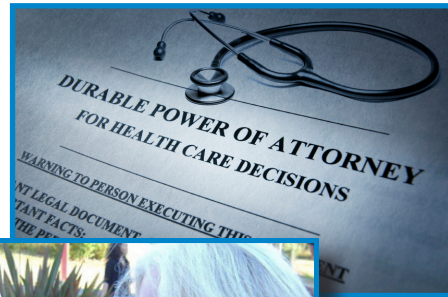




**PREPARING
FOR A
SERIOUS
HEALTH
EVENT**



A HANDBOOK FOR MEMBERS

November 2019



WIDER HORIZONS

www.widerhorizonsvillage.org

206 650-3586

Seattle, WA



ACKNOWLEDGEMENTS

Wider Horizons is proud of the work of the Health Advocacy Task Force. That Task Force—whose members (listed below) come from diverse professional backgrounds (including medical research, health care journalism, nursing, social work, and education)—accomplished a great deal over a relatively brief period of time during its 2019 deliberations.

The Task Force was convened when we realized the toll serious health events was taking on members who experienced them and on our village as a whole. We thought, “these events could be better-handled and have better outcomes with better preparation.” Hence, this document is a testament, in many ways, to the member-driven nature of our cutting edge village! We hope you find it useful.

Prepared by Denise Lishner, with the assistance of:

- Susan Adler
- Carolyn Allen
- Kay Beisse
- Jane Cotler
- Denise Klein
- Barbara Klube
- Ann Lawrence
- Sue Lerner
- Chris Morris
- Kathleen O'Connor
- Maggie Pheasant
- Donna Sunkel

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INTRODUCTION

Traversing the nooks and crannies of the health care system can be a confusing and complicated process—especially when you are ill! If you’ve ever wondered whether you can over-prepare for an impending surgery, this handbook will forevermore answer that question in the negative! Here is information about what you can do in advance to obtain the best and smoothest care, should you experience a serious health event.

The handbook first discusses how to put your house in order. Actions include collecting important papers in one place that will be needed to access health care, reviewing your health insurance benefits, and making sure your home is a safe environment—both to prevent accidents and to provide a protected place to recover from an illness.

It goes on to describe the role of a health advocate in helping you navigate the health care system, specifying what that person can do to make it more likely you receive excellent and timely care.

The next sections provide crucial details about surgery, hospitalization, post-hospital skilled nursing facility care, care at home during convalescence, and unexpected serious health occurrences or emergencies. The recommendations in this handbook describe what you can do ahead of time and what to expect during your stay, in any of these difficult situations.

Finally, it explains how *Wider Horizons* can help out when members experience health problems. An example is to remind you when to take a prescription medicine.

Each section of the handbook contains very specific recommendations to better prepare you for a serious health episode. At the end of the handbook there is a corresponding checklist for you to check off as you complete each of the recommendations that apply to you.

Being prepared, having important information about the health care system, and having health advocates who act on your behalf mean you will have a much, much better experience at a time when “good” is difficult to come by!

SECTION I

GETTING YOUR HOUSE IN ORDER

IMPORTANT DOCUMENTS

We strongly recommend you prepare the following important papers and have them signed, witnessed, or notarized (as required). These are critical both to direct the kind of care you wish to receive, and to provide the information needed to obtain support from relatives, friends, providers, and *Wider Horizons* volunteers.

Put these papers into a “red file” that you keep in or on your desk. Provide a copy of your red file to your health advocates or durable powers of attorney. (A health advocate is an individual who provides direct and personalized services to a patient and/or family member as they navigate the health care system).

Be sure any medically related papers and directives (first three items below) are in your medical records/files and are known to your providers.

