volunteer.** Though not everyone has the opportunity to get out of the house regularly, volunteering at your local library, church or charities not only provides mental challenge but also social interaction, both while working for common good for the community. Several TMA members volunteer through different organizations, including TMA's support groups.

■ **Sign language.** After reading everyone's suggestions and passing them on to her mom, Anna discovered that her mom had always wanted to learn sign language. Beth (PM) found two web sites for more on this hobby: [www.masterstech-home.com/ASLDict.html](http://www.masterstech-home.com/ASLDict.html) and <http://commtechlab.msu.edu/sites/aslweb/browser.htm>.

What do you do during the day? What do you do during the day? Send us your suggestions and ideas to share with other members and friends looking for new, practical activities.



## Helpful hints: ideas from our members and friends

Sometimes, what seems like a simple solution to you doesn't occur to someone else. Sharing your ideas, however obvious they may seem to you, may help those struggling with hassles of decreased hand strength and limited mobility. Many of these ideas are new to us while other suggestions are worth repeating:

■ Wrap rubber bands around jar lids, doorknobs and other hard-to-grasp items to give you a more secure, tighter grip.

■ Change knobbed handles to lever handles to avoid having to turn. Levers enable you to simply push, without requiring grip strength that is often decreased with myositis.

■ Remove all throw rugs scattered around your home. Though eye-catching, these rugs are an easy target to catch your foot, cane or walker. Prevent falls before they happen.

■ Purchase remote control or "clapper" lamps and lights. Or keep a table lamp close by with an easy on-off switch.

■ Place a large plastic bag on your front doorknob to collect packages and newspapers delivered to your house. This eliminates the need for you to bend to pick up these items on the doorstep.

■ Take advantage of occupational or physical therapy students in your area to assist with your home exercise program. These students can most likely receive credit for volunteering their time with you, but be sure to check with your own doctor or therapist first to make sure the exercises you're doing are appropriate for you.

■ Use Saran Wrap Quick Covers rather than plastic containers with hard-to-open lids to wrap leftovers.

■ Try a beauty salon styling chair, suggests Dianne, an IBM caregiver: "I wanted everyone to know how well it works! It swivels and can be raised higher and lower with a foot pump; it is sturdy and comfortable and small enough to fit at our dining table - much better than the desk chair we used previously. And of course anything that helps is priceless."



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# Sew easy: What to look for in clothing and accessories

There are some things most people take for granted: pulling buttons through buttonholes, tying lace-up shoes, slipping shirts over their heads. But for people whose muscles are affected by different forms of myositis, these tasks present a daily hurdle.

What can you do besides buy a closet full of new clothes? Choose a few articles of clothing that really work for you, and modify them. There are a number of web sites offering adaptive clothing for those in wheelchairs and for people with limited dexterity or finger strength. You may be able to take (and many, in fact, have already taken) these ideas and come up with "do-it-yourself" versions. Here are some useful features to keep in mind, either when planning to buy new clothes or alter your current ones:

## PANTS

**Elastic or drawstring waists and Velcro closures.** Elastic or drawstring waists make it easier to pull pants on and are more comfortable when you are seated than those with buttons or hooks. Easy Does It offers pants with hidden Velcro closures covered by a decorative button. Velcro enables people to fasten the pants more easily and adjust the waist size. To do this yourself, sew the button on top of the buttonhole, then attach Velcro where the button once was and below where you've moved the button. The Velcro is then the point of attachment, but the button is still there for looks!

**Plenty of room for comfort.** Pants without stretch or give become increasingly uncomfortable when sitting for periods of time. Find pants made from materials that have more "give" or made with extra room to avoid feeling restricted. See Changing the clothes you have, on the next page, for Dorris' instructions on

adding room to pants you already own.

**Modified fit for those in wheelchairs.** Pants in traditional styles are made for both standing and sitting. However, these trousers tend to have excess material in the front that bunches up but drop too low in the back when seated for long periods of time, particularly for those in wheelchairs. Numerous companies offer pants created specifically with these people in mind. (See Resources at the end of this article.)

## SHIRTS, SWEATERS AND OTHER TOPS

**Pull-on tops with roomy necklines and armholes.** V-neck shirts or those with wider openings at the neck and arms prevent many of the problems of pulling on traditional shirts. This extra space gives the wearer more maneuverability when dressing. Professional Fit Clothing offers custom alterations for their products, including reinforcing roomier necklines for those in need of more durable clothes.

**Tops with tie-backs or snaps down the back of the shirt.** Tops with tie-backs at the neck or snaps at the back keep you from having to lift your arms when dressing.

**Velcro closures in place of buttons.** Buttons can be difficult to maneuver through buttonholes for those without any limits to their strength and mobility. Add decreased finger strength and flexibility, and it's all but impossible. Velcro or snaps instead of buttons to close shirts can make dressing a much simpler task.

## STEPPING OUT: SHOES AND OTHER FOOTWEAR

"There came a time when too much 'non-slip' made it difficult sometimes

to move my feet and too little 'non-slip' made some maneuvers impossible or not safe," wrote the late Ann Navan on TMA's online boards. She chose Keds Classic sneakers in white leather.

"Rubbing the soles of new Keds on cement a bit seemed to make them perfect." Some other specific shoe recommendations from the bulletin boards:

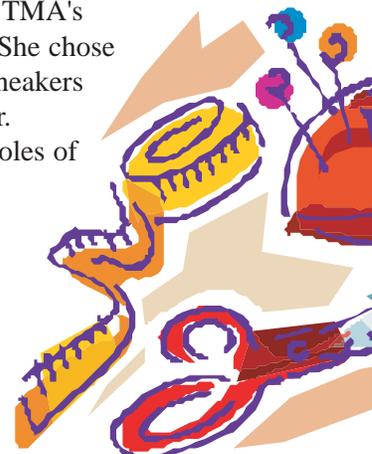
Safeet; Arcopedico; New Balance walking shoes; and Silver Series from Wal-Mart.

Many people choose instead to go barefoot or wear thick socks: "I feel most secure when my bare feet have contact with the floor," said Marilyn (IBM). Try thick socks, socks with no-slip "grips" on the bottom, and slippers with non-skid soles.

"I dislike shoes, too," wrote JoAnn. "However, I found a brand (Safeet) that feels good, expands with my feet when they swell, and are easy to put on. They are so comfortable but I have never seen them in stores."

In general, most people preferred wider shoes that were easier to slide on; Velcro closures to avoid the "too tight" feeling and eliminate the difficulty in tying lace-up shoes; and low- or no-heeled shoes. Youcan Toocan and other stores offer elastic shoelaces, instantly turning your lace-up shoes into slip-ons.

Find the shoes, socks or slippers that give you the most secure and comfortable feeling. And if you find any real treasures, be sure to let us know so we can print your finds and innovative ideas in the next Products issue of *OutLook Extra*.



## Change the clothes you have to meet your changing needs

Dorris Norris, who has IBM, has taken some clothes from her own closet and adapted them to make dressing less of a chore.

### Make pullover shirts from button-downs

Dorris altered a silky, front-button blouse into a pullover top:

- Button the lowest button and sew across the opening of the blouse, where one side overlaps the other.

- Make a casing for elastic by turning up the material below the lowest button. Dorris turned up 1 inch of fabric, stitching close to the folded end. She then turned under 1/4-inch and stitched the folded edge, leaving an opening to run elastic through the casing. She used 1/2-inch elastic, stitched the ends of the elastic, then stitched the opening.

- Cut the elastic a little longer than your waist measurement. Run this through the casing.

- Remove the buttons from the cuff and sew them on top of the button-hole. Sew a circle of Velcro under the button and at the point where the button originally was.

### Add stretch to fabric that doesn't "give"

Dorris owned elastic-waist pants made of a fabric that didn't stretch. "This made them tight across my thighs when I sat down," she said. So she set to work adapting these to add comfort but not cost:

- Open the side seams from top to bottom.

- Sew in a strip of 1-inch bias tape in a contrasting color down each side. (Dorris used navy for her green pants, white for her blue ones.)

"The 1-inch strip in each side made them more roomy and comfortable," she said. "Now, comfort is my top priority in clothes."

### Resources for adaptive clothing and more

**Appleseeds:** [www.appleseeds.com](http://www.appleseeds.com); [CustomerService@appleseeds.com](mailto:CustomerService@appleseeds.com); 800-767-6666 (to order by phone); 800-755-7557 (to order by fax); 888-430-5711 (Customer Service). Check the web site for the location of retail stores in Massachusetts and Maine.

