

[From the message boards: home school v. public school](#)

The online message boards are filled with information and reassurance for - and from - families affected by the many aspects of juvenile myositis. Visit www.myositis.org (Community Forum) to connect with other JM families.

“I am interested to see how everyone else is handling school. Currently my daughter is in public school. When we go to doctor's visits they all seem shocked that I have her in public school. Both my husband and I have to work, so I have never really thought about home school as an option. But at the same time it worries me because of the medicines she's taking and the parents that send their sick children to school disregarding the health of other children. How do you handle this?” - D.

“When our daughter was first diagnosed and appeared to have a bad case of JDM, the doctors recommended we take her and her little brother out of daycare. We did and hired a nanny. Two years later, she has progressed enough health-wise that the doctors encouraged us to send her back to daycare, saying that the benefits of social interaction outweighed the health risks. (She was getting Solumedrol every other week, daily Prednisone, and weekly methotrexate at the time.) We moved her Solumedrol treatments to Friday mornings, as our home health nurse said it would

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Keep kids moving

Doctors and others in health care encourage exercise, noting its benefits to both physical and psychological health. Children in the acute phases of juvenile myositis (JM), though, may be an exception to the rule, says Laura Rohnert, PT, physical therapist at Children's Memorial Hospital in Chicago: When it comes to exercise, wait until it's time, she says.

Upon hearing the diagnosis "juvenile myositis," parents are often overwhelmed with new terminology, medicines, schedules, and more. Where do exercise and physical therapy fit in? Your child's doctor may recommend a physical therapy evaluation, but ongoing rehabilitation is not necessary for every child, says Rohnert. Talk to your child's doctor, who may be able to recommend a local therapist.

Physical therapists test for endurance, range of motion, posture, gait, and other functions at the initial visit to determine what types of exercises need to be integrated into your child's daily program. "Typically when a child is first diagnosed," says Rohnert, "they're very limited in their function." Rehabilitation begins by working on range of motion and stretching. Passive range of motion exercises, where a therapist or parent moves the joint for the child, are easy to do at home, once the therapist has determined what exercises are right for your child and demonstrated the proper techniques.

[Working from home](#)

In the beginning, Rohnert encourages parents to allow their children

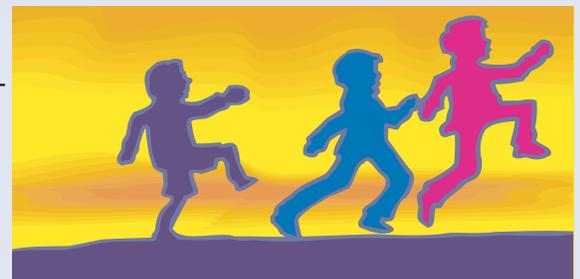
to be as active around the house as they can be. Incorporate into your child's normal daily and play routines some activities that require your children to control their muscles.

"I discourage parents from always picking up their children right away," she says. Instead of acting on the natural impulse to help your children as they struggle, allow them to try things first, doing what they can tolerate, before you help. "Then you and your child can see the progress as they start to recover," she says. This is a frustrating process for everyone at times, but even the small accomplishments make a big difference to your child. Some children need assistance in the entire process of sitting up at first; as they begin to succeed independently at any part of this - even just rolling over to the right position - they're making measurable progress.

[Add activities as you can](#)

Once the doctor approves moving forward in physical therapy, core strengthening is introduced. "The first thing typically addressed is strengthening the abdominal muscles," says Rohnert. When the child is functionally ready - and out of the acute phase of JM - therapists work

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Published by: TMA, Inc.
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Kathryn Spooner and sons Rhys (left) and Caden (right).

Dear Families:

My 4-year-old is anxiously waiting for warmer weather, asking each morning, "Is today spring?" (Of course, this is more likely due to the fact that his birthday falls in a spring month...) For many people, the spring and summer months mean more time outside enjoying the sun and exercising. This isn't always the case for those with JM, but there are precautions

children and parents can take, from applying plenty of sunscreen to deciding what level of activity is right for them. Read more about appropriate activity levels in this issue of *Companion*.

Many of you have asked about TMA's book on juvenile myositis. As of this writing, all involved in its production are pleased with how it is turning out and passionate about making it the best possible JM resource for families. We know that you're anxious to get your hands on a copy, so watch TMA's web site, the *Companion* and your e- and postal mailboxes for updates and announcements!

