



Navigating the Healthcare Environment: Becoming an Advocate for Your Loved One

March 9, 2023
10:00-11:30 a.m.

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Community Health Educator, CARES® Dementia Specialist

Upcoming Events

- ***Living with Dementia: New Diagnosis***
Thursday, April 13, 2023
10:00 – 11:30 a.m.; Q and A 11:30 a.m. – noon
- ***Hike for Hope***
Saturday, May 6, 2023
Del Valle Regional Park
Livermore



Register for all events at www.HopeHospice.com



Session Agenda

- Partnering and Communicating with Healthcare Professionals
- Organizing and Managing Personal Health Information
- Handling Hospitalizations: Your Rights
- Discharge Planning and Follow-up Care
- Questions and Answers



Communicating Effectively

- **Advocate (n):** *One who speaks or writes in defense of a person, cause, etc.*
- Communication Styles
 - Passive
 - Aggressive
 - Passive-Aggressive
 - Assertive
- *Being assertive enables us to take care of ourselves and is fundamental for good mental health and healthy relationships. It is the key to being an effective advocate.*



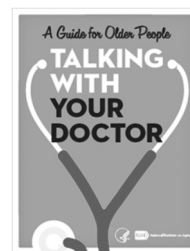
Communicating Effectively

- Communication styles affected by the situation:
 - Confidence
 - Emotions/Stress
 - Temperament
 - Old habits die hard
- Learn to change how you react:
 - Identify triggers
 - Practice



Tips for Talking with Healthcare Professionals

- Partnership
- Respect
- Honesty
- Concise/Specific Info
- Second opinions



Keeping Personal Health Records

- Identification
 - Full name, address, phone*, email*
 - Emergency contact (family caregiver)
- Health Insurance
- Healthcare Contacts/Providers
(Physicians, therapists, pharmacy, etc.)
- Legal Documents
(Advance directives, powers of attorney, etc.)
- Medications (updated)
 - Reason for Rx; dosage
 - Date prescribed; date d/c
 - OTC, supplements, herbals, cannabis
 - Allergies; drug sensitivities
- Hospitalizations/Treatments/
Surgeries
 - Date; facility
 - Physician



Organization: Web-based Systems



www.GooPatient.com



www.CaringVillage.com



www.CareZone.com




www.dropbox.com



www.NextStepinCare.org





Medication Management Form

Patient name: _____ Date of birth: _____
 Local pharmacy name: _____ Pharmacy phone number: _____
 Local pharmacy address: _____
 Mail order company name: _____ Company phone number: _____


| Name of Medication <small>Brand or Generic</small> | Dosage <small>(mg, units, puffs, drops)</small> | When to take it? <small>Times per day? AM or PM? With meals?</small> | Why take it? | Start Date | Stop Date | Monitoring Required <small>(e.g. lab test every _____ weeks)</small> | Prescribed By | Side Effects / Danger Signs |
|-------------------------------------------------------|----------------------------------------------------|---------------------------------------------------------------------------------|--------------|------------|-----------|-------------------------------------------------------------------------|---------------|-----------------------------|
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EXAMPLE

Over-the-Counter Medications (check all that your family member uses regularly)

| | | | |
|------------------------------------------------------------------------------|-----------------------------------------------------|---------------------------------------------|----------------------------------------------------|
| <input type="checkbox"/> Allergy relief, antihistamines | <input type="checkbox"/> Cold / cough medicines | <input type="checkbox"/> Laxatives | <input type="checkbox"/> Other (list below): _____ |
| <input type="checkbox"/> Antacids | <input type="checkbox"/> Diet pills | <input type="checkbox"/> Sleeping pills | _____ |
| <input type="checkbox"/> Aspirin / other relief for pain, headache, or fever | <input type="checkbox"/> Herbs, dietary supplements | <input type="checkbox"/> Vitamins, minerals | _____ |

www.nextstepincare.org ©2008 United Hospital Fund Date this form was updated: _____ 1




Electronic Health Records

(Patient Portals)

Owned and managed by medical practitioners or healthcare facilities and systems:

- Digital version of paper charts
- Diagnoses, meds, immunizations, family histories, contact info, etc.
- Protected (firewalls, anti-virus software), **BUT** . . .
- Once it's downloaded by consumer, it is now **CONSUMER'S** responsibility to protect info



Handling Hospitalizations

“Hospitals are not the most *hospitable* places for elders.”
(Nancy Kriseman, *The Mindful Caregiver*, 2015)

- Advance preparation
 - Cards: ID, Insurance, Medicare, Medi-Cal
 - Advance Health Care Directive/Power of Attorney
 - Medical history
 - Don't assume the hospital/clinic has this info in data base
- Know your rights and responsibilities
 - Family Caregiver
 - HIPAA
 - Medicare
- Where to go for help



The California Hospital and Family Caregiver Law

- Originally called C.A.R.E. Act (Caregiver Access, Record, and Enable)
- Hospitals are required to:
 - provide patients the opportunity to designate a family caregiver when admitted;
 - keep that caregiver informed of discharge plans;
 - provide education and instruction about necessary aftercare tasks that the family caregiver will perform at home: medication management, injections, wound care, transfers, etc.

CA Hospital and Family Caregiver Act - Wallet Cards

| | | |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <p>KEEP THIS CARD IN YOUR WALLET</p> <p>WHEN YOUR LOVED ONE ENTERS THE HOSPITAL</p> <p>Flip this card for information about The California Hospital and Family Caregiver Act</p> <p>I♥Caregivers™</p> | <p>FOLD</p> | <p>The California Hospital and Family Caregiver Law requires hospitals to:</p> <ul style="list-style-type: none"> ♥ Provide your loved one the opportunity to designate a family caregiver when admitted. ♥ Keep that caregiver informed of their loved one's discharge plans. ♥ Provide education and instruction, when appropriate, of aftercare tasks that the family caregiver will perform at home. <p>For more information, talk to the Primary Nurse in charge of your discharge.</p> |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|



HIPAA

- **Health Insurance Portability & Accountability Act**
 - Federal law that protects medical information from unauthorized use
 - Requires the protection and confidential handling of protected health information
- **Privacy Rule:** Right to inspect, review, and receive a copy of medical and billing records that are held by health plans & providers
- It does **NOT** prevent healthcare providers from sharing info with family caregivers as long as . . .
 - Patient does not object
 - Family member is involved in the patient's care or is responsible for healthcare bills



Emergency Room Strategies

- Medical Transport = no waiting room (usually)
- Share all important information re condition
- Come prepared with soothing music, other distractions
- Try not to let YOUR frustrations get in the way – stay calm, at least when you're around your loved one
- Understand that YOUR emergency needs are not the same as the staff needs



Advocating Tips

- Establish one family member as point of contact
- Get primary care physician involved
- Meet the hospitalist: MD who cares for patients in hospital
- Squeaky wheel – get to know the staff
- Ask questions and view records at any time – your right
- Be sure staff is aware of any dementia diagnosis or other special circumstances
- Be aware of where you can go for help:
 - Medical Social Worker
 - Hospital Patient Relations Liaisons/Patient Advocates



Inpatient vs. Observation (Outpatient)

- Inpatient
 - Formally admitted with doctor's order
 - Covered by Medicare Part A
- Observation
 - Outpatient status – “watched”
 - Doesn't meet criteria for inpatient status
 - Will receive care, then discharged when “safe”
 - Usually up to 48 hours
 - Services may be given in ER or another part of hospital
 - Covered by Medicare Part B



Issues with Observation

- Higher out-of-pocket costs
- If patient needs to be discharged to a skilled nursing facility, Medicare will only pay if:
 - Patient had inpatient status (not observation)
 - Patient had a three-night hospital stay
 - Must need “medically necessary” treatment
 - Exceptions: Kaiser Senior Advantage and Medi-Cal (Medicaid in other states)
- Ask (repeatedly) for hospital staff to confirm status
- Explore possibility of changing status



Observation and Drug Coverage

- Medicare Part B only covers certain meds:
 - Intravenous (IV)
 - Only if prescribed during hospital stay
- Won't pay for "self-administered" meds (Prescription and OTC meds not related to hospitalization)
- Part D (Medicare Prescription Drug Plan) may cover
- Some Medicare Advantage Plans have different coverage – be sure to check
- Can you bring your own meds, including OTCs?