**Buck & Buck Designs:** [www.buckandbuck.com](http://www.buckandbuck.com); [info@buckandbuck.com](mailto:info@buckandbuck.com); 800-458-0600; 3111 27th Avenue South, Seattle WA 98144-6502

**Caring Threads:** [www.caringthreads.com](http://www.caringthreads.com)

**Clothes for Seniors:** [www.clothesforseniors.com](http://www.clothesforseniors.com); [info@clothesforseniors.com](mailto:info@clothesforseniors.com); 800-252-0584; American Health Care Apparel, Ltd., 302 Town Center Blvd., Easton PA 18040

**Don Kihote:** [www.donkihote.com](http://www.donkihote.com) (Safeet Globetrotter shoes); [contact@donkihote.com](mailto:contact@donkihote.com)

**Easy Access Clothing:** [www.easyaccessclothing.com](http://www.easyaccessclothing.com); 800-775-5536; P.O. Box 6521, San Rafael CA 94903

**Easy Does It:** [www.myeasydoesit.com](http://www.myeasydoesit.com); [support@myeasydoesit.com](mailto:support@myeasydoesit.com); P.O. Box 678, Marion CT 06444-0678

**Professional Fit Clothing:** [www.professionalfit.com](http://www.professionalfit.com); 800-422-2348

**Rolli-Moden:** [www.rolli-moden.com](http://www.rolli-moden.com); [rm@rolli-moden.com](mailto:rm@rolli-moden.com); 800-707-2398 (Customer Service); Division of Manfred Sauer USA, Inc., 12225 World Trade Drive, Suite T, San Diego CA 92128

*Thanks to Tenayahh and Anami for sharing several of these web sites with everyone on TMA's online message boards.*

## STITCHING STRATEGIES

What can you do if the same muscle weakness that makes it hard to dress also makes it difficult to sew? Some tips from various disability experts:

- Woodrow Wilson Rehabilitation Center in Fishersville, VA, suggested mounting the sewing machine pedal on a block of wood and attaching it to the front of the machine or table. Lean on the pedal to operate the machine.

- When buying a new machine, look for models with touch-button controls. Models with slide controls and dials are more difficult to set accurately. Look for a machine with speed control. Running it at a slower speed accommodates pushing the fabric through at a slower speed.

- When hand-sewing, use a frame to hold the work. Typically a standing frame holds a large embroidery hoop or rollers to which the needlework is fastened. Another type is mounted on a curved frame on which you sit, bringing the work right over your lap. The frame is jointed to be tipped to comfortable angle.

- An even smaller frame clamps on the edge of a table or on your wheelchair tray. These designs eliminate the need to hold the work, can be mounted to the left or right, and let you sew with one hand.

- If you strain to see fine work, sewing shops carry magnifying glasses that rest on your chest and are held by a cord around your neck.

- Needle threaders help with large-eyed needles, but for fine sewing use a special needle that needs no threading. It is grooved at the top, with a tiny crack into the eye, so when you pull thread taut in the groove, it will pop down into the eye of the needle.

- Keep a small magnet tied to a string in your sewing basket, handy for picking up dropped pins and needles. Also, keep pins in a paper-clip holder with a magnetic top.



# Practical ideas and products for swallowing troubles

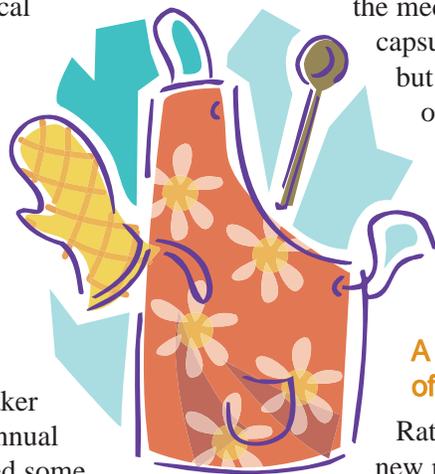
About one-third of myositis patients have swallowing problems, or dysphagia. Even without serious or clear-cut dysphagia, you may have some difficulty some of the time.

Fortunately, medical supply and other companies have developed innovative products to improve the eating process for individuals with dysphagia.

Michelle Reuther, speech therapist and speaker at TMA's 2004 Annual Conference, shared some practical suggestions for changing your eating habits. Among the products she mentioned were a variety of special cups and thickeners. Nosey Cup, Flexi-Cut Cup, Dysphagia Cup, and Kapi-Cup are just a few of the names used for the same type of innovative design (with some slight differences among them). Reuther shared her money-saving solution: cut a piece out of a small Styrofoam cup for your nose to fit in while taking pills, allowing you to drink water without tipping your head back. Extra-long straws may help as well, as you can drink without moving your head position or having to lift the cup itself. For those with limited hand strength or mobility, this may prove to be a sensible and effective way to drink without requiring help. Elayne Achilles, EdD, author of *The Dysphagia Cookbook*, points out, though, that shorter straws reduce the sucking force needed to pull the liquids from the cup to your mouth. This may or may not affect you but is important to consider.

Taking pills presents a challenge to those with dysphagia, and pill splitters and crushers come in handy for them. You'll find these at online stores or local drug stores. Achilles offers

at-home solutions to this hurdle, too: "Tablets can be crushed using a mortar and pestle, or pulverized in a coffee grinder (buy one that you use only for that purpose)." You can mix the medicine from inside the capsule with food or water, but check with your doctor or pharmacist before splitting capsules as some medicines, especially time-release capsules, must remain in the capsule form.



## A pinch of this, a dash of that...

Rather than seeking out new products, you may need to modify what you eat. There's not one specific diet for those with dysphagia. Some people struggle with thinner liquids; others have a tougher time swallowing more substantial foods. Once you find what's right for you, stick with it. If you can't find the variety of foods you'd like, transform what you have to what you need.

You can find a variety of thickeners to provide just the right consistency. Options on the market are "ThickenUp" by Resource, "Thick-It" by Milani Diafoods, "Quick Thick" by Kingmill, "Simply Thick" by Phagi-Gel, and "NutraThik" and "Thick & Easy" by Hormel. Some are fortified with vitamins; some are instant thickeners; and some are concentrated for maximum thickening. Which one you choose depends on your own needs, and a speech and language pathologist can recommend food and liquid textures that are suitable for your specific needs. These thickeners provide the consistencies of nectar (fluid); honey (soft but thicker than nectar); and pudding or spoon-thick (firm).

These products claim to add no taste to the foods they thicken. There are also conventional food products that do essentially the same thing. In

*The Dysphagia Cookbook*, Achilles suggests keeping the following items in the kitchen to help with food consistency:

- Refried beans (can be used as a thickener for soup when pureed)
- Instant mashed potatoes (to eat alone or use as a thickener for sauces and soups)
- Chicken broth (for thinning foods that are too thick)
- Unflavored gelatin (for thickening)

When you're traveling or eating out, she recommends taking along yogurt or yogurt drinks, applesauce and pudding.

## Resources for dysphagia products and ideas

### Ableware:

<http://service.maddak.com/>; 661 Route 23 South, Wayne NJ 07470; 973-628-7600

**Easy to Swallow:** [www.easytoswallow.co.uk](http://www.easytoswallow.co.uk); [info@easytoswallow.co.uk](mailto:info@easytoswallow.co.uk) or [recipes@easytoswallow.co.uk](mailto:recipes@easytoswallow.co.uk) (to share recipes or tips)

**Equipment Shop:** [www.equipmentshop.com](http://www.equipmentshop.com); [info@equipmentshop.com](mailto:info@equipmentshop.com); P.O. Box 33, Bedford MA 01730; 800-525-7681

**Novartis Medical Nutrition:** [www.novartisnutrition.com](http://www.novartisnutrition.com)

**Reliant Medical Products:** [www.reliantmp.com](http://www.reliantmp.com); 500 Beacon Parkway West, Birmingham AL 35209; 800-757-7579

**Simply Thick:** [www.simplythick.com](http://www.simplythick.com); [info@simplythick.com](mailto:info@simplythick.com); 200 South Hanley Road, Suite 1102, St. Louis MO 63105; 800-205-7115

# Recipes

Here are a few recipes to give you an idea of what's available and how to use thickeners with certain foods. You'll find more recipes on the web sites or in the books listed with each recipe.

## Blended Salad

- Puree favorite vegetables in a processor.
- Sample combination: half a peeled carrot, half an onion, a stalk of lettuce, a green pepper (or pepper makes the salad), a squeeze of lemon juice, and favorite salad dressing
- Pulse in the processor on and off for 4 times until achieved the desired consistency
- Carefully blending the mixture with crackers as a dip. The crackers help the dip hold its consistency in the mouth, not only enough to eat now because this salad has a great texture.

## A la Orange Juice

- 3 ounces of orange juice concentrate
- ½ cup milk (or half and half if desired)
- 2 cups ice
- ¼ cup vanilla extract (in the syrup of the extract)
- 1 pasteurized egg (optional)
- 1 ripe banana peeled

→ Blend all of the ingredients in the blender for 30 seconds to 3 minutes.

"Blended salad 'A la Orange Juice'" and "Zucchini Soufflé" by Achilles, Ph.D. The Dysphagia Cookbook. Nashville, Tennessee; 2004. Available from Myositis Association at [www.myositis.org](http://www.myositis.org) (Makeplace) or 800-821-7356.

## Sweet and Sour Chicken

- 500 g chicken
- 1 Tablespoon canola or olive oil
- 570 g jar sweet and sour sauce (other brands can be used)

- Fry chicken in oil for approximately 5-10 minutes until cooked through.
- Add the jar of sweet and sour sauce and mix well.
- Simmer for 5-10 minutes, blend together in a processor until desired consistency. Reheat and serve. Serves 4.

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## ThickenUp® Creamed Corn

- ½ cup creamed corn
- 1 teaspoon melted margarine
- 2 tablespoons ThickenUp

- Puree cooked cream-style corn with margarine until smooth.
- Add ThickenUp. Process briefly until mixed.
- Pour into pan coated with vegetable oil spray.
- Cover tightly with aluminum foil and bake at 350 degrees F.

From [www.noartisnutrition.com](http://www.noartisnutrition.com)

## Thick-It® Pureed Peaches

- 2 cups canned peaches
- 4 teaspoons Thick-It Instant Food Thickener

- Drain fruit, saving liquid and setting residue in disposal.
- Add 2 teaspoons Thick-It and pulse well.
- Add half of the liquid and pulse puree well.
- Add remaining Thick-It and pulse.
- Add liquid until you have moist mashed potato consistency (or to your desired consistency).

