



June 2009

# Caring Times

## The TTN Caring Collaborative Newsletter



*Members of the Caring Collaborative's Upper East Side Group met last month.*

To get help from the Caring Collaborative, email or call Laura Traynor  
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## We welcome you to our second issue of *Caring Times*.

This issue of Caring Times takes a look at the legal side of healthcare. What should you consider when drafting documents that spell out your wishes if you become unable to participate in your ongoing care? Natalie Kaplan, a leader in the Caring Collaborative and a lawyer who specializes in elder care, helps us make sense of the options and their implications.

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## What's New



***Event in two weeks!***

**TTN Joins Forces with the**

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## Visiting Nurse Service of New York

### ***VNS Offers Special Benefits and Discounts to TTN-CC Members***

VNS and the Caring Collaborative announce the first in a series of talks about Health Strategies to Promote a Long and Healthy Life

Thursday, June 11th 6:00-8:00 p.m.  
Visiting Nurse Service of New York  
1250 Broadway at 32nd Street  
7th Floor Conference Room

The event is free of charge but you must register in advance at [rsvp@thetransitionnetwork.org](mailto:rsvp@thetransitionnetwork.org) no later than June 8th. Space is limited.

The program will focus on how to resume a normal active life after an illness, medical emergency or medical procedure - with a little help from your Caring Collaborative friends and VNS. The meeting will also provide an opportunity for CC members to suggest topics for future Health Strategies meetings.

Caring Collaborative member **Diana Killip, M.D.** stresses the value of a joint venture with the Visiting Nurse Service: "Once an older person is derailed by illness or injury, or even by elective surgery, recovery must be quick or else frailty sets in - which greatly reduces life expectancy. This is where VNS and TTN-CC can help." Diana notes that VNS can do things that CC volunteers shouldn't do, such as help with bathing and wound dressings, and getting clients out of bed and into early physiotherapy."

Caring Collaborative Project Manager **Laura Traynor** vigorously supports this new affiliation: "VNS has been an integral partner with us since we began. They have supported our grant applications and helped us with our time-banking system. And now they are prepared to give us discounts on some of their services.

Navigating the hospital and dealing with emergency rooms can be a nightmare. VNS's network of nurses in virtually every hospital in the

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city can help us with this. And VNS is also expanding its home care services and providing nurse educators who can come to us."

## Neighborhood News

Our three neighborhood groups of Caring Collaborative members have become extremely popular, with more members wanting to attend than space available. We want to accommodate all our members but we need volunteers who will offer their homes for meetings and group leaders to coordinate these local gatherings. This is a volunteer effort that takes very little time. You will be helping all of us have a congenial experience while learning about critical issues concerning our health.

If you would be willing to open your home to the occasional meeting or - better yet - volunteer to coordinate a group in your neighborhood, please email either Nora Bleich, at [london28nyc@yahoo.com](mailto:london28nyc@yahoo.com) or Anita Kane at [kanes@nyc.rr.com](mailto:kanes@nyc.rr.com).

Neighborhood groups met in May and will resume their meeting schedules in September. So, if you're going to be away for the summer don't let that stop you from volunteering!

### Downtown



*A few of the Downtowners at the May meeting.*

Downtown members filled **Arline Newman's** apartment to capacity. The topic for the evening was insomnia and sleeping problems - and everyone stayed awake. After a lively discussion the conclusion was that there's no easy answer. What works for some people doesn't work for others. All agreed that stress is the big culprit in being unable to sleep and that worrying about not sleeping simply makes the problem worse.

At the next meeting, in the fall, the topic will be Balance.

### **Upper West Side Neighborhood Group Meets on May 28th**



*Photos left to right: Natalie Campbell, the gracious host for the UWS meeting; Claire Harmon and Rae-Carole Fischer; Helga Shepard and Livia Yanowicz.*

**Natalie Campbell**, full of good cheer, hosted 17 members of the UWS group, including **Rae-Carole Fischer** and **Livia Yanowicz**, both Geriatric Care Managers, who were full of useful advice and information about Health Care Proxies and related subjects. Rae-Carole talked about End-of-Life issues to discuss with your children (a far cry from those Birds and Bees conversations). Others talked about preparing for emergencies, suggested useful books and discussed their questions about giving and receiving Caring Collaborative service. The next meeting, in September, will focus on attitudes towards wellness.

### **Upper East Side**

Upper East Siders (see *photo in the masthead banner above*) gathered in **Jennifer Rushton's** apartment to discuss organizational aspects of the group, the critical issue being who would be willing to take over leadership of the group.

