

KEYSTONE of Hope

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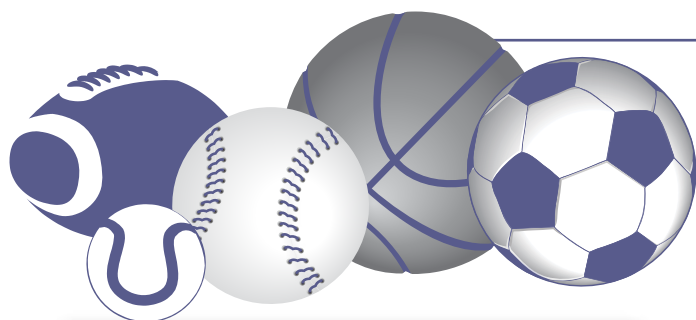


Myasthenia Gravis
Association of Western Pennsylvania
at Allegheny General Hospital
A Treatment & Advocacy Center

5th Annual POOCH PARADE the Biggest Yet!

MGA is grateful to all of our sponsors, supporters and vendors who made this year's event another fabulous success. Special thanks to MGA board members David & Arlene Weintraub, and JoBeth Barr for their outstanding support of this event.

Please see **Page 5** for list of sponsors and supporters.



20th Annual MGA SPORTS MEMORABILIA AUCTION

Proceeds benefit Myasthenia Gravis Association of Western PA

WHEN: Sunday, April 6, 2014; 3 – 7 pm

WHERE: The Club at Nevillewood

COST: \$35 / person

Includes free buffet, free celebrity autographs, free parking, plus LIVE & Silent auctions, grab bags, raffles and more!

For Reservations and information, call **(412) 566 – 1545**

Approximately 100 signed and unsigned sports related items will be available from both local and national athletes. And back again will be the ever popular “**GRAB BAGS**” many containing signed items!

ATTN: Anyone wearing their favorite team apparel to the event will be eligible for a “special” prize drawing!

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See **Page 4** for details on this new way to help support MGA's free patient services.

ADVANCE PLANNING FOR YOUR HEALTHCARE



By Alan E. Weidman, LPN, MGA Patient Care Coordinator

Recently I was asked by a health professional if I had made any provisions for advance directives and power of attorney if the time ever came that I was not able to speak for myself. Although I had discussed at length with someone what I would want done in the event that would ever occur, I had never put it in writing. I felt this might be a good time to remind our members of the importance of making your wishes known and documented in writing to ensure that your loved ones or friends can follow your wishes in the event you are unable to speak for yourself. Below is some information to help you get started. Write your directives down and share with your doctors so that loved ones have one less thing to deal with in case you are unable to speak for yourself.

What you should know about Advance Directives

As a person with a chronic illness, you have a say in the health care you receive. When you are ill, your doctor should explain what treatments there are for your illness so that you can decide which one is best for you. But if you were too ill to understand your treatment choices or to tell your doctor what treatment you want:

- Who would you want to make decisions for you?
- What type of health care would you want?
- What health care wouldn't you want?

Questions like these may be hard to think about, but they're important. That's why MGA wants you to know about a legal form you can complete. It's called an **Advance Directive**.

What is an Advance Directive?

An advance directive is a legal form that helps your doctors and family members understand your wishes about health care. It can help them decide about treatments if you are too ill to decide for yourself, such as, if you are unconscious or too weak to talk. *Your advance directive is used only when you aren't able to make decisions yourself.*

There are two types of advance directives: [durable power of attorney for health care](#) and a [living will](#).

A **durable power of attorney for healthcare** lets you name the person you trust to make health care decisions for you if you can't make them yourself – your “health care agent.” He/she will have the legal right to make health care decisions for you. You can choose any adult to be your agent. It's best to choose someone you trust – who knows you and your values well. You should make sure the person is willing to serve as your agent. If you don't choose an agent, your doctor will choose someone to make decisions for you in the following order: legal guardian (if you have one), spouse, adult child, parent, sibling, grandparent, grandchild, or a close friend. Your health care team, or a court, will make decisions for you if none of the above is available.

A **living will** is a legal form that states what kinds of treatments you would or wouldn't want if you become ill and can't decide for yourself. It can help your health care agent and your doctor make decisions that you want. Writing down what kind of treatment you would or wouldn't want can help make it easier for those who are asked to make decisions for you. Talk with your family, your health care agent, and your doctor about your wishes so they won't have to wonder what you want and if they're doing the right thing. If you don't have a living will, decisions will be made for you based on what is known about you in general and about your values. That's why it's important to discuss your wishes with your loved ones, your doctors, and your health care team.