- HealthCare Durable Power of Attorney (DPOA)
- Advance Directives/Living Will
- Physicians Orders for Life Sustaining Treatment (POLST)—also post a copy on your refrigerator
- Important contact numbers including your HealthCare DPOA, health advocate(s), relatives, primary care provider, etc.
- Copies of your Medicare and other health insurance cards
- Financial Durable Power of Attorney
- Any form your health care provider requires that allows your advocate(s) to give and receive information about you or your condition
- Copy of your Driver’s License or other ID

ACCIDENT PROOF YOUR HOME

Accidents such as falls can be prevented in the home by following safety check guidelines. Likewise, there are things you can do in your home to make it easier to recover following a major health episode. Best practice is to have a professional assessment in advance by an occupational therapist/OT (Wider Horizons can recommend one). These are typical recommendations:



- Raised toilet seat
- Bedside commode
- Shower bench or chair
- Grab bars in shower and near commode
- Handrails where there are stairs (indoors and outdoors)
- Remove throw rugs (possibly for good)

Wider Horizons has a lending “library” of medical equipment. Once you know what you need, check out what’s available by calling *Wider Horizons* staff. But note that equipment like a walker needs to be adjusted to your own height, preferably by a physical therapist.



RECOMMENDATIONS:

- Have a professional OT assessment.
- Implement the recommendations of the OT and/or your physician.
- If it’s called for by the type of surgery you are having and feasible, arrange to sleep on the first floor to avoid climbing stairs, particularly if there is an accessible bathroom nearby.

SECTION II

HEALTH ADVOCACY

WHAT DOES A HEALTH ADVOCATE DO?



Health (or health care) advocates may be relatives, friends, or other volunteers. They may also be professionals who come from a variety of disciplines and have different titles. In this handbook, we mention all of these but give special emphasis to volunteer health advocates who may be other members of *Wider Horizons*.

Your health advocates are extremely important. They help you navigate the health care system and facilitate communication between and among your care providers. They can definitely improve the quality of your health care experience and make a significant contribution to your overall health.

Here are some of the key things your health advocates can do:

- Escort you to provider appointments and take notes
- Supply practical support (like transportation, help you understand and access resources, remind you to follow up on provider recommendations, prepare for provider appointments)
- Offer emotional or moral support (e.g., to get through a rough patch, deal with a chronic illness, or implement self-care practices)
- Give information to (or get information from) providers when you or a family member are not able to do so
- Support you by describing to the provider concerns not being addressed, questions not adequately answered, or care that is not meeting your needs

ACCESSING HEALTH ADVOCACY

As a member of *Wider Horizons*, you can expect to receive significant help, support, and the referrals you need. However, in order to receive health advocacy from another *Wider Horizons* member or our staff:

You must have designated one and, preferably, two health advocates (one of whom may be a *Wider Horizons* member).

If you have not already designated a relative or friend as your health advocate, *Wider Horizons* can suggest members, or refer you to paid advocates, who could serve in this capacity. It will be up to you to contact them and decide if there is a good fit. If so, make sure your advocates understand their role as described above, as well as your specific expectations of them.

We can also help you determine what attributes are important in designating a relative or friend to serve in this role.

It may be necessary for your health advocates to contact your HealthCare Durable Power of Attorney (DPOA) during a serious health episode because the role of an advocate in terms of making health care decisions on your behalf is limited.

Therefore, you must have a HealthCare DPOA who lives in King County, is reachable by phone, and is aware they may receive a contact from us.





RECOMMENDATIONS:

- Designate one and, preferably, two health advocates to be your “team.”
- Meet with your team to describe your health issues and explain your wishes for their involvement on your behalf.
- In case you need surgery, arrange for your health advocate to be with you on the day of the surgery (in some cases for the duration of the surgery).
- Make sure your health advocate has the contact information for your HealthCare DPOA.
- Let *Wider Horizons* staff know your team members’ names and contact information.
- Fill out the forms required by your health care providers (or take other action needed) to ensure your health advocate can give and receive information about your health and care.
- Give your family and your health advocates contact information for your health care providers, including your primary care physician, any relevant specialists (like a surgeon), and any other providers or institutions you are likely to use.