Medicare Outpatient Observation Notice

- Hospitals must provide written and oral notice within 36 hours of hospital stay to all patients who are admitted under observation
- Specifies how observation status affects hospital coverage and payment of care after discharge
- If you don't recall getting this notification, be sure to ask



Medicare Outpatient Observation Notice

Hospital logo/info here

(Hospitals may include contact information or logo here)

Medicare Outpatient Observation Notice

Patient name: _____ **Patient number:** _____
 You're a hospital outpatient receiving observation services. You are not an inpatient because:

Reason for observation/outpatient status

Being an outpatient may affect what you pay in a hospital:

- When you're a hospital outpatient, your observation stay is covered under Medicare Part B.
- For Part B services, you generally pay:
 - A copayment for each outpatient hospital service you get. Part B copayments may vary by type of service.
 - 20% of the Medicare-approved amount for most doctor services, after the Part B deductible.

Observation services may affect coverage and payment of your care after you leave the hospital:

- If you need skilled nursing facility (SNF) care after you leave the hospital, Medicare Part A will only cover SNF care if you've had a 3-day minimum, medically necessary, inpatient hospital stay for a related illness or injury. An inpatient hospital stay begins the day the hospital admits you as an inpatient based on a doctor's order and doesn't include the day you're discharged.
- If you have Medicaid, a Medicare Advantage plan or other health plan, Medicaid or the plan may have different rules for SNF coverage after you leave the hospital. Check with Medicaid or your plan.

NOTE: Medicare Part A generally doesn't cover outpatient hospital services, like an observation stay. However, Part A will generally cover medically necessary inpatient services if the hospital admits you as an inpatient based on a doctor's order. In most cases, you'll pay a one-time deductible for all of your inpatient hospital services for the first 60 days you're in a hospital.

If you have any questions about your observation services, ask the hospital staff member giving you this notice or the doctor providing your hospital care. You can also ask to speak with someone from the hospital's utilization or discharge planning department.
 You can also call 1-800-MEDICARE (1-800-633-4227). TTY users should call 1-877-486-2048.

Form CMS 10811-MCOON

Expiration 11/30/2025. CMS approval 0938-1308

Your costs for medications:
 Generally, prescription and over-the-counter drugs, including "self-administered drugs," you get in a hospital outpatient setting (like an emergency department) aren't covered by Part B. "Self-administered drugs" are drugs you'd normally take on your own. For safety reasons, many hospitals don't allow you to take medications brought from home. If you have a Medicare prescription drug plan (Part D), your plan may help you pay for these drugs. You'll likely need to pay out-of-pocket for these drugs and submit a claim to your drug plan for a refund. Contact your drug plan for more information.

If you're enrolled in a Medicare Advantage plan (like an HMO or PPO) or other Medicare health plan (Part C), your costs and coverage may be different. Check with your plan to find out about coverage for outpatient observation services.

If you're a Qualified Medicare Beneficiary through your state Medicaid program, you can't be billed for Part A or Part B deductibles, coinsurance, and copayments.

Additional information (Optional):

Signature to indicate receipt of this notice

Please sign below to show you received/understand this notice.

Signature of Patient or Representative

Date / Time

You have the right to get Medicare information in an accessible format, like large print, Braille, or audio. You also have the right to file a complaint if you feel you've been discriminated against. Visit Medicare.gov/about-us/accessibility-non-discrimination-notice, or call 1-800-MEDICARE (1-800-633-4227) for more information. TTY users can call 1-877-486-2048.

According to the Paperwork Reduction Act of 1995, we cannot require you to respond to a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0938-1308. The time required to complete this information collection is estimated to average 17 minutes per response, including the time to review instructions, search existing data sources, gather the data needed, and review the information collected. This form is required to complete the process of the non-discrimination or appeal for a hospital stay. See also: CMS, 10811-MCOON, Notice: Web Request: Accessible Notice. Visit <http://www.cms.gov> for more information.