You may change or cancel your **advance directive** at any time. In fact, you should review your advance directive periodically, especially if there is a change in your health, to make sure it's up to date. If you change it, be sure to tell your health care team and have them put it in your health record. Share your new directive with your family members and other loved ones.

RELATIONSHIPS

by Michelle Dulashaw, Medical & Social Support Specialist

CHRONIC ILLNESS



When speaking to someone newly diagnosed with MG, I always stress that the most important part of dealing with this disease is your support system. Most support systems are made up of family members, significant others and close friends. Having loved ones around you to help you keep fighting is sometimes the best medicine you can get. Locking your emotions away and withdrawing socially and emotionally is one of the worst things you can do. When you withdraw and close yourself off, it can put more of a strain on those personal relationships. Communication is an integral part of having happy and lasting relationships, whether it is a friend or a significant other.

It is extremely easy for both parties in a relationship, to build walls for our own self-preservation. Here are just a few tips to help keep those relationships healthy.

1 A proper foundation of communication is key.

Being afraid to share your feelings is not a healthy way to be in a relationship-- period. Not speaking up about something that is bothering you can stoke the flames in any relationship and cause depression, resentment and hostility. If you cannot communicate effectively with your loved one, this is where a counselor or a therapist should be brought in to the equation immediately. There is no shame in asking for help here. It is common, especially in extremely long relationships, that you can just fall into a rhythm of "just dealing" and ignoring issues. It may have been an acceptable way to live for a period of time, to "keep the peace" so to speak, but with a major life change, such as a chronic illness, this can cause an overwhelming chain of emotions.

The other area of communication that is a common issue is a lack of honesty regarding the illness and the extent of its effects on the sick partner. It can be very difficult to accept the diagnosis of a chronic illness. Many who have been diagnosed attempt to go on with their life as if nothing has changed. They don't communicate to their partners the way they actually feel, out of fear of sounding whiny or burdening their partner. None of this is productive in the long run. If the sick party does not convey to their partner how they honestly feel, then their partner has no way of knowing how to help or what might be comforting.

2 Share information about the condition with each other and how it affects both of you.

The more both of partners understand what is going on with the diagnosis, the better they can figure out how to properly support and help each other. When diagnosed with a disease that has no cure, it's not only the patient that feels a "sense of loss" for the life they once had. The partner also will feel they have lost the way things were as well. Go through this grieving process together. Both the patient and the partner need to start a dialogue about how they feel about the situation.

It is essential in any relationship that you try to view things from your partner's perspective. Doing so will help everyone involved cope more effectively.

For the healthier party, it can be frustrating and heartbreaking to watch someone they love hurt or be ill. In most circumstances, this also means the healthier one has to pick up some extra responsibilities to help out. Often, they begin to cut themselves off from social activities or outings they may have once enjoyed. They themselves may begin to feel depressed and lonely.

From the sick person's perspective, having new limitations put on them and having to humble themselves to ask for help in difficult situations can be quite an adjustment. It can be rather humiliating for a physically limited person to ask for help doing things that healthy people take for granted. Again, this can also lead to feelings of isolation and depression.

Going to a support group together is a great way to help you both cope with what is going on. You can gain the perspective of how other patients/loved ones feel and deal with the diagnosis. Seeing that you are not the only ones going through this struggle can be very helpful. It takes TWO people to be in a relationship and both parties have to be invested for the relationship to be healthy.

3 As hard as it may be, stay focused on the positive.

As with any health challenges, emotional stress will do nothing but exacerbate the symptoms of the illness. It is so easy to get caught up in the endless cycle of negative thoughts. Once one of you have "given up" it will be hard to convince the other differently. Do not focus on things you are unable to do but focus instead on all the things you can do. The healing power of a positive attitude goes a long way if you have patience and keep it going. Never, ever give up.

4 Find activities that you can still do that you both enjoy.

Whether it is watching movies, playing board games or simply sitting on the porch together, make sure you take time out to enjoy one another's company. It is important for both parties to know that there is still love and compassion in the relationship. Make sure to let your partner know how much you love and care for them regularly.

5 Take advantage of the good times.

As with any chronic illness, there will be good and bad days. Take advantage of the good days by doing enjoyable things that you would likely be unable to do when you're not feeling as well. This helps to maintain the normalcy of your relationship and will help to lift the spirits of both partners. It's not easy to live with an illness that puts limitations on your ability to do the things that you love, so be sure to celebrate and take advantage of your good days. This is also a great way to gain some perspective on the bad days. Just remember that understanding your illness, accepting your physical limitations, and the unrelenting support of those around you can really prove the meaning of "love conquers all."



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AmazonSmile is a simple and automatic way for you to support MGA every time you shop, at no cost to you. When you shop at smile.amazon.com, you'll find the exact same low prices, vast selection and convenient shopping experience as Amazon.com, with the added bonus that Amazon will donate a portion of the purchase price to MGA.