From [www.precisionfoods.com](http://www.precisionfoods.com)

## Zucchini Quiche

- 3 small zucchinis, in processor and liquidize (quantity)
- 2 tablespoons pesto sauce (if prepared)
- 1/2 cup each of Parmesan and Monterey Jack cheeses, chopped red bell pepper
- 3 eggs beaten
- 1 cup half and half
- 2 frozen pie crusts
- 3/4 cup grated Swiss cheese

- Preheat oven to 375 degrees.
- In a large bowl, combine zucchini, pepper, eggs and half and half. Roll the pie crust with the mixture and top with the Swiss cheese.
- Bake for 30 minutes.

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P: 866-277-3366  
[www.asseenontv.com](http://www.asseenontv.com)

**Bruce Medical Supply**  
411 Waverly Oaks Road, #154  
Waltham MA 02452  
P: 800-225-8446  
[www.brucemedical.com](http://www.brucemedical.com)

**Great Northern Products**  
2000 E. Dowling Road #5  
Anchorage AK 99507  
P: 800-561-4394  
[www.uluum.com](http://www.uluum.com)

**Functional Solutions™**  
18305 Sutter Blvd  
Morgan Hill CA 95037-2845  
P: 800-235-7054  
[www.beabletodo.com](http://www.beabletodo.com)

# Tools and rules for successful meal preparation

Those with chronic autoimmune diseases are need to eat well, and that can be a challenge. Fresh vegetables and fruits need a lot of preparation, and often dairy products are so tightly sealed or encased that even people without disabilities have trouble opening them. Here are some tips to combat this, they come from Sue Heaton, an occupational therapist writing for the Disabled Living Center, a British specialty supply company.

## General rules

- Always keep ahead of the washing up and cleaning up.
- Get everything out of the cupboards before you start.
- Keep all you need close by.
- Have a damp cloth nearby to clean your hands, or use a bowl of hot, soapy water.
- Become familiar with cooking in a slow-cooker or crock pot, a kind of small countertop oven that cooks food over a long period of time, reducing the need for stirring and worrying about burning or splatters.
- When possible, use a sturdy, comfortable pair of kitchen shears for everything from cutting chicken to opening frozen food bags.

## Cutting, slicing and chopping

- The main difficulty is holding the food. The Swedish cutting board is very good; there are other boards that also have spikes, vises and holders that hold the food in place. You can also use the board for holding a bowl in place.
- Rubber coated bottoms on crockery are better than suction cups, as these can be difficult for those with weak fingers and wrists to remove.
- A good knife is essential. If you

find it hard to use an ordinary knife, try a rocker knife or a roller knife like a pizza cutter. Always find tools with good, non-slip grips that are comfortable to hold. One example of a rocking knife is the Ulu knife, about \$18 at [www.ulu.com](http://www.ulu.com). When requesting a knife of this sort, ask for a "mezzaluna knife."

- Become comfortable with using a food processor. Some of them are tricky to assemble, but you can do a lot with just one blade. In the newer ones, clean up is a breeze.

- Many people cut themselves trying to slice bagels. Try a bagel holder, available at most department and cookware stores.

## Stirring and mixing

- When using a mixing bowl hold it to your body or put it on a nonskid mat on the work surface.
- Try wrapping a large damp cloth around the bowl.
- Dycem (nonslip) matting keeps bowls from slipping, or use small suction pads on the base of the bowl.
- Use the clamp on the Swedish cutting board.
- A hand held electric mixer can be very good.
- Pastry blenders and mashers can be useful when the stirring motion is hard.

## Grating

- Food processors grate a pound of carrots and hard cheese literally in seconds, but they do not always work on small quantities and can be very difficult to clean up.
- Try a grater clamped on the Swedish cutting board.
- Try leaning a four-sided grater down with the end against your body and pull the food towards you.

## Peeling

- To peel a clove of garlic, place the clove on its side on the counter, then bang a mug or knife down on it. This cracks and loosens the skin making it easier to peel.
- Put an onion on a spike and cut it into quarters. The dry outer skin will fall away.
- Try the Speedypeel, a gadget operating on a battery, or another automated peeler. Speedypeel is available at [www.asseenontv.com](http://www.asseenontv.com).

## Storage

- Before you buy any boxes, check that you can open and close them easily.
- Use plastic bags rather than cling film.
- Line a bowl with a bag and pour food into it.
- Try bag clips. If twist ties are difficult, use large rubber bands to stretch around open packages of frozen foods.

## Opening

- Lay boxes down on their narrow side and push your thumb in. Use your body to steady the box.
- Some electric can openers can be used with one hand, but they are not easy.
- Some people find cans with a ring pull easier; others find these difficult.
- For jars and bottles, first tap the lid on a hard surface to loosen the seal. Run under hot water, dry well and try again.
- Hold the jar between your thighs.

## Cartons and bottles

- Do not buy large cartons or bottles if possible.
- Try to buy what you need in a

# When the itch gets under your skin

**"It feels like my skin is on fire."**

**"My skin rash hasn't responded to anything."**

**"The skin problems I had with DM were far more difficult to tolerate than the muscle weakness, and that was plenty intolerable."**

**"When I do too much during the day, my ears turn bright red and burn like crazy."**

**"It's always on the same place (the classic heliotrope rash), and it brightens or lessens like a chameleon over the course of days, hours or weeks."**

**"If I'm not careful, I might itch the skin right off"**

Are you nodding your head? These statements, I'm sure, hit home to many of you, especially those of you afflicted with dermatomyositis. The medicines you take for your muscle weakness may also improve the skin symptoms; but for many of you, there doesn't seem to be relief in sight. Borrowing from what other people have tried - whether successful for them or not - may just help you find the remedy that works for you. Just as everyone's symptoms are individual, people respond in different ways to traditional medicines and to home remedies.

## Peeling skin

Sammi struggled mostly with dry, cracked skin on the tips of her fingers, to the point of peeling off - both painful and annoying. Her doctor prescribed Fluocinonide, a topical corticosteroid cream, but she wanted to explore different options and

enlisted the help of her TMA Bulletin Board friends.

"I used to lather up my hands with cocoa butter and wear white cotton gloves," said Tricia. Before applying the lotion, she would lightly rub her skin with a pumice stone to loosen and remove the dead skin. Other responders suggested udder cream (often found in hardware stores), coconut oil, and Duo-Derm, a product like a rubber plaster that can be cut to size. Often, those suffering from persistent skin irritations wear the gloves through the night to give their hands ample time to moisturize and heal.

Christine praises pure coconut oil, with no additives, to ease the itch. "I was put onto coconut oil by a dear friend with DM," she said. "She was given it in Honolulu by a chemist there, and it really takes the itch away. It is pure coconut oil, from the pharmacist, and I use it on all my skin, top to toe."

## Irritated, itchy scalp

When the skin on your scalp is involved, it can be doubly troublesome. Not only do you itch incessantly, it's difficult to treat an area covered with hair. We've touched on this in the past, with recommendations from others including Tee Tree Shampoo by Paul Mitchell, Luxiq (generically betamethasone) foam, and Head and Shoulders soothing lotion. Since then, we've heard from you with new ideas for products and strategies that have helped, at least temporarily.

When on vacation in Florida, Carol found that using distilled water to wash her hair kept some of her itching at bay. Following up on that, Tenayahh suggested finding a showerhead that filters the chlorine and other chemicals from the water, as these chemicals only intensify your already aggravated scalp. Christine,

who uses pure coconut oil on her skin symptoms, speculated that a coconut-based shampoo might alleviate scalp itch as well as it does irritated skin.

## Stubborn symptoms

So what do you do when the medicines don't touch your itchy, irritated skin?

- **Ice packs.** Peggy finds that using ice is the most effective way to get rid of her itching.
- **Oatmeal bath.** "It is a temporary solution," says Jennifer, "but it feels good." These baths, by Aveeno and other manufacturers, are often recommended for those with chickenpox and other skin conditions.
- **Soaking solution.** Another bulletin board user mixes 32 ounces hydrogen peroxide and ½ cup Epsom salts in a warm bath for her abrasions from her constant scratching. "Do this once a week," she says. "This helped me a lot; hopefully it will help you. We're all looking for relief."
- **Witch hazel.** Kenrick suggests witch hazel, a mild astringent, to combat persistent itching. (This solution does have alcohol, so beware of the possible drying effects if you use too much too often.)
- **Liquids.** Stay hydrated with cool, refreshing liquids to stay moist from the inside out, suggests Jackie.

## Sensitivity to the sun, heat

Whether it's the sun's rays or the heat, chances are at least one of them affects how you feel when you have myositis. Some of you have said the sun's rays - or any source of ultraviolet radiation - lead to headaches, nausea, muscle pain, and feeling as if your skin is on fire. Others add joint pain, upset stomach and fatigue to the list of symptoms following expo-

sure. Using sunscreens and staying out of the sun as much as possible are two solutions that are fairly easy to follow. However, these don't always help in the workplace or at stores where fluorescent lighting emits the harmful radiation.

Many people, men and women alike, don hats to protect themselves from the effects of UV radiation. When practical, filters are available to place on fluorescent lights to help block the fluorescent light's rays. Parents have been successful in getting their children's schools to use filters, shields or replacement bulbs in the classrooms and other areas their children may be for extended periods. Offices may also allow this accommodation, and in fact, might have to in order to follow the guidelines of the Americans with Disabilities Act. TMA members suggested the following: OTT fluorescent shield tubes (LiteBrand); and ErgoMart filters.