Thanks to all of you for your continued support of TMA and its JM programs!

Warmly,
Kathryn

Create memories at summer camp

Summer is almost here - time to start thinking about your summer activities. TMA is again offering camperships up to \$100 for JM children who would like to attend summer camp this year.

What do you need to do?

First, you must be a member of TMA. Then, simply find a camp for your child and have the counselor fill out the TMA Summer Camp Scholarship forms. You'll find these on TMA's web site, or we'll be glad to mail them to you or to the camp. (If you're not already a member, that's okay. Join now at www.myositis.org or 800-821-7356.) TMA works directly with the camp so you don't have to worry with these details - just when to go and what to pack. TMA asks children with camperships to write a brief report of their experiences.

Why consider camp?

TMA's JM families tell us that attending summer camp is invaluable to their children, giving them the opportunity to relax and enjoy their time with other children who share similar experiences and challenges. They can speak openly about their frustrations, fears, anxieties, and triumphs, with the reassurance that these children will truly listen and understand.

So start planning now for a fun and unforgettable camp experience!

For more information or for help finding a camp near you, visit the *Juvenile Programs* section of www.myositis.org (under *Parents then TMA programs and services*); email kathryn@myositis.org; or call 1-800-821-7356.



Moving ,
continued from cover

on the different muscle groups affected. Therapy is individual and constantly adjusted to fit your child's situation. Many of the exercises can be done at home, with you helping your child, although for some children, continued outpatient therapy remains the best option. Even with outpatient therapy, notes Rohnert, children should have exercises to do at home. Walking up and down the stairs slowly and steadily, for example, works on muscle strength and control.

If your child is interested in organized sports and able to participate, find out about what sports might best fit his or her abilities and interests. Emily, a teenager with JM, enjoys the challenge of volleyball, where she's able to work with her teammates and doesn't have to run as much as she might in other sports. Playing on a team provides a sense of normalcy that is so important to JM children.

Keep spirits up

Encourage activities that allow your child to participate with their peers, as long as your doctor approves. Depending on your child's strength and endurance, he or she may not be able to run as fast or as far as the others on the team or in the group. As strength and endurance improve, so will your child's ability to keep up. Working on endurance, when given the go-ahead, can be as simple as walking around the block, then adding to the route as your child feels able.

"Be your child's cheerleader and coach," says Rohnert. Especially when the exercises are difficult and tiring, encourage your children with sticker charts, for instance, once they've completed their daily exercises. Be aware of any changes in your child's strength, endurance, and general activity level, Rohnert says: "And know when to ask for help."

Editor's note: Always check with the doctor or physical therapist to be sure

the activities you choose are appropriate for each stage of your child's JM.



Be creative

Range-of-motion or basic stretching exercises are important in early stages of JM, and you can be imaginative in finding big and small ways to incorporate these into your child's day:

- Have your child paint using wide-handled brushes, sponges or finger brushes. Add an easel to allow your child to stretch even more while painting.
- Integrate your child's prescribed home exercises into a game of "Simon Says." You can adapt the game as your child is able to do more over time, choosing the movements that fit your child's present abilities and adding exercises as your child's therapist recommends them. Adapt different games to your child's ability, too - hopscotch, games using balls and other equipment, and more.
- Plant a garden outside or in a window box, giving your child the chance to reach out to plant the seeds and to have fun watching their creation grow.

When your child gains strength and the therapist approves, add activities for endurance and strength:

- Take a walk through the neighborhood, searching for or collecting different items of interest (leaves, flowers, birds, cars), or to a nearby bookstore, restaurant or store.
- Learn what swim lessons, sports clinics or other organized activities are available in your area. Find those suited to your child's situation and what your child enjoys.
- Go on a family bike ride through a scenic park or just around the block.

Lower to moderate exercises don't have to feel like exercise!

Ask the Doctor with Lauren Pachman

Lauren Pachman, MD, is Director of the Disease Pathogenesis Core, Children's Memorial Research Center, and Professor of Pediatrics at Northwestern University's Feinberg School of Medicine. She has a special interest in juvenile myositis, treating patients from around the country. She represents the JM community on TMA's medical advisory board.