Members are looking forward to attending a celebratory dinner in July. Details will be emailed later this month.

## **Don't Bother Your Friends: Call the Caring Collaborative**

Does this vignette from **Debbie Harkins** sound familiar?

**I went into the hospital for elbow surgery for three days**, and I deliberately didn't tell my friends about it because it seemed like a minor problem and I didn't want them to feel they had to make a hospital visit ... but it turned out to be a distressing, week-long stay. The elbow was bad (steel rod, 16 screws, helplessness) and then I got pneumonia and colitis. I felt very isolated . . . but even so, I didn't want to bother my friends with my troubles. So, instead of calling a friend to take me home, I called a home health agency and had someone bring me home, shop, and take me to

appointments.

With CC I could have had an escort home and someone to bring me food or just visit... the point being that it's not that I don't have friends, it's just that I didn't think I should bother them. No more of that! And, though I had the luck to find a warm, attentive aide, this kind of help is very expensive.

What a boon this CC project is! We women have to learn not to be embarrassed to "bother" people by asking for help.

## Readers!! Help Us Prepare a Hospital Survival Kit



Those of us who've been in the hospital recently know just how uncomfortable the experience can be. Some things you just can't change. But there are ways to make your stay more comfortable. The Caring Collaborative is putting together a Hospital Survival Kit and we need your help. For instance, one CC member mentioned that she took a baseball cap to the hospital to shield her eyes from the harsh overhead light of the hospital room.

Do you have tips that can help others facing a hospital stay? We will print them in subsequent newsletters. Perhaps when we have a dozen or so we'll put them on our Website for permanent future reference.

## Remembering Jane



As perhaps you know by now, Jane Young died in April. It's a terrible loss. Jane

was an integral member of the Steering Committee that developed the Caring Collaborative, and a brilliant and creative colleague. She worked especially on the development of Vertical Villages. (A manual for organizing apartment buildings into Caring Collaboratives will be ready this fall.)

Our colleague, Diana Killip, sitting *shiva* with Jane's family and friends after the funeral, spoke about working on a project with Jane: "We can bring this in unfinished," Diana said. Looking astonished, Jane replied, "Oh, I wouldn't know how to do that."

I got to know Jane when she and I used to take a taxi home together from those early meetings. She got out before I did, and always gave me too much money for her share. The very last ride we took together, I said to her, "Jane, this ride is free. You've already given much more than your share." I suspect that this was typical of Jane, always giving more, with a warm and generous spirit. Boy, do I miss her - as do we all.

*Lynn Minton*

## Natalie Kaplan: The Legal Eagle on Our Caring Collaborative Team



**Natalie Kaplan is a member of the Caring Collaborative Steering Committee** and a founding member and fellow of the National Academy of Elder Law Attorneys. She is also a founder of Elder Law on Wheels and a former Adjunct Professor of Elder Law at New York Law School. She has a private practice in Westchester and New York City, where she kindly lends her midtown conference room for Caring Collaborative meetings.

Today, Natalie answers our questions to help Caring Collaborative members become prepared. She wants us to avoid the pitfalls that can come from lack of planning - particularly if we become incapacitated.

### **Q: What should women aged 50 or 60 - or more - be doing right now about their medical-legal affairs?**

**Natalie:** Everyone 18 or over should have a Health Care Proxy. The Proxy is used to appoint a Health Care Agent - and, if possible, an alternate Agent - who can make medical decisions for a person who is unable to make them herself. Medical people will look to an Agent only if a person is unconscious or otherwise incompetent when a medical decision is needed. Treatment questions arise: Should they operate? Should they use feeding tubes? Should they withdraw a respirator? The Proxy document is not only for older people because anyone can be hit by a flying brick or caught in a car crash.

Any adult can name a Health Care Agent. Everyone is presumed competent. There's no law that says how alert or how competent a person has to be to sign a Health Care Proxy. I recommend using the New York State Department of Health form because it is familiar to all hospital personnel and is widely accepted without having to be reviewed by legal counsel. You can access this form, with accompanying instructions, FAQs and related information, at [www.health.ny.us/forms/doh-1430.pdf](http://www.health.ny.us/forms/doh-1430.pdf).

**Q: How does it work?**

**Natalie:** It says, "I, Natalie Kaplan, appoint Mary Jones to be my Health Care Agent." Other details, like address and telephone numbers are needed and it requires the signatures of two witnesses who affirm that the person wasn't coerced into signing.

