

Advocating For Yourself in Today's Stressed Healthcare System
Nancy Euchner

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Objectives

- Make a plan to prepare essential medical information ahead of time
- Learn how to develop a partnership with your PCP
- Navigating likely scenarios (hospital, urgent care, PCP and new specialists)
- Identify ways to speak up effectively when challenges arise

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The Art of Preparation

The **MUST HAVE** elements you can prepare ahead

- Complete contact information (for yourself and your agent/alternate)
- Current medications
- Allergies
- Surgical History – including implants like stents, pacemakers, knees
- Immunization history – tetanus, COVID, pneumonia flu
- Health insurance information
- Name/contact information for PCP

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Example

HEALTH CARE UPDATE

SINCE THE LAST VISIT, I HAVE SEEN THE FOLLOWING PROVIDERS

Hospital visit – name of hospital – knee replacement
 Specialty visit – name of provider – procedure

MEDICATION UPDATE (started/stopped by other providers and over the counter)
 Added – pain medication for post-op pain
 Started taking probiotics

GOALS / QUESTIONS / CONCERNS FOR TODAY'S VISIT
 Getting therapy at home but it's not challenging enough
 Having trouble sleeping now

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Prepare Your Team

CLARIFY YOUR WISHES AND EXPECTATIONS

- They need to know!
 - Which person will provide support during a short illness
 - Who can provide longer term support
 - Who will make medical decisions should the need arise?
 - Who would make the best advocate?
- They need the authority
 - HIPAA release in provider offices
 - Copy of Advance Directives if they are agent

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Knowledge is Power

UNDERSTAND HOW TO ACCESS INFORMATION

- Learn to use the portal for your PCP
- Learn to use the portal for your preferred hospital
- Encourage all providers to share info with your PCP
- Use a member of your team to help keep track of hospital events if you are there overnight

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Situation Specific Tips

IF AN AMBULANCE IS INVOLVED

- Provide them with a copy of your Emergency Medical Information Form when they arrive at your house
- If it's an emergency, they'll take you to the closest hospital – make sure your family knows which hospital is closest
- Put your medication basket – meds in their original bottles – in your "hospital grab and go" bag

IT'S IMPORTANT TO KEEP THIS UP TO DATE
REVIEW AFTER EACH MEDICAL ENCOUNTER AND UPDATE IF NEEDED



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Situation Specific Tips

IN THE ER OR URGENT CARE

- Find out the name of the doctor/PA/NP in charge of your care and make note of it. While you're waiting, make notes about questions.
- In the hospital, the admitting doctor may be different from both the ER doc and the hospitalist who will care for you on the floor. Keep track of the names of each one.
- You will sign consents for treatment with the admission clerk – ask to look at your "Face Sheet" to make sure the information is correct



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Situation Specific Tips

ONCE IN YOUR HOSPITAL ROOM

- Again - who are these people? At the least, identify:
 - Case Manager
 - Hospitalist – they rotate every few days
 - Primary nurse for the shift
- Sounds crazy, but find out whether or not you are admitted
- Fending for yourself can be a little tricky – prepare ahead



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Hospital Survival Kit

- ❖ Sturdy secure bag with zipper compartment
- ❖ Glasses, hearing aids and teeth
- ❖ Dry erase markers – thick – in several colors
- ❖ Notepad and several pens
- ❖ Phone numbers of key contacts
- ❖ Another Emergency Medical Information envelope
- ❖ Your essential medications in original bottles



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Situation Specific Tips

IF YOU CAN'T MANAGE ON YOUR OWN

- Designate your strongest team member to be with you when rounds and planning happen
 - ** this can be hard to predict
- Look for the helpers – the person who will give you the best info may not have the title you expect
- Don't sign insurance or hospital papers without a family member present (remember that Face Sheet)



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Situation Specific Tips

IF YOU CAN'T GO HOME FROM THE HOSPITAL

- Have the names of your top 3 choices for rehab ready to share
 - ask someone to help you with the referral
 - COVID and staffing shortages have closed many rehab beds in our area.**
- This is when it's really important to know whether or not you've been admitted



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If things go wrong

DON'T CONTRIBUTE TO THE PROBLEM

- Stay cool and get the facts
- Ask for help in understanding their side
- Ask who to speak with to get better understanding

Start as close to the problem or issue as you can
Don't be a jerk



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If things go wrong

WHAT'S OFTEN BEHIND THE PROBLEM

- Time crunch – your insurance is making demands
- Time crunch – the person who needs to help you doesn't have the time or demeanor to help you see your options
- Miscommunication among team members



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If things go wrong

IF YOU HIT A SNAG AND SOMEONE'S UNREASONABLY DIFFICULT

- Take a deep breath and tell them you appreciate that their job has its demands
- Don't talk over them – listen and ask for clarification
- Ask for a follow up meeting when a family member can be present before making a decision
- Ask to speak with a supervisor or patient advocate if you are at an impasse



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SUMMARY

PREVENTION IS KEY

- Prepare your emergency medical information ahead of time
- Talk to your family about your wishes and expectations
- Forge a partnership with your PCP
- Get to know the key players in your PCP office



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SUMMARY

IN THE HOSPITAL

- Check your face sheet when you sign admitting forms
- Don't sign insurance or hospital forms without a family member present if you aren't fully capable
- Know your admission status
- Think now about where you would go for rehab if you couldn't go home from the hospital right away



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SUMMARY

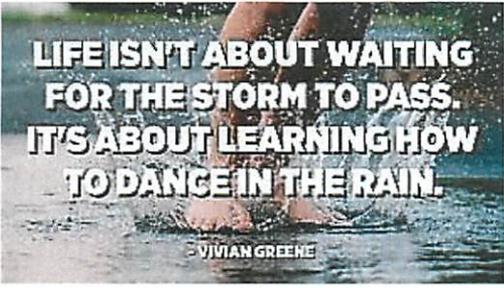
IF YOU HIT A SNAG

- Maintain your cool!
- Don't make big decisions without a family member present
- Get curious, stay respectful
- Keep track of the people you work with to solve problems and their contact information
- Thank those who help



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Remember



LIFE ISN'T ABOUT WAITING FOR THE STORM TO PASS. IT'S ABOUT LEARNING HOW TO DANCE IN THE RAIN.
- VIVIAN GREENE

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SeniorSAFE
Aging In Place Advisors
Kris Rench, CEO
603-263-4720 x800
www.seniorsafeaging.com
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Our Contact Information

Seacoast Village Project
400 Little Harbor Road
Mailbox 1101
Portsmouth, NH 03801
603-373-8429
info@seacoastvillageproject.org
<https://www.seacoastvillageproject.org>



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