Q: Can you discuss the role of the sun in JDM? What do researchers currently know about how and why UV rays are involved?

A: We still have a lot to learn about the interaction of our environment and factors that promote or alter the course of JM. For children with JM, the sun can be both helpful and troublesome. On the helpful side, the brighter light can diminish some of the sad feelings encountered on darker days. Some sun exposure promotes the skin's production of vitamin D, needed for healthy bones. But this vitamin can be taken as a pill (the amount depends on the child's weight) and is very useful in conjunction with adequate calcium intake for children taking corticosteroids or with low bone density.

There is some information about problems from too much direct sun exposure. Excessive sun exposure is not good for anyone and has been linked to premature aging of the skin as well as several types of skin cancer. Some people with autoimmune problems find that they sunburn more easily when exposed to the sunlight for short periods of time. We have understood for several years that sun exposure plays a significant role in the activation of the clinical signs of JDM, but this topic is just starting to be explored in depth. In fact, several

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GROWING UP WITH JM: KAITLIN'S STORY

By Kaitlin Maher, juvenile dermatomyositis

Editor's note: Kaitlin lives in Connecticut with her parents and three sisters. She is currently in the seventh grade. She graciously took the time to put her thoughts on paper about her life with juvenile myositis for the past six years.

I am twelve years old and have had juvenile myositis for six years. It has brought me through some very difficult stages, both physically and emotionally. My past is difficult to put down on paper, and to me some things might seem a little more drastic than they seem to you.

As an energetic six-year-old, I was on a soccer team. I was not very athletic, but I enjoyed sports and playing outdoors. That November, my father left for a two-week business trip and came back noticing I was very stiff while running. In my child point-of-view, I realized I was always tired and running out of energy easily. I couldn't run or do the things I enjoyed doing. I also couldn't do regular everyday things, like pulling a sweatshirt over my head or climbing a flight of stairs without using the banister. My family and I noticed a red rash on my joints, especially on my hands, and a "butterfly rash" on my face that went across my nose and onto my cheeks. The ultimate fright came when I went ice skating with my friend Elizabeth and I fell down. I couldn't get up. Getting up from a fall on the ice is difficult to begin with, but this was like my muscles had reached a wall and couldn't move. This scared both of us, and that was a day neither of us will ever forget!

Finding answers

My mother took me to the doctor's office immediately after this. My physician knew almost at once that I had JDMS, but he did not know how

to treat it, so I went to a lot of specialists (or so it seemed to a six-year-old) before we finally met Dr. Zemel. Although I was not awake during the biopsy, it was definitely an interesting day. I clearly remember going home that night to unravel the bandage on my leg, revealing a heart-shaped scar in the middle of my thigh. The scar, although not in a heart-shaped form, is still on my leg today.

I do not remember at what times I had what medicines, but I do remember what they did to me. First, Dr. Zemel put me on prednisone. That drastically changed my life, with side effects that seemed worse than how much the medicine helped me (which was not very much). It made me extremely emotional! I couldn't enjoy the normal things like watching movies (they made me really sad and even sick). The simple Disney story Tarzan was more than I could take. I cried a lot those few years, and my weight exceeded what it should have been.

After a while, we tried methotrexate, which was injected into my body by a needle every week. Of course, my mother had to do this. Most children do not enjoy shots, and I was no different. And through all the pain, it didn't even work! I was still really weak. Since the prednisone and methotrexate didn't work, Dr. Zemel lowered the dose I took, and I started a new treatment, called IVIG. I was to go to the hospital about once a

month in the beginning and sit there for six hours with a needle going into my hand or wrist. This was also something no kid likes, but it worked. With IVIG and some physical therapy, I slowly but surely got better.

Moving on

I love swimming. I swam competitively, but I never could keep up with the others after JDMS. I tried very hard for a few years, but nothing could get me over the feeling of continually being behind the others in my lane during practice or the sixth and fifth place ribbons. In my heart I knew this wasn't going to work out for me, so I stopped. But I still swim in the summer at my family's pool club. Sometimes I really miss competing, but I know I'll never go back to what I had to go through every week.