Most Health Care Proxies now have a place that indicates that the Agent knows the person's wishes concerning artificial nutrition and hydration, that is, tube feeding. This is important because New York requires an Agent to know - or be able to ascertain - the patient's wishes concerning tube feeding, in order to make decisions about its use. For all other medical decisions, the standard Health Care Proxy form is sufficient.

After a Health Care Proxy is signed, however, it's important to talk to your Agent so she knows your personal wishes, how you feel about quality of life issues. What makes life meaningful for you - and what doesn't. The Agent should know, for example, that being able to relate to relatives and friends is the most important thing to a person and even if she has to be wheelchair bound, she wants to live like that. For another person, the ability to walk makes life worth living and a wheelchair existence would be intolerable. An Agent would know that if a grandchild is going to be married the day after the person has a stroke, maybe the person does want to be resuscitated. And so on. Many people avoid talking to their Agents because it's hard to have a conversation like this. So their Agents aren't even aware of their preferences.

**Q: Shouldn't we also indicate our wishes on one of those forms that says, I want this, I don't want that?**

**Natalie:** The document that indicates specific wishes is usually called a "Living Will." Sometimes those kinds of wishes are included in Health Care Proxies, but I recommend against it. Specific directions in Proxies or in Living Wills, can cause problems. For example, they can be interpreted to limit an Agent's power if there's the slightest inconsistency between the written word and the Agent's directions, under evolving medical conditions.

For instance, say a person puts this standard sentence in a Living Will: "If I am terminally ill, with no hope of recovery, I wish to refuse all medical treatment." Then the patient becomes terminally ill and develops pneumonia, which would allow her a peaceful death. But because there is "hope of recovery" from pneumonia, the Living Will requires her to be treated. So she's given antibiotics and recovers, to face again her agonizing terminal condition. By contrast, without the rigid language of the Living Will, an Agent could authorize the withholding of

the antibiotics and allow her to die.

I recommend a Living Will only to clients who have no Agent to appoint, or whose Agents may die before them. I use it in conjunction with a values questionnaire that people can leave with their doctors. It is designed to elicit feelings about a variety of medical situations. A document called "Five Wishes" is extremely useful in helping people - using Living Wills or not - to determine what their medical treatment wishes would be under various conditions of deterioration that they are unlikely to think up on their own. It's worth looking at and can be found at [www.agingwithdignity.org](http://www.agingwithdignity.org).

**Q: What is a Health Care Power of Attorney?**

**Natalie:** That's the name used in other states for documents like our Health Care Proxy. New York law says no Health Care Agent may be appointed by a Power of Attorney form. New York will, however, recognize a properly signed Health Care Power of Attorney from a state that uses them.

**Q: Why would someone have a Power of Attorney?**

**Natalie:** A regular Durable Power of Attorney is a document that empowers an Agent to conduct business and financial transactions for another person, who could be incapacitated or merely unavailable. Powers of Attorney are used all the time for title closings when the buyer or seller can't be present. For a patient in a hospital, it can be invaluable to have someone who has the authority to withdraw money from the bank, pay rent, or sign a new lease. The Power of Attorney is a powerful document though, and should only be given to someone who's trustworthy.

The New York State Power of Attorney form is changing as of September 1, 2009. It's been modified from a 4-page form that lay people can figure out, to a 6-page form that virtually requires a lawyer. Those with signed forms of the old version will be entitled to have them honored, if they were signed before September 1, 2009. You can Google a New York State Power of Attorney form. Use only that form if you live in New York State.

**Q: Suppose you want to have a Power of Attorney available, but you don't want to give it to the person right now. Could you sign one and put it in a drawer?**

**Natalie:** Yes. Most Powers of Attorney become effective immediately upon signing, but it doesn't have to be given to your Agent. You can retain it and release it only when you want it to be used. Your agent should know where it is kept, however, and have access to it in case of emergency. It becomes void upon death.

**Q: What are some possible legal pitfalls for our members to avoid?**

**Natalie:**

- **Don't take legal advice from lay people, which includes people in other professions.** Lay people with partial understanding of the law offer free

legal advice, often with great certainty. They are often wrong and their advice leads people to agonize unnecessarily and to forgo benefits they would otherwise receive. I can't tell you how often I've heard of people being incorrectly told that they can't get Medicaid because they own their home, or because their income is too high. Medicaid is particularly complex and rules vary widely from state to state. New York, for example, allows Medicaid recipients to retain \$13,800. Many other states allow only \$2,000.