Form CMS 10811-MCOON

Expiration 11/30/2025. CMS approval 0938-1308

Medicare Rights

During admission process and again prior to discharge, hospital must provide **An Important Message from Medicare About Your Rights:**

- Receive all necessary hospital care as covered by Medicare or Medicare health plan
- Informed of decisions made by hospital, physician, and Medicare health plan re hospital stay and *who will pay*
- Right to appeal discharge; process for appeal
- Hospital, physician, or Medicare health plan should arrange for services needed after leaving hospital – *who will pay and where to get them*



Important Message from Medicare

Hospital logo/info here

Important Message from Medicare

Patient name: _____ Patient number: _____

Your Rights as a Hospital Inpatient:

- You can receive Medicare covered services. This includes medically necessary hospital services and services you may need after you are discharged, if ordered by your doctor. You have a right to know about these services, who will pay for them, and where you can get them.
- You can be involved in any decisions about your hospital stay.
- You can report any concerns you have about the quality of care you receive to your QIO at: (insert QIO name and toll-free number of QIO). The QIO is the independent reviewer authorized by Medicare to review the decision to discharge you.
- You can work with the hospital to prepare for your safe discharge and arrange for services you may need after you leave the hospital. When you no longer need inpatient hospital care, your doctor or the hospital staff will inform you of your planned discharge date.
- You can speak with your doctor or other hospital staff if you have concerns about being discharged.

Your Right to Appeal Your Hospital Discharge:

- You have the right to an immediate, independent medical review (appeal) of the decision to discharge you from the hospital. If you do this, you will not have to pay for the services you receive during the appeal (except for charges like copays and deductibles).
- If you choose to appeal, the independent reviewer will ask for your opinion. The reviewer also will look at your medical records and/or other relevant information. You do not have to prepare anything in writing, but you have the right to do so, if you wish.
- If you choose to appeal, you and the reviewer will each receive a copy of a detailed explanation about why your covered hospital stay should not continue. You will receive this detailed notice only after you request an appeal.
- If the QIO finds that you are not ready to be discharged from the hospital, Medicare will continue to cover your hospital services.
- If the QIO agrees services should no longer be covered after the discharge date, neither Medicare nor your Medicare health plan will pay for your hospital stay after noon of the day after the QIO notifies you of its decision. If you stop services no later than that time, you will avoid financial liability.
- If you do not appeal, you may have to pay for any services you receive after your discharge date.

See page 2 of this notice for more information.

How to Ask For an Appeal of your Hospital Discharge

- You must make your request to the QIO listed above.
- Your request for an appeal should be made as soon as possible, but no later than your planned discharge date and before you leave the hospital.
- The QIO will notify you of its decision as soon as possible, generally no later than 1 day after it receives all necessary information.
- Call the QIO listed on Page 1 to appeal, or if you have questions.

If You Miss The Deadline to Request An Appeal, You May Have Other Appeal Rights:

- If you have Original Medicare: Call the QIO listed on Page 1.
- If you belong to a Medicare health plan: Call your plan at (insert plan name and toll-free number of plan)

Additional Information (Optional):

Livanta Helpline (877) 588-1123

Please sign below to indicate you received and understood this notice.

I have been notified of my rights as a hospital inpatient and that I may appeal my discharge by calling _____

Signature to indicate receipt of this notice

Signature of Patient or Representative _____ Date / Time _____

You have the right to get Medicare information in an accessible format, like large print, Braille, or audio. You also have the right to file a complaint if you feel you've been discriminated against. Visit Medicare.gov/about-us/accessibility-notice for more information, or call 1-800-MEDICARE (1-800-633-6227) for more information. TTY users can call 1-877-486-2048.

According to the Payment Reduction Act of 1995, no person is required to furnish a collection of information unless it displays a valid OMB control number. The valid OMB control number for this information collection is 0938-0105. This form requests complete the information collection, as indicated by marking "I" in the appropriate column. If you have any questions about this notice or information, please contact your Medicare plan, your state health care assistance, or the Medicare helpline at 1-800-MEDICARE. If you have any questions concerning the accuracy of the information or questions for improving this form, please write to: CMS, 7500 Security Boulevard, Room 5A14, Baltimore, Maryland 21244. Mail Stop 9724, Baltimore, Maryland 21285-9724.