Applying sunscreen may already be a part of your daily routine; if it's not, consider making it a habit. Though some people find sunscreens greasy or oily, others have come across brands that work for them. (*See Sunscreen specifics.*) As long as the sunscreens have what you need, the exact brand is more a matter of personal preference. Make sure it has SPF (sun protection factor) of 30 or higher; protects against both UVA and UVB rays (broad-spectrum); and is ideally waterproof. Other helpful features found in most sunscreens today are that the sunscreens are PABA-free and contain moisturizers like aloe vera, cocoa butter or Vitamin E.

We've written several times about sun protective clothing and accessories, but Jane added her own resourceful idea for those needing specific styles.

Recommending Solumbra ([www.solumbra.com](http://www.solumbra.com)), she said: "They offer lots of styles of clothing, and if they don't have what you can wear for nursing, just buy something in a much bigger size and then cut out your pattern from the large size item." Jennifer, a JM mom, found Solarweave Fabric online at [www.sungrubbies.com/Solarweave.htm](http://www.sungrubbies.com/Solarweave.htm). The fabric has a UPF of 40+ (SPF of 30+); is 60 inches wide; comes in whole yard lengths; is offered in pink, blue, tan, and white; and claims to be non-irritating. She added: "Knowing that tightly woven clothing helps block harmful solar radiation from reaching your skin - loosely woven clothing is not adequate since the gaps in the weave allow the radiation to pass through - what about using the fabric from sheets, like the 200 plus thread count, and then using the Rit Sun Guard ([www.rit-dye.com/sun\\_guard/](http://www.rit-dye.com/sun_guard/))? The possibilities would be endless in the types of clothing we could make our children."

Sometimes not only the sun's rays affect people, but the heat saps their energy, leaving them feeling queasy, tired and uncomfortable. "We found that her hands and body [become] warm," says Lea of her mother (IBM), "so sometimes I open the air conditioning to cool her; and other times (she is bedridden), I just cool her body with lightly wet towels. These solutions almost always help. When the heat goes away she always feels much better." Stay in the shade as much as possible, and move to an air-conditioned room when the heat is unbearable. Also, take in plenty of cool, clear liquids to keep yourself properly hydrated.



Get more skin tips, next page.

## SUNSCREEN SPECIFICS AS RECOMMENDED BY YOU...

### **Blue Lizard Suncream:**

[www.crownlaboratories.com/bluelizard.asp](http://www.crownlaboratories.com/bluelizard.asp). Broad-spectrum protection; SPF 30+; water resistant. With zinc oxide. Available at specialty retail stores, dermatology offices and online.

**Bullfrog Sunscreen:** [www.bullfrog-sunscreen.com](http://www.bullfrog-sunscreen.com). UVA and UVB protection; SPF 30-45; waterproof; PABA-free. With aloe and Vitamin E. Available in gels, sprays and lotions at most drug, food and merchandise stores.

**Hawaiian Tropic Ozone Sunblock SPF 70+:** Available at most drug stores.

**Neutrogena Sunblock:** Available at most drug stores.

**No-Ad Sunblock:** [www.no-ad.com](http://www.no-ad.com). UVA and UVB protection; SPF 15+; waterproof; PABA-free; non-greasy. With aloe vera, cocoa butter and Vitamin E. Available at most drug stores.

**Shiseido Ultimate Sun Protection Cream SPF 55 (for face):** UVA and UVB protection; SPF 55; water resistant; PABA-free. With Xylitol to counteract rough skin. Available at department store cosmetic counters or online (enter "Shiseido" in your search engine for possibilities).

## RESOURCES FOR SUN PROTECTION

The Myositis Association provides a listing of sun protective clothing resources on its web site at [www.myositis.org](http://www.myositis.org), or you can call 800-821-7356 to receive a hard copy of this list. If you've found companies you particularly like, share them with us!



# Skin products that have worked for you

## More helpful hints from members

Our friends who use the online bulletin boards at [www.myositis.org](http://www.myositis.org) offer an endless supply of possible products and strategies to help with just about any obstacle you might encounter. One poster recently asked, "A question for the ladies - what kind of make up do you use? I have DM and my face is starting to get red and I already have the rash on my eyes, which by the way are very dark. I have tried numerous make-ups and concealers but nothing covers me." The following is a sampling of the responses she received:

I am in remission and had brown patches on my face. I started using the **Aveeno Soy Positively Radiant** line and my skin has not looked better. Another great product is **Origins Neutralizer** - it is a concealer in a tiny tube (color is neutral, but comes in others too). For \$8 it lasted me a year, and you just use the tiniest bit over the discolored areas and then apply whatever foundation you like. It really does a great job! I also use the **Coppertone Oil Free** for faces sunscreen on my face following moisturizing. Liesl/DM

I use **Cover Girl Aqua Smooth** foundation. It does a pretty good job of coverage, but I don't think it's in the league of Dermablend. It works well for me, but my rash isn't horrible. For my eyelids, I use **Lancome eyeshadow base**. It's a cream base that you put on before eye shadow, and it covers the red on my lids. I think I paid about \$28 for it, but I've had it for two years, and I think I have at least 6 months left in the jar, even though I use it every day. I've been using the **Olay Regenerist** products, including the eye cream, and they are pretty gentle. They leave my skin feeling silky and not greasy. I ran some prod-

ucts by my dermatologist, and she approved of these. I have pretty dry skin. I've also had good luck with the **Aveeno skin lotion**, so I suspect their new facial products would be good for itchy skin, too. Peggy/DM

I have PM, but have been fighting the acne that comes with the prednisone (I am extremely fair-skinned, so every little blotch shows like neon) and can recommend some of these items:

■ for acne, **Tea Tree Oil** from The Body Shop - I smear it on my face before I moisturize;

■ for coverage, right after I moisturize, I use the **mineral powder** you can get from QVC...this stuff really does cover a lot;

■ for moisturizing, **The Body Shop** has excellent products. They are high quality but reasonable in cost. I like the fact that it moisturizes, but you can get one that doesn't leave you feeling oily in the areas that need less help.

Most of the products you get in the grocery store, Bath & Body Works, drug store, etc., have things that irritate the skin and plug the pores (no matter what the ads say). The Body Shop's products are not tested on animals, and use ingredients that won't harm the skin. Sdiedre/PM



## A Reader Recommends

Linda Poland of Landsdale Pennsylvania writes;

I came across a great sun umbrella and thought your newsletter readers might want to order one. It is so lightweight, yet very durable, and folds up to about the size of a cell phone. It also has a carrying case you can attach with a Velcro "bracelet" to our belt, backpack or purse.

I ordered mine from a catalog

company called Walter Drake at 1-800-525-9291; webste: [www.walter-drake.com](http://www.walter-drake.com). I believed I paid \$19.99. You can order directly from the company that makes the umbrella, but I do not know how much they charge. Call 1-888-225-6665, or go to the web site: [raybeth.com](http://raybeth.com).

Sun Precautions also sells good umbrellas, but they do not fold to such a small size, and they cost \$42.95



## A tip for your toes

From Mariuca/PM:

I usually get pedicures in the summer because my PM makes it awfully difficult to reach my feet. Applying lotion can be tough depending on the state of my PM, and especially applying lotion to my feet, which I can barely reach on a good day! So I found out **The Body Shop** makes this product called **Dry Oil Mist**. I bought it in sesame, and it contains wheat germ oil and soy oil, among other things.

I just spray it on my feet and use one foot to rub it into the other, using my heel to rub the top and toes of the other foot and vice versa. My feet look great from day to day, and I don't have to even touch them! The Dry Oil Mist comes in other varieties, too. Of course, it can be used all over the body, not just on the feet!

From Tenayyah/PM:

There are **long-handled wands** that can be used to apply lotion to the back and shoulders, [and other hard-to-reach places]. One person [on a Sjogren's board] mentioned that **Johnson's** has a "**light oil mist**" spray. She said she lives alone and has given up trying to teach her cat and dog to put lotion on her shoulders!



# Efforts target safety and independence of disabled

## Clearinghouse matches disabled with training and jobs

A national jobs clearinghouse based at West Virginia University that matches positions with the needs and talents of disabled people has won a \$9.5 million, five-year contract to continue its work for the U.S. Department of Labor. The Job Accommodation Network (JAN) - the only nationwide program of its kind - answers more than 32,000 calls each year, primarily from employers and their workers with disabilities.

JAN is housed within the WVU College of Human Resources and Education's International Center for Disability Information and administered by the U.S. Department of Labor's Office of Disability Employment Policy. A staff of 25 runs the jobs network.

D.J. Hendricks, JAN program manager, told the story of a bus driver who had undergone two years of physical therapy after a severe back injury. His doctor would not allow him to return to work, concerned the vibration would cause further injury. The network located a seat that would eliminate much of the vibration and sent the information to the driver and the employer. A few weeks later, he was back on the job.