SECTION III

BEING PREPARED FOR SURGERY OR OTHER SERIOUS HEALTH EVENTS

The experience of being in a hospital will teach you a lot about not being in control. However, when you know ahead of time you require surgery or hospitalization, there are many things you can do to prepare in advance.

UNDERSTAND YOUR INSURANCE BENEFITS



Even if you think you know what your insurance coverage is, carefully review your benefits and coverages well in advance of a planned surgery or hospitalization.

Here are a few points to remember:

- A hospital admission following an emergency room visit is virtually always covered by insurance, while a stay “in observation” may not be.
- To be placed in a skilled nursing facility (SNF), Medicare requires you to have been hospitalized for at least three days before covering these costs.
- Be aware that you may receive bills that you were not expecting, for example, if you are placed under observation care instead of being hospitalized, if you choose to have elective surgery, or if one of the providers who cared for you is not in your insurance network.



RECOMMENDATIONS:

- Review general Medicare coverage or your managed Medicare (or Medicare Advantage) plan’s specific provisions.
- Review your long term care insurance policy if you have one. Learn what it provides and when these benefits may be available when you need help with activities of daily living.
- Understand what your co-pays and deductibles for the planned event are likely to be.

HOW AND WHERE YOU WILL RECEIVE NEEDED CARE

Hospital Care

If you need to stay in a hospital for a major procedure, surgery or serious illness, your provider and insurer will recommend a hospital for you that is in their network. Sometimes you can choose the hospital that you prefer, but often that will be determined by your provider or insurer.

If possible, choose a reputable provider who has performed a given surgery multiple times. During your hospitalization, you will not be cared for directly by your primary care physician. Instead, you will be seen by your surgeon, other specialist(s), and/or a hospitalist. Your health advocate can be a conduit between you and your hospital providers to help ensure accurate information is conveyed between and among all your care providers.



RECOMMENDATIONS:

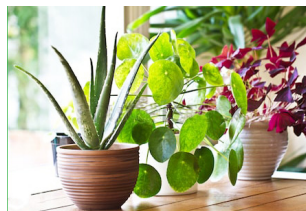
- In planning for a hospitalization or other institutional stay, make a trusted individual a co-maker on a checking or other account that has funds to cover expenditures needed on your behalf while you are hospitalized.
- Designate those with whom you wish your providers to share your health information and status updates.
- If your health advocate is not going to provide transportation to and from surgery or a hospitalization make a plan for getting transportation (from *Wider Horizons* or elsewhere) well in advance.
- Let *Wider Horizons* staff know about any uncovered needs so they can arrange for assistance.
- Find out ahead of time what procedure will be performed, the treatment plan, and your expected recovery time.

Besides these important steps related to your hospital (or other facility) stay, you can also make sure your home is well-cared for and ready for you when you return to it.



RECOMMENDATIONS:

- Arrange for yard work and/or watering.
- Have your paper and mail stopped, or else delivered to your door rather than curbside.
- Arrange for pet care.
- Have frozen meals and arrange for meal preparation and/or delivery upon your return home.
- Fill your pill box with your routine meds and locate it in the area you'll be using during home recovery—add newly prescribed medications after your hospitalization. Place an updated list of medications with frequency and timing of dosing by the pillbox.



“I didn’t anticipate that my surgery would result in a temporary disability and my physician didn’t mention this. Now I know I should have asked my physician to fill out and sign a disability parking sticker form. Then I could have mailed it in or taken it to the Washington State Department of Licensing.”

—Donna Sunkel, *Wider Horizons* member

Post Hospital Facility Care

Typically, after a hospital stay, you will either be released to your home, or discharged to a skilled nursing facility (SNF) for care and rehabilitation. Ask your physician to tell you beforehand the expected trajectory of your recovery, and whether you are likely to go directly home or be sent to a SNF. Since this is often not finally determined until the day of discharge, it is best to check your health benefits and options in advance.

