

# **Meeting Minutes**

## **A Backup Plan for Solos Task Force**

**Tuesday, November 7, 2017 – 7:30 to 9:30 AM**  
**Wilder Center, St Paul, MN**

**Task Force Members Present:** Kathleen Dempsey, Joyce Edwards, James Falvey, Ellie Hands (co-chair), Susan Henry, Darla Kashian, Greg Owen, Karen Peterson, Mark Peterson (co-chair), Peter Rothe, Martin Wera

**Members Not Present:** Genevieve Gaboriault, Sabina Sten

**Staff & Staff Support Present:** Linda Camp, Marit Peterson, Julie Roles, Pahoua Yang-Hoffman

### **Overarching Goal**

Stimulate the development of a supportive infrastructure to help solo older adults successfully navigate health related events and, therefore, be less likely to become vulnerable adults—with its accompanying loss of self-determination for the individual and high costs to society.

### **Expected Outcomes of the Project**

- General profiles of solo older adults (situation, needs, perceived barriers)
- A description of the current Minnesota infrastructure to support solos health decision making
- Description of the core elements of a health decision “backup plan”
- A list of important resource gaps and potential solutions
- A list of recommended priorities for future action and preliminary work plan

### **Proposed Outcomes for November 7 meeting:**

#### **Welcome/Negotiate Agenda**

Co-chair, Ellie Hands, called the meeting to order at 7:30 AM. Asked for additions, deletions, changes to the minutes of the 10/24/17 meeting. Minutes were approved as submitted.

Ellie introduced new task force member, Patty Thorsen, and Patty introduced herself (see bio sent earlier).

“I’m a single woman by choice. I am 57 years old. Have a single friend who recently became very ill. I went to her place and needed to contact her brother and help her in other ways. Made me think about what kind of support do we provide one another.”

Ellie reviewed overarching goal of the project and expected outcomes with the task force.

#### **Updates and Check-in**

- Last time we agreed to keep our November 21 meeting time even though neither of the co-chairs will be there. Darla Kashian has agreed to chair that meeting.
- Advisory group update. We have continued to have difficulty attracting people who will make an ongoing commitment. Staff has decided to call a one-time meeting and see where that can take us. We expect to do that in early December.
- A member shared that she was at a meeting at Gilda’s House, a support organization for people with cancer. Mentioned task force. Staff said we get so many of solos with no one. Will keep them apprised of our work.
- A member said that in her work as a private care manager she gets phone calls all the time with people saying they don’t have anyone else. They often ask if I will be their health care

agent, which we will do. I am seeing how important this is. Physicians are raising the issue more often and that is driving people looking for answers.

- A member mentioned a report from Grantmakers in Aging that mentions the FrameWorks Institute's work on aging. <http://frameworksinstitute.org/reframing-aging.html>. He particularly noted the communications work around aging: "Gaining Momentum: A FrameWorks Communications Toolkit" (<http://frameworksinstitute.org/toolkits/aging/>).
- Marit Peterson mentioned FrameWorks Institute's work on elder abuse. <http://frameworksinstitute.org/elder-abuse.html>.
- Marit reported on a presentation about solos that she and Linda Camp did at the American Bar Association conference in Washington DC. Great experience. Standing room only, 70 people. Excited to find that the attorneys were open to the idea that they might not have the entire answer. The session was engaging and energizing.

### **Dr. Carolyn McClain, Emergency Room Physician**

Mark introduced Dr. Carolyn McClain, Emergency Room Physician, Emergency Physician Providers Association.

#### *Dr. McClain's comments:*

Recent experience with a 100 years old. Did not have a POLST but had a health care directive. I called his health care agent and he had been dead for five years. 90% of people have someone but have never had a conversation about what the person wants. If you don't have anyone, the medical system will generally do everything to save someone. Sometimes that means we are just keeping a person suffering longer.

Another thing we see frequently is the son is in Chicago and people want to keep the patient alive until the son gets there. I can do that but the patient will suffer until he gets here. Is that fair? No one wants to talk about dying, and the ER is the worst place to talk about it. If you have pancreatic cancer and you're 80 lbs and no one has told you that you are going to die, it's not right. It is left to me when you enter the emergency room. I shouldn't be the one to have that conversation. I just met you. I don't know you. Should be happening much more upstream.

One situation that makes me particularly sad is people who live with Downs Syndrome. As they age they often have profound dementia and are wards of the state. No one will let them die. We side with life over dying all the time and that might not be the best.

The best thing you can do is to have a plan and have that plan in the system. If you don't, the medical system will generally do everything.

*Member:* What do you mean by "the system."? Is it cross-system? Do I need to be taken to a Fairview hospital for you to have access to my directive?

*Member:* Some phones have ICE (In Case of Emergency) apps.

We try to break into people's phones to find a contact. It is difficult and takes time. We don't have 15 minutes.

If you have a POLST form it is helpful. We know it represents what the patient wants. People who come from nursing homes usually have a POLST and that is helpful. Having an health care agent that you need to call isn't as helpful. People are not usually prepared to make a life or death decision on the spot. You are asking them to let mom or dad die. It is hard for anyone to stomach in an emergency.