"This is what JAN is all about," Hendricks said. In particular, Dr. Hendricks, also associate director of WVU's International Center for Disability Information, plans to improve three primary electronic services:

- A web site that serves as a gateway to information on accommodations, disability laws, publications and other resources to assist employment of people with disabilities ([www.jan.wvu.edu](http://www.jan.wvu.edu))

- Project SOAR - a Searchable

Online Accommodation Resource to provide information on accommodation options and products ([www.jan.wvu.edu/soar](http://www.jan.wvu.edu/soar))

- The Small Business and Self-Employment Service to provide information about Resources available for people with disabilities who wish to be self-employed or to start a small business

Since 1983, JAN consultants have provided workplace accommodations information to more than 300,000 employers, rehabilitation professionals and individuals with disabilities.



## Wheelchair users neglected in disaster planning

The reports of wheelchair users being left behind in the World Trade Center on September 11 because they were unable to evacuate revealed the acute need for better disaster planning, says Glen White, director of the Research and Training Center for Independent Living at the University of Kansas.

The Nobody Left Behind Project, directed by White, has begun that process. The research is funded by a \$615,000 three-year grant from the Centers for Disease Control and Prevention in Atlanta through the Association of Teachers of Preventive Medicine in Washington, DC. The grant was awarded in 2002. The research team investigated 30 randomly selected U.S. counties, cities, parishes and boroughs where a natural or man-made disaster occurred between 1999 and 2004 to determine whether disaster plans and emergency response systems met the needs of people with mobility impairments.

Some findings of the research indicate that:

- few county emergency managers

have taken the Emergency Planning and Special Needs course offered by the Federal Emergency Management Agency, even though most felt it could be helpful.

- county-level surveillance efforts to identify people with mobility impairments both before and after disasters are generally weak. Only 40 percent of emergency managers reported having specific guidelines in place to assist people with mobility impairments during emergencies.

- among the 60 percent who did not have specific guidelines, virtually all felt that having guidelines was important, and many had made some provisions anyway, such as with transportation, where more than half identified transportation accommodations that they have in place.

The team presented the early results of the study at the first Conference on Emergency Preparedness for People with Disabilities last September. The team has also set up a web survey for people with mobility impairments to share their experiences during recent emergencies and disasters at <http://www.nobodyleftbehind2.org>. The survey responses collected to date suggest:

- many public buildings have inaccessible escape routes
- few people know how to use adaptive escape chairs for wheelchair users
- there is a lack of accessible transportation after a disaster event
- very slow response in moving debris or rebuilding ramps hindered citizens with disabilities from returning to their homes
- shelters, including bathrooms,

See Disaster planning, page 17

# New "Pointsmart" mouse refined for people with muscle weakness

Using a computer mouse can be a difficult and embarrassing task for children and adults with disabilities affecting fine motor skills, but a new software application, available soon, promises to ease the frustration of using a mouse - and provide greater computer access - for people who suffer from muscle weakness in arms and fingers that makes it very difficult to point and click.



PointSmart, developed by Infogrip of Ventura, CA, with assistance from the University at Buffalo Rehabilitation Engineering Research Center on Technology Transfer, helps stabilize erratic mouse movements by allowing users to adjust the sensitivity of those movements beyond standard speed and acceleration adjustments found on most personal computers. A beta version of PointSmart was tested by consumers in January, and a final version of the product is now for sale.

PointSmart is one of a handful of new products recently developed, improved or tested by the Buffalo Center (called UB T2RERC), which works with companies to research, evaluate, transfer and commercialize assistive devices for persons affected by disabilities. The center is one unit under the umbrella of UB's Center for Assistive Technology.

"We're a one-of-a-kind research center," says Stephen Bauer, PhD, clinical assistant professor of rehabilitation science and director of T2RERC. "We're entirely focused on transferring beneficial technologies and products, like PointSmart, to persons affected by disabilities and older

Americans." PointSmart features a joystick mode that starts the mouse in one direction and allows it to continue without continuous control until the user chooses to change direction or select an object. PointSmart users also can change the functionality of mouse clicks and buttons - switching the left click and right click functions, for example.

For visually impaired users, PointSmart can display very large and easy-to-read mouse pointers on the computer screen.

"In schools, PointSmart will allow children with disabilities that affect fine motor control to effectively access computers that their classmates use on a daily basis," says Wendy Strobel, T2RERC project manager. "It will allow all children to learn together on computers in their classrooms."

"In work environments, people with disabilities that affect fine motor control will be able to use a mouse without the frustration of missed targets or misplaced information - misjudgments that often affect productivity negatively," she says. Moreover, Americans who have weakness due to age or disability can continue to access personal computers using PointSmart, Strobel points out. PointSmart is available for \$99, and there is a demonstration on the web site at [www.infogrip.com](http://www.infogrip.com).

Other new products developed, improved or tested by T2RERC are:

- CaptionSync, by Automatic Sync Technologies, an automated captioning system for the hearing-impaired or learning-disabled that within 10 minutes can develop captions from any electronic media file and its transcript.

- For the visually impaired, the PDA Line Magnifier and Text Isolator, which attaches easily to any personal digital assistant.

- The UpStop Wheelchair Braking System, developed with AliMed. The only automatic braking system for manual wheelchairs, it is designed to reduce patient falls.

- An Automated Pill Crusher for patients with arthritis or Alzheimer's disease who have difficulty crushing their medications.

- The Black & Decker Digital Advantage Countertop Oven™, a combination toaster/convection oven, built with user-friendly features for the elderly.

Another UB T2RERC collaborative product, the Black & Decker Lids-Off™ Automatic Jar Opener for people with poor grip strength, is expected to be a big seller again this holiday season, says James Leahy, UB T2RERC project administrative officer, who worked with Black & Decker to commercialize the jar opener in 2003.

According to Leahy, the UB T2RERC will soon begin to work with other major consumer products companies, in addition to Black & Decker, through the center's new Fortune 500 Project.

"We're showing companies how they can broaden their market by increasing the usability and accessibility features of mainstream consumer products," Leahy explains. "These companies are very interested in trans-generational design - designing products with usability that spans generations - because they're very attune to the fact that baby boomers are aging and will need products

## Assistive technology has innovative solutions to common problems

Don't overlook small companies in your search for solutions. There are many products out there from small, specialized vendors, including daily living aids, learning devices and computer software. Other products are developed by smaller arms of large corporations and are often released with little fanfare.

Since the late 1980s, RJ Cooper has been developing materials in response to requests from teachers, speech and language pathologists, and professionals. His company, RJ Cooper and Associates, develops and manufactures assistive technology (AT) for computers for people with disabilities across the country and in Canada.

Along with creating AT devices, Cooper plans road trips to cities across the country, helping children, adults and their families find the right products. "There is always something else needed," Cooper said. "We can create it. We must create it." For more information on RJ Cooper and Associates or the company's road trips, please visit the web site at [www.rjcooper.com](http://www.rjcooper.com).

A number of corporations have products on the market that they have modified from other released products. Independence Technology, a subsidiary of Johnson & Johnson, has launched a hybrid wheelchair that combines both human and motorized propulsion.

Using sensors and small motors located on the chair's axis just beneath the seat, the iGlide wheelchair allows a person with limited upper body strength to propel the chair and to keep it moving at a consistent pace, regardless if traveling up or down a hill or across bumpy terrain. The iGlide is marketed to people with disabilities who have degenerative diseases that limit the use of one's upper body. Independence Technology will also promote the chair to stronger manual wheelchair users as a way to prevent injuries.

Toyota Motor Sales, USA, Inc. and Independent Mobility Systems, Inc. collaborated on the 2004 Sienna Rampvan, the first Toyota vehicle created for Americans with mobility impairments. This is the first time a major auto manufacturer has introduced a new mobility vehicle at the same time it announced its mainstream counterpart. At a Detroit media event, a prototype of the converted 2004 Sienna was displayed. It included an automatic in-floor ramp, automatic passenger sliding door, and "power kneel" system, which compresses the suspension while extending the ramp to create a more gentle angle for entrance and egress.

Despite collaboration and a great deal of interest and government sponsorship, accessible technology is still an undeveloped science, with high prices for many devices. Experts suggest that first-time buyers get a thorough assessment of what they need and what will work for them. Ray Grott, an AT Specialist at San Francisco State University, recommends that people analyze the activities they have trouble with and research the available devices. The Internet is an invaluable resource. Other factors should also be considered: the availability of the device; the price, and the user's temperament. Assessments can be done through physical or occupational therapists or through a state's department of rehabilitation.

"It is a lot more than just a physical match of the activity to the device," said Grott. "It has to be a holistic process that looks at all the aspects of the person (using the device)."

*These notes on assistive technology used with permission from "Atnet." Although the database operated by [www.atnet.org](http://www.atnet.org) was developed for residents of California, it offers resources throughout the country, including a database for products, services and education.*



## KIT Groups collect ideas

Many thanks to Harley Russell and members for the Kansas-Nebraska KIT group. They've compiled a "Home Remedies" collection, only in this case, they didn't collect the kind of home remedies like putting baking soda on a bee sting or using vinegar to clean your windows. Russell asked members to send in catalog descriptions, magazine ads, or just their own description of what helped them, whether it was a common household object they used to make a task easier, or a commercially-ordered device they found particularly helpful.

One such item is the "handybar," a simple but effective tool that a KIT group member nominated for the catalog because it helped him get out of his car. The Handybar inserts into the U-shaped striker plate on a car or truck. The striker plate is one of the strongest parts of the vehicle because it's designed to keep the door closed in case of a side-impact collision. It can be used on either the driver or passenger side of the car. Simply insert the Handybar into the striker plate. Once inserted, use the Handybar to support yourself as you move yourself in and out of the vehicle.