You may be discharged to a facility that will be covered by your insurance. This is typically a decision made by your provider (in some cases, your insurer), in consultation with the hospital team of physicians, nurses, social workers and physical therapists. Often, you can find out in advance whether a stay at a SNF will be covered. However, that decision can change based on your care needs at the time of discharge.

If your insurer will not cover a facility stay, but you want one, you can decide to pay privately.

If you think you are being discharged prematurely, you have the right to appeal that decision.

At the time of facility discharge, whether from a hospital or SNF, you or your health advocate should be sure to go to the pharmacy to get any newly prescribed medications.



RECOMMENDATIONS:

- In the event you need to go to a SNF that is not covered by your insurance, be prepared to pay privately.
- If you have a preference for one or more SNFs, bring with you to the hospital contact information for these and share this information with the hospital discharge staff if appropriate.
- You or your health advocate should read and carefully follow the hospital or facility discharge instructions provided to you.
- You or your health advocate should make sure to pick up new prescriptions at the appropriate pharmacy upon discharge.

Care at Home

Even if you are discharged directly home from the hospital, you may well need health care support for a while, either from family, friends, or paid caregivers. For example, you may need help getting out of bed, getting to the bathroom, dressing, bathing, or managing your medications. If you need “medically necessary” care (a term used by Medicare and insurance defined by specific medical conditions and criteria), your provider/insurer likely will provide/cover it.

Typically, the following providers will supply home care: a professional registered nurse (RN), a certified nursing assistant (CNA) who works under the supervision of an RN, or a physical or occupational therapist. When care is provided, and covered by insurance, Medicare and your provider will decide its frequency, length, and when it occurs.

You may, however, locate and/or pay for care at home yourself. How long and what type of care you have is a highly individual decision and depends on many factors. Again, *Wider Horizons* can help you with decisions about this. See *Wider Horizons* publication, “When You Need Help in Your Home” for the options including details about costs and other factors.



“After 5 days in the hospital for a complicated back surgery, I was told at discharge that I didn’t meet Medicare criteria for a SNF or home care. I didn’t agree with this recommendation and thought I would need care for an extended period of time. On the spur of the moment and at the point of discharge, I decided to pay privately and contacted a reputable home care placement agency. Through them, I hired a 24/7 certified nursing assistant. As it turned out, I needed that level of care for several months. Thank goodness my friends and *Wider Horizons* members visited, took me to doctor appointments, and brought me hot meals each day for that period of my convalescence!”

—Denise Lishner, *Wider Horizons* Member



RECOMMENDATIONS:

- If you choose to have care at home (either when you return home directly from the hospital or after a facility stay), decide if that care will be provided by professionals or paraprofessionals, family members, friends, or other voluntary caregivers.
- Arrange for someone with the appropriate qualifications to take care of you for a period of time when you return home. Understand the costs of this and be prepared to pay out of pocket.

SECTION IV

WHAT ABOUT AN *UNEXPECTED* HEALTH EVENT—A *WHOOPS*?

A *Whoops* is a serious health problem that happens “out of the blue,” such as a fall that causes injury, a car accident, a stroke, or a heart attack. Even though the event happens unexpectedly, you can minimize its ill effects by planning ahead of time and knowing what to do.

If you experience a sudden and serious health emergency, you or a bystander should call 911. If someone is with you, they can make the call to describe what is happening to you and can answer the dispatcher’s questions. Answer as clearly as possible and stay on the line. The dispatcher will make the decision as to what you need. Emergency Medical Technicians (EMTs), paramedics, and firefighters will evaluate the immediate problem and either provide life-saving care or drive you to the most appropriate hospital.

Many people are embarrassed to call 911 but remember
this action can save your life!

If you need to go to the emergency room (ER), the following will greatly improve your visit:

- Have a relative, friend, or health advocate drive you and stay by your side.
- Contact your health advocate and HealthCare DPOA.
- Bring along your insurance cards and a list of your medications.
- Staff shift changes usually occur at 7 am, 3 pm and 11 pm, so this may delay care as incoming providers catch up on patient issues.
- You or your advocate should provide as much information as you can and ask any questions you have about what the ER provider intends to do.
- Ask for copies of any test results and be sure they are sent to your doctor.
- Make sure ER staff provide you with written follow-up instructions and new prescriptions.