Form CMS 10065-IM (Exp. 12/31/2025)

OMB approval 0938-1019

Discharge Process

"A process used to decide what a patient needs for a smooth move from one level of care to another." - Medicare

- Discharge planner, aka Medical Social Worker or Nurse Case Manager
- Evaluation of the patient by qualified personnel
- Plan for going home or transfer to care facility
- Discussion with the patient or his/her representative (care partner)
- At least 24-hour notice



Discharge Order

- Challenges
 - Availability of care providers, facilities
 - Type or lack of insurance coverage; narrow networks
- Where will the patient receive post-acute care?
 - Home (patient's or family's)
 - Support from Home Health agency – Medicare pays
 - Caregiver willing and able?
 - Home safe? Modifications needed?
 - Acute Rehab Hospital
 - Short stay; intensive therapies
 - Covered by insurance, Medicare
 - Skilled Nursing Facility (SNF)



Discharge Order

- Medications: new, changes, discontinued (d/c)
(ask about financial assistance, coupons, samples)
- Determine whether caregiver training or other support is needed:
 - In hospital: verbal, written, video, demonstration
 - Home health or personal care agencies
 - Special equipment and devices (bed, wheelchair, walker, cryotherapy cuff, commode, oxygen, etc.) *Who pays?*
 - Follow up visits: appointments with physician and/or other MD specialists – be sure they're covered by your insurance (in-network)



Family Caregiver's Discharge Rights

- To know the expected date of discharge
- To have an explanation of staff recommendations for after-discharge care
- To be involved in choosing where your family member will go after discharge
- To be given a list of providers for after-care (home health and personal care agencies; rehab facilities; skilled nursing)
www.Medicare.gov/Care-Compare/
- To be able to appeal a discharge

Source: www.NextStepinCare



Medicare's Discharge Planning Checklist

Your Discharge Planning Checklist:

For patients and their caregivers preparing to leave a hospital, nursing home, or other care setting



Name: _____
Reason for admission: _____

During your stay, your doctor and the staff will work with you to plan for your discharge. You and your caregiver (a family member or friend who may be helping you) are important members of the planning team. You and your caregiver can use this checklist to prepare for your discharge.

Instructions:

- Use this checklist early and often during your stay.
- Talk to your doctor and the staff (like a discharge planner, social worker, or nurse) about the items on this checklist.
- Check the box next to each item when you and your caregiver complete it.
- Use the notes column to write down important information (like names and phone numbers).
- Skip any items that don't apply to you.

| Action Items | Notes |
|------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------|
| Care after discharge | |
| <input type="checkbox"/> Ask where you'll get care after you're discharged. Do you have options (like home health care)? Tell the staff what you prefer. | |
| <input type="checkbox"/> If a caregiver will be helping you after discharge, write down their name and phone number. | |
| Your health | |
| <input type="checkbox"/> Ask the staff about your health condition and what you can do to get better. | |
| <input type="checkbox"/> Ask about problems to watch for and what to do about them. Write down a name and phone number of a person to call if you have problems. | |



Appealing a Discharge

- First, always discuss concerns with physician and discharge planner
- Remember the *Important Message from Medicare . . .*
 - Explains appeals process
 - Provides phone number of Livanta (in CA) – Quality Improvement Organization
 - Immediate appeal of the notice (fast appeal) allows for stay in hospital without financial risk until appeal determined
 - Must follow time-line for immediate appeal
- “Unsafe discharge”



Notice of Medicare Non-Coverage

Informs patient in writing:

- What services Medicare/Medicare Advantage plan probably will not pay for after a designated date
 - Home Health
 - Outpatient rehab
 - Skilled Nursing
- Right to appeal the decision
- How to ask for immediate appeal; timeline
- If denied, neither Medicare or Medicare Advantage plan will pay for services



Notice of Medicare Non-Coverage

Hospital logo/info here
(insert provider contact information here)
Notice of Medicare Non-Coverage

Patient name: _____ **Patient number:** _____

The Effective Date Coverage of Your Current (insert type) Services Will End: (insert effective date) _____

- Your Medicare provider and/or health plan have determined that Medicare probably will not pay for your current (insert type) services after the effective date indicated above.
- You may have to pay for any services you receive after the above date.