For your copy of "Home Remedies," call Harley Russell at 913-682-8520, or email [hcrussell@prodigy.net](mailto:hcrussell@prodigy.net).



Not currently involved in TMA's "Keep In Touch" Support Groups? You can join easily by calling or emailing TMA, or by logging into "My TMA" online and changing your support group option.

## Bathing independence study supports importance of lifestyle and modifications

Although bathing gets more difficult with both age and disability, many people can largely compensate for their loss of function with grab bars and other bathroom devices, according to a Cornell University study. They also can make bathing easier with a good diet. The benefits of using assistive devices, such as grab bars, are so great, says Nandinee Kutty, assistant professor of policy analysis and management, that if Medicare and other health insurance programs were to cover them, the resulting benefits would likely far outweigh the costs by preventing falls and injuries and reducing the need for long-term care. Kutty said that assistive devices for bathing are a truly significant piece of independent living.

"People in their 80s who use grab bars, shower stools and other devices gain even more in bathing function than what they would lose if they had a severe stroke," she says. "Although we can't do much about getting older or reversing chronic health problems, these factors are some of the very few things the elderly can do to dramatically reverse loss of function in old age," says Kutty.

Analyzing data from the "Survey of Asset and Health Dynamics Among the Oldest-Old," a nationally representative data set acquired in 1993-94 of 7,500 people age 70 or older, 2,500 of whom were age 80 or older, Kutty found that assistive devices as well as diet stood out as being statistically significant in helping the "oldest-old" continue to function well while bathing.

The National Center for Health



Statistics reports that almost 40 percent of the elderly who do not live in institutions have some limitation of activity caused by chronic conditions.

"The most common activity that the elderly have difficulty performing is walking. The second and third most difficult common activities are bathing and getting outside," Kutty points out. As a housing economist with a particular expertise in economic issues related to the elderly, Kutty is interested in how home modifications can help the elderly. In a study earlier this year she reported that despite the high cost of assistive devices, 40 percent of Americans over age 70, regardless of income, have modified their homes with grab bars, bathroom railings, wheelchair ramps and other aids. She found that the most common types of home modification are bathroom related, such as grab bars or shower seats.

In this study, recently published as a Bronfenbrenner Life Course Center Working Paper at Cornell, Kutty set out to determine how useful these bathroom modifications really are. Her conclusion - extremely useful: "Implementing these factors can enhance the life quality of the elderly and make it easier for them to live in their communities and not need nursing home care. Health care providers should incorporate this knowledge when offering health advice to the elderly," she concludes.

Kutty recommends that policymakers should recognize home modifications as important means of improving the health and functionality of the elderly. Medicare currently does not cover home modifications, although in some states Medicaid does. Kutty recommends the expansion of Medicare coverage to include specific home modifications that help the elderly cope with disabilities.



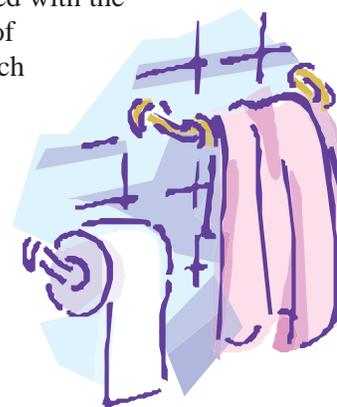
## New folding wheelchair solves problem of commode transfer

A new folding, commode-shower wheelchair developed by Milwaukee and Tampa Veterans Administration researchers addresses the needs of people to have a special commode wheelchair for personal hygiene.

The wheelchair is the first commercial product collaboratively designed by researchers at the Milwaukee Institute of Art & Design (MIAD), the Veterans Affairs Medical Centers in Milwaukee and Tampa, and the Medical College of Wisconsin in Milwaukee. It is designed to solve the serious problems of injuries and falls posed by current commode-shower wheelchairs while adding esthetic design and function that can significantly improve the quality of life for people who are wheelchair-bound.

The wheelchair's development was funded by \$230,000 merit grants from the Merit Intramural Research Program of the Department of Veterans Affairs in Washington, DC, and jointly patented with the Medical College of Wisconsin Research Foundation. A commercial version of the wheelchair was displayed for the first time on October 26, 2004, at the Medtrade show in Orlando. The wheelchair will be produced commercially by Activeaid, Inc., located in Redwood Falls, MN. The manufacturers say the wheelchair will be very competitively priced.

"Current wheelchairs have serious problems that can contribute to significant health complications. Yet little design research focusing on this problem has been done until now," says Pascal Malassigné, professor of



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industrial design at MIAD and the lead research industrial designer at the Milwaukee VA Medical Center.

A survey conducted by the design team found that many users complained that the brakes on commode wheelchairs were ineffective. More than 47 percent felt unsafe when transferring to a commode wheelchair and more than 35 percent reported one or more falls from commode-shower wheelchairs. Of those, more than 23 percent were hospitalized for between one month and four years from the fall.

These problems were brought to the attention of Prof. Malassigné by Audrey Nelson, RN, PhD, director of the Patient Safety Center at Tampa VA Medical Center. Prof. Malassigné and his design team rolled out prototypes of a folding wheelchair for use over a toilet and in the shower. Patients who tried the prototypes considered them far superior to their current wheelchairs. Ninety-five percent wanted one for home use and 89 per-

cent would use them on trips.

Dr. Nelson is the past president of the American Association of Spinal Cord Injury Nurses. "Designed to maximize patient independence and reduce caregiver strain, this new wheelchair will reduce falls and prevent pressure ulcers which were all too common in other commode-shower wheelchair designs," she said.

The largest purchaser of the wheelchair will likely be the U.S. government through Medicare reimbursements.



**To order Activeaid products:**

The company ordinarily markets through local dealers. To find details and a dealer in your area go to [www.activeaid.com](http://www.activeaid.com), or write ACTIVEAID, Inc., 101 Activeaid Road, Box 359, Redwood Falls MN 56283-0359; call 800-533-5330; or email [activeaid@activeaid.com](mailto:activeaid@activeaid.com).



**Disaster planning**, from page 13

were not accessible for wheelchair users

- during extended power outages, people were unable to use assistive equipment and medical devices
- power outages disabled elevators, forcing people with mobility limitations to be dependent upon neighbors or emergency workers

"There is virtually no empirical data on the safe and efficient evacuation of persons with disabilities in disaster planning," White said. "We hope this study will lead to a national model that can prevent death and injury for this population in future disaster situations."

important update

# home IVIG for myositis



IgG America, a national infusion pharmacy, specializes in providing immune globulin (IVIG) services in the home. IVIG may be used to treat myositis, but individual response depends on many factors. Be sure to discuss immune globulin therapy with your doctor.

Reimbursement for IVIG in myositis is complex. Medicare and public assistance programs do not pay for home IVIG. However, if you have other insurance, you may be eligible to receive treatment at home. Home IVIG has been shown to be safe, effective and convenient.

- ▶ All supplies and equipment are shipped directly to you before the treatment date.
- ▶ An experienced infusion nurse will be with you throughout your home treatment.
- ▶ You will receive personalized service and IVIG information from our specialist pharmacists.
- ▶ Infusion dates and times are scheduled according to your needs, including evenings and weekends.

We invite you to call our office for a private, no-cost consultation to determine if home IVIG may be available within your plan of treatment. Please call us toll free at **877.674.9700** or visit [www.iggamerica.com](http://www.iggamerica.com).



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## Students design voice-activated "arm" for man with IBM

Using two motors, speech-recognition software and an exo-skeleton inspired by science fiction, three Johns Hopkins University undergraduates have designed and built a muscle enhancement device that will help a disabled man grasp and lift a cup, a book and other household items. By uttering commands such as "open" and "raise," the man will receive mechanical help in moving his fingers and bending his elbow. The motorized plastic shell will fit over the right arm of the man, who has inclusion-body myositis.

This device, which could be adapted for people with other disabilities, was developed during two semesters by students in the Department of Mechanical Engineering's Senior Design Project course. The project originated last summer when the man with the muscle disease sought help from Volunteers for Medical Engineering, a nonprofit Baltimore group that uses technology to assist people with disabilities. The client, who asked that his name not be disclosed, explained that his nerves were intact, meaning that he could control the placement of his fingers around an object. But progressive muscle deterioration left him unable to grasp and lift even small objects.

To help him, the VME sponsored a project in the Johns Hopkins course. The task of designing and building the device went to a team consisting of three senior students. The students researched prosthetic limbs and, taking a cue from props featured in the film "Aliens," they designed a plastic exo-skeleton to slide over the client's right hand and arm. To help move his fingers and elbow, the students tested and rejected systems using electromagnets and air pressure systems. They finally settled on two small but powerful stepper motors. These could move the fingers and elbow in small, slow increments, allowing the client

to clasp a cup firmly without crushing it. In addition, these motors did not require continuous electrical current to stay in position, which preserves battery power. The students linked the motors to a series of cables and springs to enable the device to move the man's arm into position and help his fingers grasp and release.

The students opted for voice recognition software as an easy way for the disabled man to control the grasping device. After the software is trained to the client's voice, saying "arm" or "hand" will take command of one of the two motors. The elbow motor will then respond to "raise," "down" or "stop." The hand motor will respond to "open," "close" and "stop." The device is hard-wired to a control box that contains a miniature computer programmed to turn the voice commands into signals that tell the motors how to operate. The unit is powered by a rechargeable 12-volt lead-acid battery commonly used for remote-control boats and airplanes. The control box fits inside a small pack that can be carried on the waist, making the device fully portable.