*Member:* What if the POLST is in the Allina system and you are in HealthPartners.

You can't access their POLST form across systems. But most people will have information in the Dr. notes and they are available across systems. Problem with that is that people change their minds all the time. Call a random family member and they say something different from what's on the directive, we will error on the side of saving the life.

If we know it is an end-of-life situation, we will hunt out other systems and 90% of the time we can find it if it is in a system.

*Member:* Minnesota Department of Human Services has been working on personal portable health records for some time. We don't have a good system worked out. Have you ever encountered one? Do you like the idea?

Most of the time if you are in the Twin Cities we can get at your health record particularly if you have been in a hospital. Electronic Medical Records systems are so expensive (like \$300 million). If you are with a small physicians group that can't afford that kind of system the record might not be available.

The system for recording immunizations is a model that might work for POLSTs. If there were a system where every POLST goes into no matter where created, it would make them universally accessible.

*Member:* Our lives are in our phones. Can they be photographed and be easily accessible?

It's hard to get into the phone.

*Member:* I keep my healthcare directive in the glove compartment in my car. I expect that the most likely way that I am going to end up in the ER is because of a car accident.

*Member:* I keep mine on a thumb drive on my keychain and a copy in my wallet. Also have a copy taped to my bedroom wall and on my refrigerator.

The wallet idea is great. We always look in the wallet. We don't have the ability to access a thumb drive. None of our computers accept a thumb drive.

A frequent scenario is that someone has a heart attack while driving. The cops don't check for stuff in the car. They will bring a purse and/or wallet.

*Member:* What's your plan?

I am otherwise healthy. If I had a medical event, I would want people to give me a few days. In my extended family we have 30 docs. We all have different views. My experience in ER makes me not want to extend life beyond what is meaningful. I talk about what I want all the time to family members and friends but it is not in writing. In the ER, no matter what's in writing if we have someone who can speak for the person we will do what he or she says.

*Member:* What happens when there isn't a person to call.

If you don't find someone you do what is in writing.

*Member:* What is in writing is not necessarily up to date. The people closest to that person is always the best source for what the person might want because circumstances change.

Sometimes it's something like a wedding coming up and a DNR/DNI exists but in these circumstances they want to continue to live.

I had a man come in who had a DNR/DNI in a POLST. He had depression. All he needed was a pacemaker. Is that what he meant by DNR/DNI? We put the pacemaker in. If we take an action and in a few days you will be the same as you were yesterday, we are likely to take the action.

*Member:* A lot of what we do is by probability. When resuscitate a 100 year old, I blanch. When you are young you should do everything you can. If you are over 90 (or some age), in general the default should be "do nothing" unless there is something to say you should do otherwise. In my mind, unfortunately that isn't the case. We tend to do everything no matter what your age.

*Member:* It is important that we are aware of the gray areas in the role of the health care agent. It is a difficult role and we need to keep that in mind as we think about someone becoming someone else's decision maker. I was a health care power of attorney for someone for one of my clients. Had many discussions over the years. Late-stage Parkinson. Went into atrial fibrillation. The doctor asked if they should cardiovert him. Very difficult decision for me. We did it and he survived momentarily but died a few days later. It is difficult to take on the role of making those decisions, many gray areas and decisions are often very complex.

The question might be: Will what we do get you back roughly to the person you were before this event? But even that doesn't cover all situations. For example, for many people with dementia dying from pneumonia is often a peaceful way to go. That means not administering antibiotics. That's not on a health care directive.

*Member:* It is on a POLST. I go over it with my patients all the time.

*Member:* Does your malpractice provider influence your decisions? Do you worry about litigation?

No. You get sued for screwing up on a 25 year old. As people age they rarely sue. Hardest thing is kids come into town at Christmas and say do everything no matter what the forms say.

*Linda:* In some states there is a default surrogate law which means that doctors can go to an extended group of people for input in the decision.

We engage the hospital Ethics Committee at times but that takes time. We don't reach out to extended group in the ER.

*Linda:* There are national databases where people can store health care directives. Do you use them?

No.

*Pahoua:* Changing demographics in Minnesota. Greater number of immigrants. How does that impact what happens in the ER? What challenges or opportunities has it presented?

Tons of issues. For example in the Hmong community, we are often asked to get a Shaman involved. Can make it difficult. Russian community will want to do everything to keep people alive no matter what. Cultural issues are huge. I worked in Baltimore before coming here. 18 year olds with no family. Distrust of the medical system in the Native American community. 99% of the doctors just want to do what's right.

*Member:* I was on the Hennepin County Medical System ethics committee. I was amazed at the extent to which they would go to find someone.

Sometimes it is complicated. Man with his mistress, has a heart attack. Contacted the wife and she said “the bastard is DNR.” I thought I needed to save even if it wasn’t clear what he would want.

*Member:* Is finding a person who can make a decision for the person in distress or is it for the medical system to feel comfortable in the situation? Sometimes useful having the contact; sometimes just muddies the water.

*Member:* How could we be most helpful to you?