As discussed in Section I, prepare the **red file** and implement a home safety check to lessen the chance of falls and accidents. Here are a few additional steps you can take to get optimal care, even in the case of an unexpected medical emergency:



RECOMMENDATIONS:

- Have a phone by your side at night with a list of your important contacts.
- Don't minimize symptoms like shortness of breath, faintness, dizziness, bleeding, or acute pain—and call 911 immediately.

One note: Some health related, life-changing issues not typically defined as an emergency (and probably not requiring 911 or even a sudden trip to a health care facility) can be cataclysmic (a *Whoops*) and trigger a relatively sudden need for help, advocacy, or resource referral.

Examples:

- Cognitive decline
- A serious diagnosis such as cancer
- Loss of a partner or other loved one

A final recommendation that applies to both a *Whoops* and to planning for a serious health event: Familiarize yourself with the support that **Wider Horizons** can provide to you as well as with the resources available in the wider community. The more you know, the better prepared you will be.

SECTION V:

GUIDELINES FOR HELPING OTHER *WIDER HORIZONS* MEMBERS

Wider Horizons members have done a stellar job of supporting other members who have experienced serious health events and will continue to do so as part of our mission and community-building. One thing we have learned from members' experiences is how difficult it can be to set boundaries and to avoid becoming over-extended. The guidelines below should help you to understand and establish both your personal limitations and those of the organization.

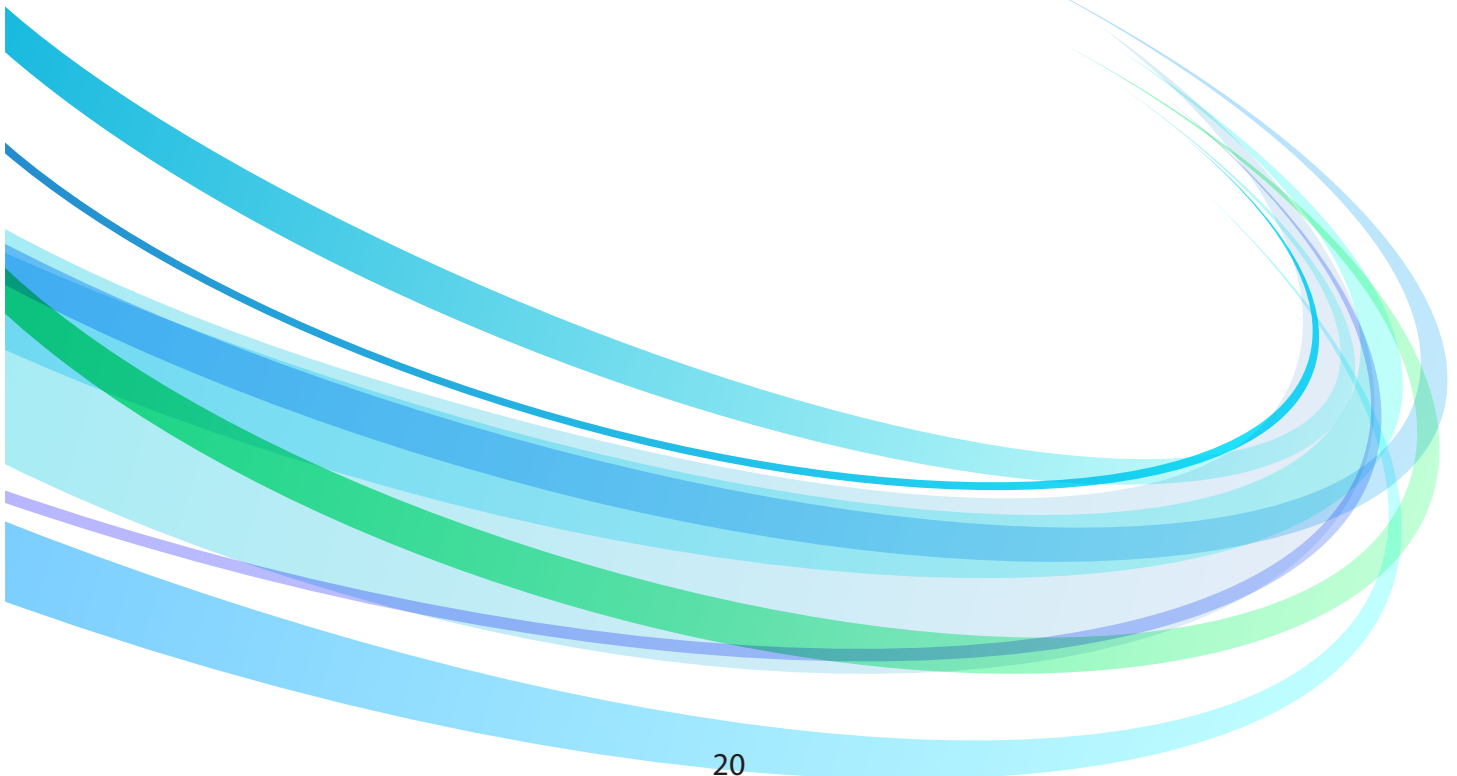
- If the member you are helping has serious symptoms like severe pain, trouble breathing, or uncontrollable bleeding, call 911 immediately.
- Don't do anything that makes you at all uncomfortable. Call *Wider Horizons* staff for advice, and, if you cannot reach them, contact the member's health advocate or primary care provider.
- You can give physical assistance involving "light touch," e.g., on the arm or elbow. You can lift and open the member's walker or transfer chair if you feel you are strong enough. But do not attempt to move or lift another member.
- Keep private any information you receive unless you have asked the member if they would like you to share it. You can share this information with *Wider Horizons* staff to get advice.
- You should not administer medications to another member, but you may fill a Mediset (pill dispensary) from a current prescription list if you are comfortable with that, and you may remind a member to take a medication.
- We discourage our members from providing overnight support unless it is just for companionship. If a member requires help at night, they should hire a paid caregiver or ask a friend or relative with the appropriate skills to provide the help needed.