"The students did a wonderful job," said Jan Hoffberger, executive director of Volunteers for Medical Engineering. "They came up with a very creative design for the device. They purposely set it up to move very slowly, so that at any time in the grasping and lifting process, our client can tell it to stop. We believe he will find it very helpful."

The students had to work within a budget of \$10,000; they ended up spending about \$8,000 on the device. Designing and building it helped the undergraduates to understand some of the challenges that working engineers face. Find this project and other projects on the VME Web site at [www.toad.net/~vme/](http://www.toad.net/~vme/) or contact the VME Main Office at 2301 Argonne Drive, Baltimore MD 21218; 410-243-7495; [vme@toad.net](mailto:vme@toad.net).

## Swallowing trouble, from page 6

**Specialty Food Shop at The Hospital for Sick Children:** [www.specialtyfoodshop.com](http://www.specialtyfoodshop.com); [sfs@sickkids.ca](mailto:sfs@sickkids.ca); 800-737-7976

**Walgreens:** [www.resource.walgreens.com](http://www.resource.walgreens.com) [ThickenUp now available in store.]

**Youcan Toocan, Inc.:** [www.youcantocan.com](http://www.youcantocan.com); 2223 S. Monaco Pkwy, Denver CO 80222; 888-663-9396 [Visit the "Arthritis Center" to find "Myositis Products" for some ideas.]



To find a speech-language pathologist near you, visit the American Speech-Language Hearing Association's searchable web site at [www.asha.org/findpro/default.htm](http://www.asha.org/findpro/default.htm).

## Meal preparation, from page 9

### Cartons and bottles

- Do not buy large cartons or bottles if possible.
- Try to buy what you need in a plastic bottle.
- For ice-cubes, use a flexible tray that can be bent easily to let the cubes fall out.

### Carrying

- Slide rather than lift.
- Wheel rather than carry.
- Use a basket or steamer for draining.

### Pouring

- Teapot and kettle tippers can be very useful.
- If you can find an automatic kettle as a source of hot water, these are safer and easier.
- Drink dispensers for your refrigerator are easy to use, once filled.



# Accessibility: Does your home measure up?

One of the biggest concerns of the homebuyer with a potential future disability is the adaptability of the home he buys to accommodate his condition. The same is true of someone who plans not to move from his present home. There are a great number of resources available to judge the ability of your home - or a home you may buy in the future - to be safe for you and your family members in the event that you must use a wheelchair or a walker.

Many common-sense suggestions are available from The American National Standards Institute (ANSI), and many of the physical dimensions cited here are from the Institute's Web site, [www.ansi.org](http://www.ansi.org). You can also use these dimensions to find out if you will be able to configure your present space in the event of future physical challenges.

"Adaptability" as used by government authorities means the flexibility of building elements (like kitchen counters, sinks and grab bars) to be changed to accommodate the needs of people with different types or degrees of disability.

## What about your present home?

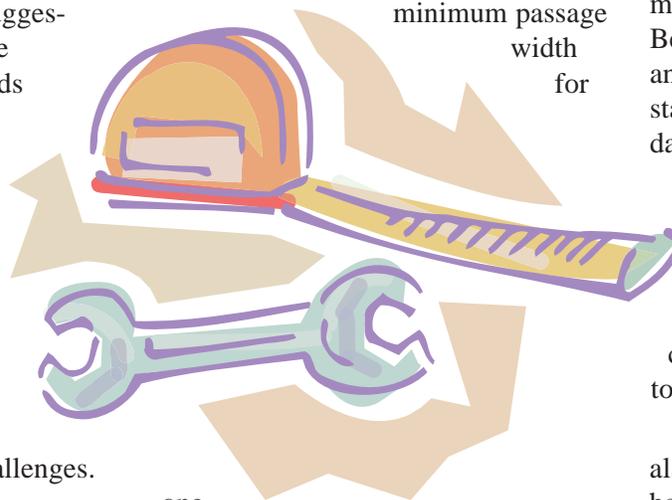
Can it accommodate a wheelchair? The average dimensions of a standard adult manual wheelchair with its occupant are:

- length: 46 to 50 inches including allowance for projection of feet to overhang,
- width: 23 to 32 inches allowing for hands and elbows,
- seat depth: 16 inches,
- seat height: 19 to 20 inches, and
- arm height: 29 to 30 inches from floor.

The sports wheelchair has cambered wheels, has a lower seat and is wider, but the overhead reach is not as high as the standard model.

The average distance needed for an adult in a wheelchair to make a complete circle is 60 inches of clear floor space. The minimum clearing width for a wheelchair is 36 inches for a hall and 32 inches for a door. Minimum clear space for a T-shaped turn of 180 degrees is 36 inches in all directions, and the

minimum passage width for



one wheelchair and one ambulatory person is 48 inches.

The average reaching distance of a seated adult reaching to the side and overhead is 54 inches and the low side reach is about nine inches above the floor. This doesn't include reaching over an obstacle like a counter. The maximum forward reach is 48 inches above the floor, also not over an obstacle.

## Can your home accommodate a ramp?

A safe, sturdy ramp can replace stairs or be part of an accessible route to a building's entrance. An accessible route is the shortest possible path from a handicapped parking space to an accessible entrance. There should be at least one accessible route from a public street, sidewalk or parking space, to an accessible entrance, as

well as routes from adjacent buildings like garages and workshops. Ramps are required any time there is an elevation in the grade of the land that wheelchairs must maneuver. The maximum slope of any ramp is 1:12. This ratio means that for every inch of height in grade change, you'll need 12 inches of ramp length for safe entrance. The ramp length (or run) should not go more than 30 feet without a landing, nor should the ramp rise more than 30 inches. The minimum width of a ramp is 36 inches. Because conditions like snow, ice and wind add to the hazard, some states have developed a second standard for exterior ramps and walkways. Landings are required at both the top and bottom of a ramp and should be at least as wide as the ramp (36 inches).

Landings should have 60 inches of clear space at both the top and bottom.

If a ramp longer than 6 feet will also be used by ambulatory people, a handrail is needed on both sides of the ramp. The handrails should extend 12 inches beyond the top and bottom of the ramp and should have a clear space of 1 1/2 inches between the handrail and the wall. There should be 30 to 34 inches from the floor of the ramp to the top of the handrail. Children require a lower handrail.

The two most common materials for ramp construction are wood and concrete. Wood is easier and faster to construct, relatively inexpensive, and can last for years. All ramps and landings need a nonskid surface and should be designed so water will not accumulate. The surface of concrete ramps must be textured. Two ways to make wooden ramps nonskid are pebble-grained paper or sand mixed with paint. Although these are general rules, every ramp must be custom built to conform to the specific site.

Once you get to the entrance, a clearance of 18 inches on the latch side of the door allows for an easier and safer opening. A shelved, attached wall near the door on both sides permits a wheelchair user to put packages down while unlocking and opening the door.

If you can't afford a ramp, perhaps you can find a group to help. Civic and church volunteers all over the country are finding that one of their most rewarding projects - and the one in most demand - is ramp building. Some of the groups involved in this effort are Kiwanis Clubs, Habitat for Humanity, Church Groups, The United Way, Centers for Independent Living, and individual state groups that receive partial funding from public sources. A ramp building project can be undertaken by any group from a single-purpose non-profit to a program within an existing fraternal, social service agency or church group with an informal needs list. Some agencies have funds to partially pay for ramp materials. A typical ramp to replace four seven-inch steps will have 30 feet of incline. Each foot of ramp will require from about \$25-\$30 for materials; or between \$750-\$900 for typical four-step ramps.



For information - including design, plans and specifications in every area of home modification - you'll want to start at the Center for Universal Design online at [www.design.ncsu.edu/cud/](http://www.design.ncsu.edu/cud/). The Center for Universal Design is a national research, information, and technical assistance center that evaluates, develops, and promotes universal design in housing, public and commercial facilities, and related products.

## Products of the past: index of articles

Below is a list of articles, divided by topic, from the 2003 and 2004 issues of *OutLook Extra* focusing on products and strategies to help people with daily tasks and everyday decisions. To obtain your copy of these publications or specific articles, visit your "My TMA" section of the web site at [www.myositis.org](http://www.myositis.org) by clicking LOGIN at the top of the page; email [tma@myositis.org](mailto:tma@myositis.org); or call 800-821-7356.

### Do-it-yourself and other helpful gadgets

Classic common-sense solutions: The Moench Buttonhook and The Half-Step [2003]

Helpful hints: Members share their ideas [2003]

He said, she said: Your everyday tips [2004]

Gadgets for myositis [2004]

Ingenious solutions keep gardens growing [2004]

### Fashion/clothes

Clothes for all ages [2004]

Dress yourself in style: Tips for wheelchair users [2004]

### For children and families

Adapt to your child's changing needs [2004]

Help your children help themselves [2004]

Beyond medicines: Strategies for JM families [2004]

### General

Staying on the road [2003]

Finding funding for your needs [2003]

The search is on: But why start now? [2003]

Time for a change? [2004]

Myositis 24/7 [2004]

Companions save the disabled in surprising ways (companion animals) [2004]

### Room-by-room

Tried and tested ideas for bed and bath [2003]

More than making do: Building a house that works [2004]

The tailored kitchen [2004]

### Skin products

Relief from dry skin [2003]

### Strategies

Discover your creative side [2004]

### Walking aids

What about canes and walkers? [2003]

### Wheelchairs, power chairs and scooters

Need a lift? Decide whether you should drive or push [2003]

Wheelchair users have more choices than ever before [2003]

Buying and using your scooter or power chair [2003]

In the market for a wheelchair? Start with a mouse [2004]

# Independence issues come into national focus

## As of press time, several dozen

U.S. senators had joined their House colleagues in calling for changes to **Medicare's wheelchair policy**.