I had always loved dancing, too. Although I still had a lot of limits in the beginning, music has definitely always been my thing, and moving to it makes me feel so much better. There were times when I couldn't reach my stomach to the floor, while the rest of the class got lollipops for doing it. There were times when I couldn't keep myself up in a lunge position. But I loved dancing and after quitting swimming, I decided to get more serious about it. My sister Becca, friends Elizabeth and Katie, and I all transferred to a more challenging dance school. There I really progressed and began to build up my strength.

Playing the piano has always been one of my favorite hobbies, too. I have been playing since third grade. My piano teacher is so much fun to practice with! However, now that the arthritis in my wrists has gotten worse, it hurts a lot to play. Most of



Kaitlin Maher, JDM patient

the time, I live through the pain and play anyway.

My arthritis also affects me in school. My wrists are so incredibly weak that I cannot write a half a page without them throbbing. They affect me anywhere I go. In gym class, I often can't participate in volleyball and basketball. I can't do push-ups because, not only can I not hold myself up in that position, I can't bend my wrists far enough to get into that position. And, if someone accidentally bumps into me and knocks my wrist, it kills.

[Dreaming of the future](#)

I want to be a politician or rheumatologist when I grow up. My goal is to become President and make the world a safer, better place. But, if I become a rheumatologist, I can help people with diseases like mine and maybe even find a cure! So I have big hopes and dreams, and I am not letting JDMS get in the way. Even though it may give me limits, there are a lot more paths to take than just sports.

So now I'm a lot better, but not 100%. The rash is still there almost as bad as ever, but my muscles are a lot better. The prednisone still affects my emotions, which is very difficult to deal with in my middle school years, but I have fun with dancing and piano and am very good in school. (I use the computer a lot to do my homework so my wrists don't hurt.)

My family and friends have been very supportive since the day I was diagnosed. I wish the best for all of the kids with JDMS and other diseases, that they will have a fast recovery. And for those kids, my advice is to just reach for your goals and work hard. As said in the movie *A Cinderella Story*, "Never let the fear of striking out keep you from playing the game."



[Messages , from cover](#)

take about 24 hours for the immune system to take the full hit from the steroids - so that would minimize some exposures." - K.M.

“My granddaughter missed 15 weeks of school last year due to the flu, colds and a staph infection, in addition to the chicken pox. In an effort to get her a proper education and eliminate the problem of exposure to illness, she is being home schooled this year. She is monitored online by a teacher who also interfaces with her regarding her assignments and progress, and provides reports to her mother. She can jump ahead if she likes or has extra time to catch up if need be.

We didn't know how this would work out or if she would even like it. She says she likes it a lot. Her mother makes sure she has other activities where she can be with kids her age - art classes, field trips, etc. Most communities have 'Home Schooling Groups' that get together one day a week, outside the home, for things like science projects, sports and field trips." - H.B.



[Ask the Doctor , from page 3](#)

scientific publications show that people with SLE (and presumably JDM) tend to have more sensitive skin with respect to sun exposure. Compared with normal skin, some children with JDM and perhaps PM may require less exposure to the sun's rays to cause a "sunburn."

Genetics may contribute to sun sensitivity. Research suggests that if adults have the type of genetic make-up associated with increased production of the factors that promote inflammation, such as Tumor Necrosis Factor alpha (TNF-alpha), they may be more susceptible to developing a rash after excessive

sun exposure. These are research tests, not available to the general consumer, and give investigators clues about the pathways that relate the sun to damage. Another clue may be related to a specific component of the sun's rays, called ultraviolet B. The actual amount of UVB exposure may vary with latitude as well as altitude. Several studies suggest that UVB may play a role at the start of the symptoms of JDM/DM, but more data is needed to further define the specific relationship of UVB to the mechanism of inflammation. Again, this is an area of active research and collaboration among investigators.

Until we have more research information about the sun, what can we do? The simplest and most useful approach is to avoid being outside in direct light between 10AM to 2PM. When someone with JM goes out the door, make sure they have covered all exposed skin with sunblock of SPF 30 or greater that is relatively resistant to sweat. Reapply the sunblock every few hours. There are new kinds of sunblock each year. Clothing can also provide protection, so long sleeves and long pants help cut down contact with the sun's rays. Clothing can be treated to provide further blocks itself. Don't forget a hat that shades the face (the back of the neck is also vulnerable), such as a baseball hat, which may be more acceptable to your child. Many of our children wear shirts when they swim, just to avoid the sun's reflected rays from the water.