Your Right to Appeal This Decision

- You have the right to an immediate, independent medical review (appeal) of the decision to end Medicare coverage of these services. Your services will continue during the appeal.
- If you choose to appeal, the independent reviewer will ask for your opinion. The reviewer also will look at your medical records and/or other relevant information. You do not have to prepare anything in writing, but you have the right to do so if you wish.
- If you choose to appeal, you and the independent reviewer will each receive a copy of the detailed explanation about why your coverage for services should not continue. You will receive this detailed notice only after you request an appeal.
- If you choose to appeal, and the independent reviewer agrees services should no longer be covered after the effective date indicated above:
 - Neither Medicare nor your plan will pay for these services after that date.
- If you stop services no later than the effective date indicated above, you will avoid financial liability.

How to Ask For an Immediate Appeal

- You must make your request to your Quality Improvement Organization (also known as a QIO). A QIO is the independent reviewer authorized by Medicare to review the decision to end these services.
- Your request for an immediate appeal should be made as soon as possible, but no later than noon of the day before the effective date indicated above.
- The QIO will notify you of its decision as soon as possible, generally no later than two days after the effective date of this notice if you are in Original Medicare. If you are in a Medicare health plan, the QIO generally will notify you of its decision by the effective date of this notice.
- Call your QIO at: (insert QIO name and toll-free number of QIO) to appeal, or if you have questions.

See page 2 of this notice for more information.

Form CMS 10122-AD-NC (Approved 10/01/2011) QIO approval 08/08/08/3

If You Miss The Deadline to Request An Immediate Appeal, You May Have Other Appeal Rights:

- If you have Original Medicare: Call the QIO listed on page 1.
- If you belong to a Medicare health plan: Call your plan at the number given below.

Plan contact information _____

Additional Information (Optional):

Livanta Helpline (877) 588-1123
QIO - Quality Improvement Organization

Please sign below to indicate you received and understood this notice.

I have been notified that coverage of my services will end on the effective date indicated on this notice and that I may appeal this decision by contacting my QIO.


Signature of Patient or Representative _____ Date _____

Form CMS 10122-AD-NC (Approved 10/01/2011) QIO approval 08/08/08/3

The Jimmo Settlement Agreement

(2013-14)

- ~~No progress = no coverage.~~
- If patient needs skilled home health care, or outpatient therapy services in order to maintain current condition or prevent decline or deterioration
- . . . **coverage cannot be denied based on the absence of potential for improvement or restoration.**



Advocacy Organizations

- **Beneficiary & Family Centered Care Quality Improvement Organization (BFCC-QIO)**
In California:
Livanta (877) 588-1123
www.livantaqio.com/en/states/california
- **CA Advocates for Nursing Home Reform**
www.CANHR.org
- **Center for Medicare Advocacy**
www.MedicareAdvocacy.org
- **Medicare Rights Center**
www.MedicareRights.org
- **Long Term Care Ombudsman (LTC facilities)**
www.ltcombudsman.org
- **Hospital Patient Relations Department,**
Hospital Privacy Officer, or
Medical Social Worker



Filing a Complaint

- **Community Care Licensing**
(CA Dept of Social Services)
Online Complaint Form:
<https://complaints.cclld.dss.ca.gov/>
1-844-538-8766
- **Medicare/CMS Reporting**
(US Dept. HHS – Office of Inspector General)
<https://tips.oig.hhs.gov/>
1-800-447-8477
- **CA Advocates for Nursing Home Reform (CANHR)**
Online Complaint Form:
<http://canhr.org/bnbform.html>
1-800-474-1116



Remember . . .

- You are an important member of the care team
- Be prepared, organized, and assertive
- Be an informed consumer of healthcare services
- Be aware of your rights
- Advocate



Questions and Answers



Don't forget to complete the online evaluation upon leaving the webinar – or when you get the link in tomorrow's follow-up email.

THANK YOU!

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www.HopeHospice.com/donate

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