

Dear Classmates,

Thanks for your quick and timely response to issues related to “Navigating the Medical System”. We were struck by the creativity, seriousness and quality of the responses from classmates, including a few who had never responded before, as well as from members of other classes.

Our biggest challenge was sorting and categorizing them in a beneficial and comprehensive way that offered practical advice and new insights to help all of us through the maze. The most important and oft stated conclusion was that we and our families are ultimately responsible for our healthcare decisions and that time spent researching all aspects of care is well spent.

## RECORDS

1. Update all medical records including dental records, family history, and list of medications and put them on a disc. The family doctor may be able to do this; if not, pay for a service that will transcribe them. ( Ex. Rolfe –During first knee operation they discovered an aneurysm that was the result of genetic issues going back four generations. This information proved useful for diagnosis and treatment)
2. Keep disc in your car, especially when traveling. Also, give a family member or attorney a copy of it along with contact information for individuals mentioned.
3. You are entitled by law to records. Some health plans have allowable charges for copying.
4. After discussing Living Wills and other “personal directives” with clergy, doctors, and family members, have them officially written down and signed by attorney. If you move to another state, be sure that all these papers are applicable or if they have to be revised to meet the standards of that state.
5. Personally request records and take them with you when referred to a different facility. Only 20% of hospitals can readily access records. (Rolfe’s daughter goes around the country training hospital personnel on programs and formats that allow hospitals to communicate easily and access records – it is a work in progress!)\_Have blood work sent to all your doctors

## INSURANCE

1. Meet with doctor and/or hospital representative prior to surgery to discuss what is covered by Medicare and Medicaid. (Rolfe- Medicare would pay for a full wheelchair at \$450 that I did not want or need but would not pay \$110 for a transporter one.)
2. Even at our age, you need supplemental insurance, even if it is more expensive. (Rolfe – the bills for two operations in Florida to remove an infected knee prosthesis and install all new one, a rehab facility for 3 months, IV’s for 3 hrs a day, plus surgeon’s fees etc. is close to \$160,000)
3. MEDICARE DOES NOT COVER ANY EXPENSES IF YOU ARE OUT OF THE COUNTRY. Usually supplemental private insurance plans cover most things but check on specifics. Other options include looking for “perks” on credit cards like American Express that include travel medical insurance, or retirement programs where for about \$200 a year you receive a credit card if you need an ambulance in a different company or transport back to the US; all your expenses, including family members will be paid for. Group travel companies often have the option of medical coverage.
4. Costs significantly vary around the country for the same operation. A University of Utah researcher has analyzed the costs of various operations throughout the country and suggests researching this before making a decision (Gwen- family members may live closer to a region

where the cost of a given surgery is less, so again, looking at all the alternatives is worth the effort.)

5. If possible stay with one pharmacy that has a computer record of your prescriptions, especially when traveling. (Gwen- Be sure to bring narcotic medicine with you or carry a prescription with you- I forgot mine one time and wasted countless hours figuring out how to get them and then had to pay out of pocket)
6. Long term care insurance is expensive, especially at our ages, and not everyone will qualify for it. Decide with family, clergy, doctor etc what your wishes are as you reach the end of life and place in writing with an attorney. There are many options available for care and each health plan seems to have a different formula for what services are paid for and for how long.