It's especially true in JDM that more research is needed. Our own published investigations suggest that skin inflammation, which is most affected by the sun, may follow a different path than muscle inflammation in children with untreated JDM. Until we know more, it's best to respect the power of the sun!



PARENTS REACH OUT TO PHYSICIANS

They just don't understand. That's what parents of JM children say when their physician asks them to wait six weeks for an appointment with a rheumatologist while their school-aged child loses the ability to walk or even stand up. Or when the rheumatologist sends them home with a prescription for prednisone, reminding them to watch for "side effects," but without telling them which of those side effects needs immediate attention. A group of women, all parents of children with chronic disease, finally realized that their physicians really DIDN'T understand, so they decided to teach them.

Maggie Hoffman, Donna Appell and Nancy Speller founded DOCC (Delivery of Chronic Care) in 1994 to improve the quality of care for severely chronically ill children by educating pediatricians-in-training about what they needed as parents.

They tell the story of Angela Cano, sent home with her Downs Syndrome child and a feeding tube. The mother worried about missing her baby's stomach and pushing the tube from nose to lung. She was told the mistake would kill her baby and "good luck." The New York mother of Joanna, now 11, believed doctors could provide better care and better advice if they understood what families were going through. Cano joined Project DOCC, which brings doctors out of the hospital and into the home to learn firsthand how families deal with the long-term care of chronically ill children.

Project DOCC is now a part of the training of more than 800 medical residents at 20 hospitals in the United States and Australia. It has trained hundreds of family members to act as "family faculty," to help with the educating of young physi-

cians through home visits, parent interviews, and grand rounds presentations. Project DOCC works with the United Hospital Fund, which provided early grant support for the program, to evaluate and improve the current pediatric programs in hospitals and work towards a similar program for children who will make the transition into adult medicine. Simply put, the mission of Project DOCC is to put the family at the center of the health care system.

How Project DOCC works

At medical centers with a Project DOCC program, the center and family members form teams. The curriculum becomes a part of the general pediatrics or internal medicine rotation, and is required for all residents and medical students during their training. Teaching videos, manuals, and slides are free. Each team completes a two-day training workshop. The curriculum taught by parent-teachers includes a grand rounds panel presentation, a home visit, and parent interview, which takes the chronic illness history of the patient. Any parent or family member of a chronically ill child is invited to get involved, says Hoffman, who serves as the program's coordinator. Many centers pay stipends to the parent-teachers.

Hoffman said the first step is to visit the web site (www.project-docc.org). If a parent or doctor is interested in starting a Project DOCC program at his or her medical center, send an email to Hoffman through the site, and she will send out a packet of orientation materials. Hoffman also suggests that parents look to see if any of the 21 programs currently active are in their area. In that case, she said, the existing DOCC teams would welcome them.

Current Project DOCC Teams

Children's Hospital at Montefiore, New York, NY
Children's Hospital of New York - Presbyterian, New York, NY
Children's Memorial Hospital, Chicago, IL
Driscoll Children's Hospital, Corpus Cristi, TX
Emory University School of Medicine, Atlanta, GA
Good Samaritan Hospital Medical Center, West Islip, NY
Maimonides Medical Center, New York, NY
Marshall University, Huntington, WV
Massachusetts General Hospital for Children, Boston, MA
NYU Medical Center/Bellevue Hospital, New York, NY
North Shore University Hospital, Manhasset, NY
Schneider Children's Hospital, New York, NY
T. C. Thompson Children's Hospital, Chattanooga, TN
Texas Children's Hospital, Houston, TX
The Canberra Hospital, Canberra, Australia
University of Arkansas for Medical Sciences, Little Rock, AK
University of Nebraska Medical Center, Omaha, NE
University of Tennessee Health Science Center, Memphis, TN
University of Tennessee Medical Center, Knoxville, TN
University of Texas Health Science Center (CAMP), San Antonio, TX



JUST FOR ME

SPRING 2005

Fun facts and news for JM patients and friends

Consider this

Sunscreen is important year-round, but as spring and summer approach for many of us, it's even more important to remember to put on sun lotion every day. Here are some basic tips for protecting your skin:

- Read the label. Choose sunscreen with SPF 30 or higher, and make sure it is broad spectrum, meaning it filters both UVA and UVB rays.
- Rub on the sunscreen 20 to 30 minutes before going outside, and use as much sunscreen as you would lotion on dry skin. Put it on every two hours - more if you're swimming or more active.
- Dress in sun protective clothing or hats, or wear clothes where the fabric is woven tightly together to help filter the sun's rays.