Think about the kind of language you use when you discuss dying with people. Not so simple. Idea of suffering needs to be a part of the discussion. Are you willing to suffer for two weeks if you have a good shot at getting back to where you were? What life do you want to lead? It’s more complicated than just DNR/DNI.

*Member:* 58-year-old friend of mine had a devastating stroke. Lost most language skills. Talked about suicide often. Over some time he found that he adjusted to his new life. He had experiences that were worth having. The pressure that comes at times of crisis changes one’s perspective.

That might be different at age 98. What is your potential recovery in this situation? People want to know the exact likelihood. How much time? I have no idea. Everyone is different.

*Member:* Atul Gawande’s book, *Being Mortal*. Do doctors in your hospital extend death because they can’t face the idea of not saving a life?

Not so much in the ER because we deal with death all the time. The more death you are around the more you are not afraid of it. For a surgeon or an oncologist, death often feels like defeat.

*Member:* Surgeon told me that he would not honor a DNR for my mother if she died on an operating table.

*Member:* That’s very different. If you have an arrest in an operating room your chances of recovery are very high. May feel self-serving but in general if I am well enough to have the surgery, resuscitating makes sense. A DNR should be “do not attempt resuscitation.” If you are coming from a nursing home coming into the ER your chances of success are about 1%. That’s about as clear as it can be and if people still want to resuscitate it is usually because they don’t understand the likely outcome.

*Member:* What if the Wellness visit that is available to people on Medicare was also a point where a POLST discussion occurred and was entered into a statewide registry. Would that be helpful?

Yes. The more people who have talked about it, the better off we are and the more readily available the documents are the better. If a person has a health care power of attorney we will listen to them.

*Member:* If one person is the health care agent and another is the attorney in fact who decides?

*Marit:* This is a gray area. The health care agent is the decision maker for health care decisions. Used to be called the durable power of attorney for healthcare. There is a lot of confusion.

*Member:* So important to have the health care directive updated regularly.

*Marit:* There are two things medical order (POLST) and a planning tool. We should not use a medical order as a planning tool. If we are going to use a POLST as a planning tool we MUST have them sign it. The POLST requires the physician's signature but does not require the patient's signature.

*Member:* POLST does have a place where you can check off who was involved in the decision-making. Problem with requiring the signature is that sometimes the person is incapacitated and cannot provide the signature.

*Marit:* There will always be a need for medical orders but we need to be sure people understand the distinction between it and a health care directive.

## **Interviews with Solos**

One of our work products is to create profiles of solos. Stories about people experiences will be an important part of that. We are proposing that each of you interview at least one solo during the next few months with a deadline of the January 16 meeting. Linda distributed a draft set of questions and gave the group time to discuss. Staff will work with Greg Owen to develop a final set and distribute for feedback.

*Ellie:* Can we help people find a solo to interview if they need it?

Yes, but think about your extended network. Who do you know?

*Member:* Do you want to have us do this personally ourselves? At Little Brothers we might be able to ask some volunteers to do additional interviews.

*Member:* Might we add a question about people's sense of personal safety?

*Member:* When my friend was in an emergency situation she displayed different characteristics. People have questioned whether or not she should live independently. Part of her reluctance to reach out was that she might lose her independence.

*Member:* When doing the interviews, try to stay as closely focused on the solo issue as possible. Recommended entry point would be a question such as "Have you had experiences that raised concerns for you about handling a health care crisis?"

*Member:* Need to be aware of the kind of relationship we have with the person which might influence how people respond. Pretty personal issues. Maybe add a question about the relationship with the person doing the interview.

*Member:* How do we get to the social-economic status?

## **Evaluation**

Members rated the meeting: 5, 4.5, 4.5, 5, 4+, 5, 5, 4.5, 4.5, 5

- Good to have medical viewpoint. Made me think more about the many different situations in the medical environment.
- Really helpful to have the ER doc and Peter. Went a little long on that session. Would like to have had more time planning on the questionnaire.
- Felt a little incomplete. We didn't take the next step into medical roles.
- Learned a lot. See a lot of questions for me to explore.
- Dr. McClain gave good context into the complexity at end of life decisions. Reinforced for me the importance of having those conversations and importance of our endeavors here.

- In all of our previous discussions we have been discovering information and finally today we have a potential action item. The potential for a universal database for accessing health care directives.
- Agree. My hope was we would come out with something tangible. I would think the Twin Cities Medical Association might also be excited about. I thought Dr. McClain was fantastic, providing needed nuts and bolts around how it works. Was moved by her description of working with people at end of life. I would ask for her if I need to die in an ER.
- I would love to hear Carl the social worker's perspective. Valued Peter's perspective. See we are starting to build a pretty clear understanding of the medical environment.
- Happy with the progress we are making in the task force. Disappointed that we haven't moved farther on this issue as a society.
- Good dialogue with Dr. McClain and Peter. Led us to a different place, beyond the document. Hasn't changed over the years I have been involved as much as it should have.

*Ellie:* Next meeting is November 21 at Wilder Center, 451 Lexington Pkwy N. St Paul, MN, 7:30 to 9:30 AM. A meeting notice will be sent out. Thank you all.