Because *Wider Horizons's* excellent liability insurance requires it, we have policies for what our members and other volunteers can and cannot do to help others in medical situations, without putting them at risk.

Washington State's Good Samaritan Act also provides protection to unpaid volunteers offering to help or transport someone in case of a medical emergency.

We hope these recommendations are useful to you should you experience a serious health event. We believe that being prepared makes it easier to obtain the best health care possible.

On the next several pages, there is a handy checklist. Use it to check off recommendations as you complete them.





CHECKLIST

SECTION I: GETTING MY HOUSE IN ORDER

Important Documents

- ☐ HealthCare Durable Power of Attorney (DPOA)
- ☐ Advance Directives/Living Will
- ☐ Physicians Orders for Life Sustaining Treatment (POLST)—I posted a copy on my refrigerator
- ☐ Important contact numbers including my HealthCare DPOA, health advocate(s), relatives, primary care provider, etc.
- ☐ Copies of my Medicare and other health insurance cards
- ☐ Financial Durable Power of Attorney
- ☐ Any form my health care provider requires that allows my advocate(s) to give and receive information about me or my condition
- ☐ Copy of my Driver's License or other ID

Accident Proof My Home

- ☐ I had a professional OT assessment.
- ☐ I implemented the recommendations of the OT and/or my physician.
- ☐ If it's called for by the type of surgery I am having and feasible, I have arranged to sleep on the first floor to avoid climbing stairs.