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To shop at AmazonSmile simply go to smile.amazon.com from the web browser on your computer or mobile device. You may also want to add a bookmark to AmazonSmile to make it even easier to return and start your shopping at AmazonSmile.

Which products on AmazonSmile are eligible for charitable donations?

Tens of millions of products on AmazonSmile are eligible for donations. You will see eligible products marked "Eligible for AmazonSmile donation" on their product detail pages.

Can I use my existing Amazon.com account on AmazonSmile?

Yes, you use the same account on Amazon.com and AmazonSmile. Your shopping cart, Wish List, wedding or baby registry, and other account settings are also the same.

How do I select a charitable organization to support when shopping on AmazonSmile?

On your first visit to AmazonSmile, you need to select Myasthenia Gravis of Western Pennsylvania to receive donations from eligible purchases before you begin shopping. AmazonSmile will remember your selection, and then every eligible purchase you make on AmazonSmile will result in a donation to MGA.



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Help Support MGA

MGA has partnered with Goodwill Industries for many years now that benefits our organization when you donate your unwanted vehicle to Goodwill. All types of vehicles are accepted – *cars, trucks, motorcycles, vans, boats* and even *motor homes*, whether they are **running or not running**.

And donating your unwanted vehicle is so easy! It takes just one phone call to MGA **(412) 566-1545**. All of the paperwork and details are also done for you. Your vehicle will be towed to the auction site – all at no cost to you. When your vehicle sells, **you receive a tax-deduction in the full amount of the sale.**

Best of all, proceeds raised from the auction of your vehicle help support MGA's FREE patient services. Avoid the hassle of trying to sell it for yourself – simply call the MGA office for more details.



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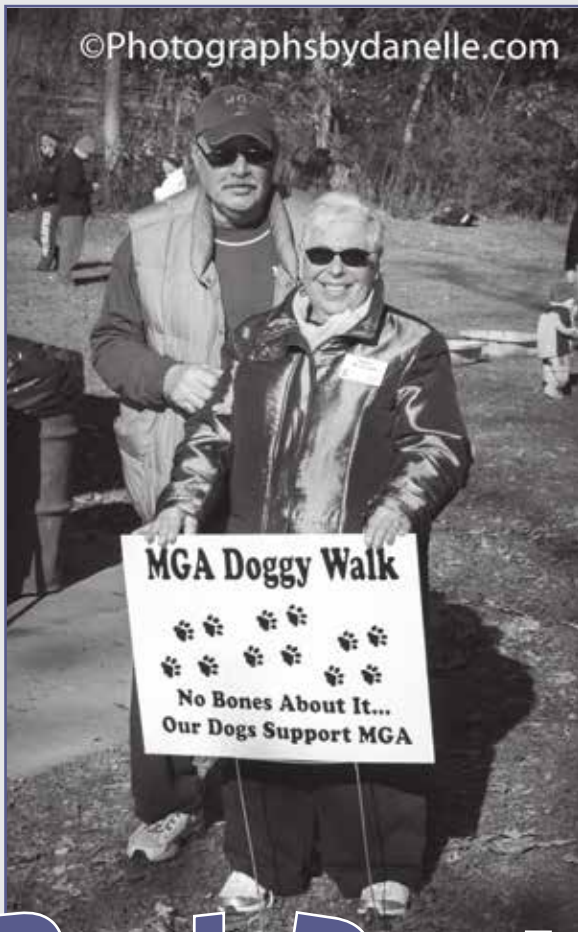
If you have any questions regarding United Way donor designation, SECA or CFC, please feel free to call the MGA office. **THANK YOU** for your continued and generous support of MGA.



Dolores Kalisek, who passed away on December 16, 2013. Donna is known to many as the receptionist at treatment center and the "cookie lady" for her homemade cookies available each week.

Donations in Dolores' memory were directed to MGA because of Donna, who was diagnosed with MG at the age of nine. Dolores was preceded in death by her husband Edward Sr in 2003. The dedication of Donna's parents to the Myasthenia Gravis Association stemmed from their daughter's diagnosis of MG at a very early age. Dolores' support of her daughter was manifested in all that she did for her during the many hard times during those early years. She used to push her in a wheelchair to a local school yard just to get her out of the house. She sat at Donna's bedside throughout many hospital stays and she never shooed her out of the kitchen, that's where Donna's cookie baking began.

MGA's Board and staff extend condolences to Donna and her brothers for the loss of their mother and for thinking of MGA during their time of loss.



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Pooch Parade

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1 pm to 2:30 pm

AGH, Singer Library

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