## RESEARCH AND SERVICES

1. Many commented on the importance of researching doctors, hospitals, rehab centers or any facility where you are receiving care. Between the library, word of mouth, and the computer much information is available. (Gwen, I tend to put things off like this, but so many classmates mentioned this, it has been a good wake-up call)
2. Whole Food Plant Based Nutrition has been researched fully and used by Ede Roberts Trockells for years. She and her husband had dealt with cancer, and other health ailments and surgeries and encountered medical complications and misinformation. After following the plan above, they have refused many common prescriptions and Ede wishes she had refused chemotherapy. They have lost weight, and have an active life style ("able to hike at elevations up to 11,500 ft in Colorado".) She is willing to share with others: phone 505 681 4458 or [rmroadrunner1@gmail.com](mailto:rmroadrunner1@gmail.com).
3. Obtain a first and second opinion and even a third if there is not agreement between the first two. (Rolfe-a friend with a disc problem went to a surgeon he liked and had a long history with who did not advise surgery; a second surgeon recommended invasive surgery; after 6 months of pain, went for third opinion and surgeon said he required immediate invasive surgery.) DO NOT ACCEPT DOCTORS DIAGNOSIS WITHOUT QUESTION, ESPECIALLY IF IT IS CONTRARY TO YOUR OWN REASONING.
4. For important appointments have another person with you to verify what was said or take notes. If possible have someone stay overnight the day of surgery.
5. In many large metropolitan areas there are "Patient Interventionists" who are hired by you and will take over as your advocate especially for surgery or if you need to go to a facility for more care. Ask your doctor or the hospital social worker if such a service is available.
6. If your doctor is old, it is not inappropriate to inquire about their retirement plans.
7. If having surgery, communication between your doctor and other people involved in your care is very important. (See section 5 under Records). Learn vocabulary, outcomes to be expected, medications that need to be stopped or started, side effects or medicines and procedures etc.
8. Many studies are disproportionately completed on males; women need to search for studies related to how an issue affects women in particular. 9.
9. If at all possible, visit and research rehab facilities before surgery. Look especially at the physical therapy and occupational therapy that will be available and the reputation of that group. Then you can make your choice known. (Rolfe- after one surgery, the hospital called 9 facilities before finding a "bed".)

10. Hospice care has additional services available both at home and in nursing facilities. In some areas of the country there are private hospice facilities which provide 24 hour care and can average between \$2500 and \$3000 per week.

#### **OTHER USEFUL BUT IMPORTANT TIDBITS FROM CLASSMATES**

1. When you receive excellent care by an individual, provide written feedback to the facility administration and to the person. (Rolfe-one comment by a care provider summed it up: "I have worked here for 15 years and this is only the second time that I have received written comments for my folder")
2. Long term health care can be obtained through AARP or company health plans
3. Participate in groups that specialize in issues related to health care: ( one group was the Woman's Health Initiative)
4. Obtain a common medical form to carry with you. One potential web site for such a form is [advonarx@comcast.net](mailto:advonarx@comcast.net).
5. Make sure you have proper permissions on file for others to access your records, especially if you are not capable of doing so. Likewise, check that you can access loved ones records.
6. Fight medical "bitches" (classmates term) "They are people one phones and in medical offices who truly believe that you are an annoyance rather than a reason for their jobs."
7. Don't trust your memory! Have a clearly defined and accessible schedule of appointments, exams, treatments, medications, etc.
8. Discuss and put in writing decisions for burial arrangements, including cremation...A search on line using the following terms supplies useful information: Globe Burial Insurance; AARP50+life insurance; Seniors Funeral Insurance; "Senior Age Life Insurance-mutual of Omaha
9. [info@allprintalbe.com](mailto:info@allprintalbe.com) has great articles that focus on medical issues
10. BE AGGRESSIVE IN ADVOCATING FOR YOURSELF. Be in charge of navigating the system!

*As Juniata College graduates we have learned how to research more fully and advocate for the good advice that is pertinent to us. It is nice to know that classmates wanted to help others navigate the medical system and reinforce the importance of being in charge of our care. Thank you!*

We already have an idea for next year's newsletter, so start thinking about questions you would like to ask President Troha.

*Sincerely,  
Rolfe and Gwen*

#### **ADDENDUM –TERRY GROVE has forwarded the following information to us. Please review very carefully.**

"We can win each of these cups (see info below) this year. But WE NEED EVERY CLASS MEMBER TO MAKE A CONTRIBUTION. PLEASE USE THE ENVELOPE YOU RECENTLY RECEIVED IN THE LETTER FROM RICH MORGAN AND BILL CHEW. THANKS FOR YOUR CONTINUED COMMITMENT TO JUNIATA AND OUR CLASS OF 1964 GOALS".

Cloister Cup- first to reach 50% participation -71% is our goal: – so far,27 participants so 44 needed - PLEASE SEND IN YOUR CONTRIBUTION ASAP, SO WE CAN BE THE FIRST TO ACHIEVE 50% PARTICIPATON  
Soaring Eagles Cup - largest increase in scholarships funded/dollars: Last year our total was 24,688.00 - end of first quarter -total is 17,688.00 KEEP UP THE GOOD WORK  
Feathering the Nest Cup - largest increase in number of donors - so far, we have 27 donors and 6 are new and thus increase number of donors - PLEASE PARTICIPATE THIS YEAR.