- **Don't sign anything when you're overcome by emotion, as at the time of a relative's death or at the time of a frightening medical diagnosis.** These are the times when concentration, attentiveness to detail and recognition of implications are lowest and distraction is highest. No one can fault a person who says, "I need some time to think about this."
- **Don't sign medical papers you don't understand.** Getting an informed consent to a medical procedure requires the person performing the procedure to explain, in language the patient can understand, the procedure, the risks, the benefits and the alternatives to the procedure. Sometimes it takes nerve to ask questions or to say no. Fight the urge to go along with "Anything you say, Doc." Instead, recognize that you are entitled to be treated as an adult and to understand your own treatment.
- **If you are being treated improperly, report it to an oversight authority.** If an insurance company is giving you weak excuses for refusing your claims, or if they are denying you a policy for which you are eligible, call the New York State Department of Insurance or the Attorney General's Consumer Complaint Bureau. Don't just give up and overlook it. Keep in mind that others may also be improperly treated.
- **For long-distance care of elderly relatives, hire a local geriatric care manager.** Local geriatric care managers can coordinate and supervise the care of a patient far distant from the responsible relative. They have banks of resources unknown to most lay people, and experience with Medicare and Medicaid. They can be invaluable.

## Keep Your Own Health Records Electronically

It's going to be a long time before the medical establishment creates a seamless way to access your medical records electronically. But in the meantime, Internet sites have devised online record-keeping systems that can help you organize the many facets of your medical life - keeping track of such items as prescriptions, tests and medical procedures, diagnoses, dates for routine doctor visits and check-ups. This information is particularly valuable for people with chronic conditions, such as diabetes or heart disease. The electronic data base prepared by the patient could store blood sugar readings and other vital data to help track the progress of the condition. A recent article in the New York Times listed four online health record systems that are being offered free of charge, at least at the outset.



- [Google Health](#) connects consumers to vendors who will input paper medical records into your electronic file for a fee.
- [Microsoft Healthvault](#) has agreements with New York Presbyterian Hospital,

Quest Laboratories and several pharmacies and medical device makers that allow patients to import data.

- [Revolutionhealth Health Records](#) allows patients to input their own data or have information faxed directly by health care providers and added to the electronic file.
- [WebMD Personal Health Record](#) allows consumers to input medical records and health data.

These websites are relatively new and are bound to be improved over time. You may want to begin to accumulate the pertinent information and keep it within your own electronic file system. This would make it easier to transfer the data to an integrated system when the sites have been refined.

## Answer Woman

*We welcome your questions which will be included in the FAQ section of the Caring Collaborative website.*

### **Why must I attend an orientation session before I can become a Caring Collaborative member?**

Orientation is a crucial link for members to learn what's expected of them, both as volunteers helping members and as members who are requesting services. Orientation familiarizes members with the concept of the Time Bank and offers an opportunity to discuss the service model that we have pioneered. Key concepts -- such as all-important confidentiality requirements, the need to set boundaries on expectations and the distinction between sharing experiences and giving advice -- are addressed. In addition, guidelines are provided for accompanying a member on a medical/hospital visit. At the conclusion of the session, you will be asked to sign a Member's Service Agreement; then you'll be part of this growing network of members who stand ready to help each other when medical problems arise.

### **Why does the Caring Collaborative have neighborhood groups?**

Many Caring Collaborative members want to become acquainted with others who live nearby. The neighborhood groups meet every few months to socialize and exchange information on health-related topics. To join a neighborhood group, please email either Nora Bleich, at [london28nyc@yahoo.com](mailto:london28nyc@yahoo.com) or Anita Kane at [kanes@nyc.rr.com](mailto:kanes@nyc.rr.com) to learn the name of the leader for the group nearest you.

### **Who Pays for the Taxi When a CC Member is Taken Home from the Hospital?**

The person who requests the service always pays for the taxi. It may be that having just been discharged from the hospital she's not in a position to handle the actual money and the tip, but payment is her responsibility. Taxis now allow riders to pay and tip with credit cards; the member is likely to carry her credit card with her.

### **How Does it Work When I Pay for a Prescription or Groceries?**

Here again, all financial outlays made on behalf of the person who requested help should be paid by her. Of course there can be notable exceptions. If you, as the

volunteer want to bring in a cup of tea and a scone to cheer up a member who is home-bound, that would be your decision. The general rule is, if you ask for the prescription or need groceries, it's your responsibility to pay or promptly repay the volunteer.

## The Caring Collaborative - Members Helping Members.

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