CHECKLIST

SECTION II: HEALTH ADVOCACY

Accessing Health Advocacy

- ☐ I designated one or two health advocates to be my “team.”
- ☐ I met with my team to describe my health issues and explained my wishes for their involvement on my behalf.
- ☐ Because I need surgery, I arranged for my health advocate to be with me on the day of the surgery (for the duration of the surgery if required).
- ☐ My health advocate has the contact information for my HealthCare DPOA.
- ☐ I let *Wider Horizons* staff know my team members’ names and contact information.
- ☐ I filled out the forms required by my health care providers (or took other action needed) to ensure my health advocate can give and receive information about my health and care.
- ☐ I gave my family and my health advocates contact information for my health care providers, including my primary care physician, my specialists, and any other providers or institutions I am using.



CHECKLIST

SECTION III: BEING PREPARED FOR SURGERY OR OTHER SERIOUS HEALTH EVENT

Understanding my Health Insurance Benefits

- ☐ I reviewed general Medicare coverage or my managed Medicare (or Medicare Advantage) plan's specific provisions.
- ☐ I reviewed my long term care insurance policy, its provisions, and when these benefits will be available if I need help with activities of daily living.
- ☐ I understand what my co-pays and deductibles for the planned event are likely to be.

Hospital Care

- ☐ In planning for a hospitalization or other institutional stay, I made a trusted individual a co-maker on a checking or other account that has funds to cover expenditures needed on my behalf while I am hospitalized.
- ☐ I designated those with whom I wish my providers to share my health information and status updates.
- ☐ Since my health advocate is not going to transport me to and from surgery or a hospitalization, I made a plan for getting transportation (from *Wider Horizons* or elsewhere).
- ☐ I let *Wider Horizons* staff know about any uncovered needs I have so they can arrange for assistance.
- ☐ I found out ahead of time what procedure will be performed, the treatment plan, and my expected recovery time.
- ☐ I arranged for yard work and/or watering.
- ☐ I had my paper and mail stopped, or else delivered to my door rather than curbside.



CHECKLIST

- ☐ I arranged for pet care.
- ☐ I have meals in my freezer and have arranged for meal preparation and/or delivery upon my return home.
- ☐ I filled my pill box with my routine meds and located it in the area I'll be using during home recovery—I added newly prescribed medications after my hospitalization. I placed an updated list of medications with frequency and timing of dosing by the pillbox.

Post Hospital Facility Care

- ☐ I am prepared to pay privately in the event I need to go to a SNF that is not covered by my insurance.
- ☐ Because I have a preference for one or more SNFs, I will bring with me to the hospital contact information for these and share this information with the hospital discharge staff.
- ☐ I or my health advocate read and carefully followed the hospital or facility discharge instructions provided to me.
- ☐ I or my health advocate picked up new prescriptions at the pharmacy upon my discharge.



CHECKLIST

Care at Home

- ☐ I chose to have care at home after my hospital or facility stay, and decided whether that care will be provided by professionals or paraprofessionals, family members, friends, or other voluntary caregivers.
- ☐ I arranged for someone with the appropriate qualifications to take care of me upon my return home. I am prepared to pay out of pocket.

SECTION IV: PREPARING FOR A *WHOOPS*

- ☐ I have a phone by my side at night with a list of my important contacts.
- ☐ I will not minimize symptoms like shortness of breath, faintness, dizziness, bleeding, or acute pain—and I will call 911 immediately.

NOTES:

Wider Horizons Village has been open since June of 2015. Our 82 members range in age from late 40's to mid 90's, with an average age of 74. They are fascinating, independent people who want to age in community. Many joined as an extension of a lifetime of citizen activism.

We do the things many close-knit families and friends do together—dinners, social events, rides to the doctor or the airport when needed, light home repairs, help with gardening and computer issues, and the like.

We have fun together; we take care of each other; we learn new things; we have adventures; we feel engaged and worthy. And, in the aftermath of a serious health event, we have each other's backs.

For more information go to our website: www.widerhorizonsvillage.org or call 206 650-3586.



Some of the members of *Wider Horizons* who stand ready to help each other in multiple ways



WIDER HORIZONS

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