Parents and children: For a list of resources offering sun protective clothing and accessories, email kathryn@myositis.org or call 1-800-821-7356.



Keep moving

Exercise is good for everyone, but if you're feeling especially tired or weak from juvenile myositis or your medicines, exercise can wait. Waiting to get out there and play doesn't have to be dull and boring. There are things you can do to stretch and use your muscles and joints as much as you can.

Here are some ideas:

- Paint using sponges or finger brushes. Your muscles and joints work and move while you paint.
- Take a walk through the neighborhood, looking for different kinds of leaves, rocks or birds - whatever you like. Or walk to a nearby bookshop, restaurant or store.
- Plant a garden outside or in a window box. Reaching to plant the seeds and pack the soil helps you stretch.



Riddle me this...

If yesterday had been Wednesday's tomorrow and tomorrow is Sunday's yesterday, what day would today be?

Answer: Friday

PROFILE: KAITLIN MAHER

Kaitlin is 12 years old and has had juvenile dermatomyositis (JDM or JM) for six years. When she was 6, she and her family noticed she was running out of energy easily and couldn't do what she was used to doing, even some everyday things like pulling a shirt over her head. She also had a rash, especially on her hands and face.

Though the doctors knew right away that she had JM, they didn't know how to treat it. She went to different doctors until she found one who knew what to do. The prednisone made her very emotional and sensitive, and in the end, it didn't help her JM. She tried methotrexate, but it didn't work either. After slowly stopping those medicines, she started IVIG, a medicine familiar to many who have juvenile myositis. With this and some physical therapy, she slowly got better.

She still gets the IVIG every month, sitting for six hours while the medicine is given to her through a needle in her hand or wrist. "This was something no kid likes," she says, "but it worked."

[Learn more about Kaitlin...](#)

Nickname: Kadie

What she likes: dancing, piano, swimming

What she wants to be: politician or rheumatologist - "My goal is to become President and make the world a safer, better place. But, if I become a rheumatologist, I can help people with diseases like mine and maybe even find a cure! So I have big hopes and dreams, and I am not letting JDMS get in the way of them!"

Kaitlin's advice for others with JM: "Reach for your goals and work hard."



Build a time capsule!

Time capsules are a fun way to preserve memories!

The first time capsules were found in temples in Egypt and Babylon. Those ancient time capsules were filled with small statues and scrolls as was their custom. Some modern-day religious temples still practice this tradition of placing items of significance in the corner stone of the building.

You can make your own time capsule as a fun activity with your family or friends.

You'll need:

Shoebox
Contact paper (clear and patterned)
Clear tape
Markers
Pencil
Scissors
Paper

Note: Items to store might include photos of friends, family, your house

or pets; drawings, newspaper and magazine clippings; and lists of how much different things cost or your favorite songs and groups -- even lists of your favorite movies and television shows. Include any personal items that mean something to you and that say something about who you are.

1. Wrap your box and the lid separately with a contact paper that has a design on it. For a neat job measure out a piece of contact paper that will wrap all the way around your box. Peel back paper and set the shoebox in the middle. You may need a friend to help keep the paper from curling up.

2. Wrap the long sides first and cut a flap for the extra paper to fold inside your box. Now cut the end flaps and fold in the excess from the long sides first then fold up the end pieces. Fold extra over the edges for a more finished look.

3. Next, cut smaller pieces to finish lining the inside of your box and lid.

4. Now, on paper, draw and color in pictures to decorate your box. Cut them out and tape them on.

5. Cover the box again, in the same manner, with clear contact paper.

6. Select the most memorable items for the year - things about you, your family, your town, and pop culture - and place your items in the box.

7. Finally, store your time capsule in a dark, out-of-the-way place, but not totally and altogether forgotten!

Tips:

- Have an adult supervise when you use scissors.
- Either by hand or by computer -- make a list of things you like. Example: Favorite books, favorite movies or what things cost.



THE MYOSITIS ASSOCIATION

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