Thirty-four senators, including seven members of the powerful Senate Finance Committee, signed a letter asking Health & Human Services Secretary Michael Leavitt to change a Medicare policy preventing coverage of mobility devices for use outside the patient's home. Sens. Jeff Bingman (D-MN) and Rick Santorum (R-PA) initiated the July 13 letter. Earlier this year, 61 House members signed a similar letter. To view copies of those letters, visit [www.itemcoalition.org](http://www.itemcoalition.org).

## New regulations make it more

complicated for your doctor to determine **when you need a wheelchair**. The Centers for Medicare & Medicaid Services wants doctors to disregard the old "bed- or chair-confined" criteria when determining whether their Medicare patient needs a wheelchair, according to a recent Medlearn Matters article. Instead, they must consider the patient's physical and psychological functional limitations, other support availability and living environment, CMS says. The new coverage was effective May 5 and includes canes, crutches, walkers, manual wheelchairs, power wheelchairs and scooters.

CMS set forth nine sequential questions for doctors to use to decide the appropriate type and complexity of mobility aids needed to restore the patient's mobility-related activities of daily living, such as toileting, feeding, grooming, dressing and bathing.

## States would have more control

over benefit packages under a **Medicaid reform proposal** crafted by the nation's governors. Presented in July to members of Congress, the plan would allow states to establish

different benefit plans for different beneficiaries, the Wall Street Journal reports. It would create tax incentives to encourage people to buy private long-term care insurance and take reverse mortgages on their homes to pay for long-term care. The plan also would tighten restrictions on the transfer of assets to qualify for Medicaid, according to the paper. Congressional Democrats criticized the proposal as an "immoral" attempt to fund tax cuts for the rich at the expense of the most vulnerable Americans.

## Power wheelchair manufacturers

will have to submit **test results and an application for their products** to the Statistical Analysis Durable Medical Equipment Regional Carrier by September 1, the Centers for Medicare & Medicaid Services says.

The new codes for the devices posted last month include performance standards, and every power wheelchair product must be tested at one of the approximately 30 testing facilities worldwide certified by the Rehabilitation Engineering and Assistive Technology Society of North America. The purpose of submitting the application and test results is to verify the code the product will get under the new set of power wheelchair codes announced February 3.

Starting January 1, 2006, Medicare will not pay for products under the old codes, nor will it pay for products under the new codes that have not been tested and received a coding verification.

## Three policy analysts at Johns

Hopkins Bloomberg School of Public Health in Baltimore undertook a study of **Medicare spending on durable equipment**. Saying that Medicare's role in the distribution of mobility-related assistive technology has not been well documented, the

authors said that rapid growth and regional variation in spending, and concerns over "in-the-home" coverage criteria, highlight the need for facts. Using the 2001 Medicare Current Beneficiary Survey, they found that 6.2 percent of beneficiaries obtained mobility assistive technology under the Medicare durable medical equipment (DME) benefit. These beneficiaries were disproportionately poor, disabled, and users of both acute and postacute services. Average per item spending ranged from \$52 for canes to \$6,208 for power wheelchairs. Among beneficiaries who acquired such technology through the DME benefit, these devices comprised just 2 percent of overall Medicare spending.



## Mouse, from page 14

made with features that ensure usability and access as they age."

The UB T2RERC is funded by a five-year \$4.75 million grant from the National Institute on Disability Rehabilitation Research.

Infogrip, Inc., was founded in 1986, with a mission to develop and market products that provide people with healthier and more productive ways to interact with computers. The company offers a low-price guarantee and a 30-day refund policy. If you don't see what you are looking for, they promise to get it or refer you to another company that can.

Infogrip has been providing solutions for more than sixteen years to the disability, ergonomic, education and graphic design markets. On the web, reach Infogrip at [www.infogrip.com](http://www.infogrip.com). If you have questions or would like a printed copy of the catalog, call 805-652-0770 or email [sales@infogrip.com](mailto:sales@infogrip.com).



# 2005 Annual Conference

The Myositis Association's Annual Conference, which drew over 300 attendees last year, will be held in downtown Cleveland from October 6-9, 2005.

Once again, the Conference will be highlighted by an expert Medical Panel presenting the latest news about the disease and treatment options. The Conference will include various workshops, roundtables and informal sessions to provide patients, family members and caregivers with the opportunity to learn more about living with myositis as well as to share experiences with others who have learned to cope.

The Annual Conference is a great way to become more informed about myositis as well as to renew acquaintances and make new friends. Cleveland offers a central location within driving distance of many major metropolitan areas as well as the excitement and vibrancy of one of America's revitalized urban areas.

Plan to be with us this holiday weekend (Columbus Day) in October to take advantage of this unique opportunity!

## Register with TMA!

You can register online at [www.myositis.org](http://www.myositis.org), or by calling 800-821-7356.

## Reserve your room!

Remember to mention The Myositis Association conference or the reservation code MYAMYAA, to receive the discounted room rate of \$109/night for regular rooms or \$199/night for suites.

## Cleveland Marriot Downtown at Key Center

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Fax: 1-216-696-0966



## Agenda, October 6 - 9, 2005

### Thursday, October 6

11:00 am	Registration (until 5:00 pm)
3:00 pm	Cookie and Punch Reception
4:00 pm	Get Acquainted Sessions
12pm-12am	Hospitality Suite

### Friday, October 7

7:30 am	Orientation for First Time Attendees
8:00 am	Breakfast and Welcome
9:00 am	Concurrent Sessions*
10:30 am	Patient-led Panels**
12:00 noon	Lunch on your own
1:15 pm	Welcome to Cleveland
2:00 pm	Concurrent Sessions*
3:30 pm	Meet the TMA Board of Directors
4:30 pm	Reception (Light Hors d'oeuvres)
6:30 pm	Optional: Cleveland Playhouses or Orchestra**

### Saturday, October 8

8:00 am	Breakfast and Program: Participating in a Clinical Trial
9:00 am	Expert Medical Panel
10:45 am	Down through the Ages: "A Historical Look at Myositis"
12:15 pm	Luncheon and Program: Music as Therapy
1:45 pm	Questions & Answers with the Experts (By disease type)
3:15pm	Filmaking Workshop
6:30 pm	Dinner on your own OR Optional: Cleveland Playhouses or Orchestra**

### Sunday, October 9

8:15 am	Breakfast
9:00 am	"Humor as Therapy"
10:30 am	Conference Adjournment

### Special Juvenile Myositis Program:

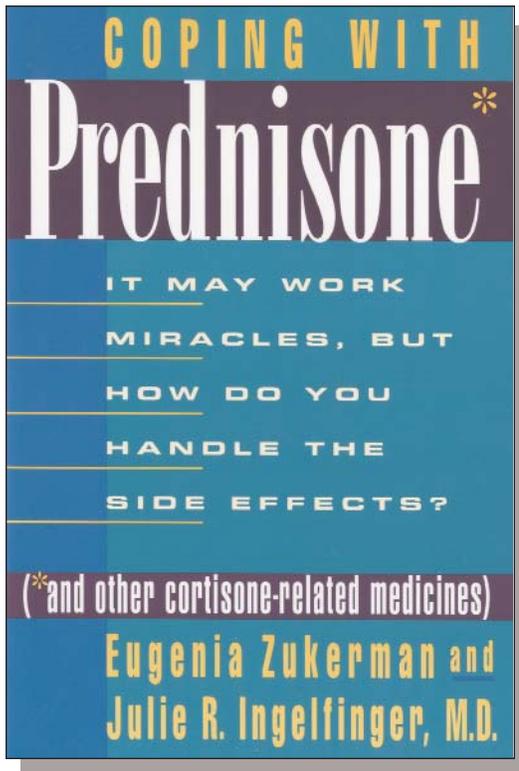
10:30 am	-	4:30 pm
	"Coping with JM as a Family"	
	"JM: What to Expect During its Course"	
	"Partnering with Your Health Care Team"	
	"Complements to Medicine"	
	"Great Lakes Science Center" - Field Trip	

### \*Concurrent sessions include:

- "Understanding the National Institutes of Health"
- "Myositis for Beginners"
- "Living Well with Chronic Illness"
- "Dysphagia"
- "Exercise for Every Level of Ability"
- "Pain Management"
- "Stretching and Strengthening"
- "Water Exercise" (Poolside)

### \*\*Patient-led Panels include:

- "Choosing a Physician"
- "Resources for Information"
- "Support Groups"
- "Creating Awareness and Fundraising"



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It may work miracles, but how do you handle the side effects?

Approximately one million Americans per year take high doses of prednisone and other corticosteroids to treat serious illnesses and conditions. While these medicines may have unpleasant side effects, including gastrointestinal problems, intense mood swings, changes in hair and skin, and increased susceptibility to infection, they may also be the only treatment available for serious life-threatening illnesses.

Packed recipes, exercises and tips based on personal experience, Coping with Prednisone is an invaluable handbook for health-care workers, caregivers, and especially the patients themselves.

Now available in TMA's marketplace at [www.myositis.org](http://www.myositis.org).  
Order your copy of Coping with Prednisone for just \$13.95.



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