Caring House

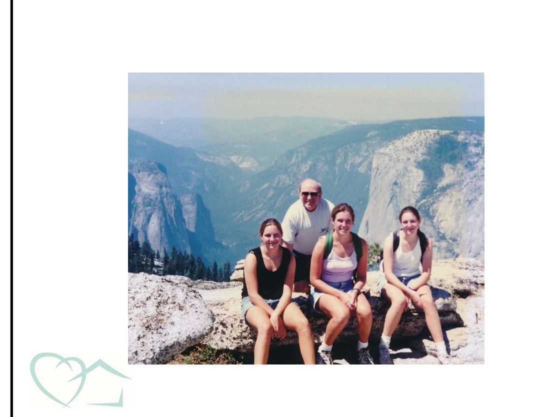
The Keys to
Care Planning
Success

January 28, 2020

Providing peace, comfort and support to men and women at the ends of their lives

Discussion Leaders

- Ed Long, JD
- Ellen Gorbunoff, RN



Housekeeping

- Handouts
  - Slides and handouts available at peaceattheend.org on the Care Planning page
- Time
- Questions

Care Planning – What's It For?

Care planning is the way you can

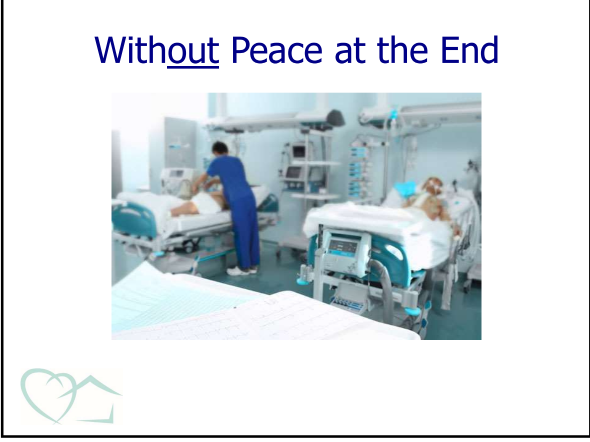
- ✓ Obtain the health and medical care you want and
- ✓ Avoid the care you don't want,
- ✓ Even if you can't speak for yourself.

Why do care planning? – Let's drill down

Peace at the End

SUPPORT
Peace at the End
peaceattheend.org

Without Peace at the End



Without Peace at the End

- Last days in a hospital or skilled nursing facility.
  - An ER, ICU, rehab unit, etc.
- Surrounded by machines, likely to be prodded and awakened at all hours.
- Not peaceful or dignified.

Where We Die

- 68% of Californians don't die at home*, they die at
  - A hospital, SNF or assisted living (large or small) facility

* Source: MacPherson and Parikh, 2017

With Peace at the End

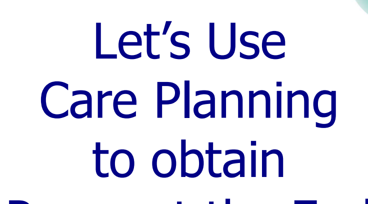
- Each of us has time and makes space near the end of life for peace, comfort, support and dignity.
- Pain, anxiety and other symptoms are appropriately and professionally handled.

With Peace at the End

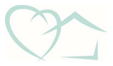
We have time and space,
- To be with those we love.
- To achieve, resolve and prepare.
- For meaningful conversations, fulfilling wishes and sharing stories and laughter.
- For quiet reflections.
- To reconcile, connect and support each other.

Your Experiences

- Have you seen the end-of-life go well?
- Have you seen the end-of-life go badly?



Let's Use Care Planning to obtain Peace at the End



Care Planning – Who Needs It?

Care planning is for all adults – not just those who are older than I am.

Core Legal Concepts

1. You have a **right to decide** whether to
   -- start,
   -- decline or
   -- stop
   available medical treatment ("care decisions").
2. You have a **right to name** another person to make care decisions for you.

Sometimes It's Hard . . .

- "I'm not a planner"
- "I'll probably need a lawyer . . . "
- "I don't want to think about illness or dying or leaving loved ones behind"
- "I don't want to talk about those things"
- "If I raise this with family I could open up issues that are uncomfortable"

What can happen without Care Planning?

People-work
before
Paperwork

It Ain't Automatic

Under CA law, who has priority to make care decisions for a married 50 year old woman who is incapacitated?

a. Spouse
b. Oldest child
c. Parents
d. None of the above

It Ain't Automatic (cont'd)

Under CA law, who has priority to make care decisions for an unmarried 25 year old man who is incapacitated?

a. Parents
b. Oldest sibling
c. Best friend
d. None of the above

It Ain't Automatic (cont'd)

Under CA law, who has priority to make care decisions for an unmarried 25 year old man who is incapacitated?

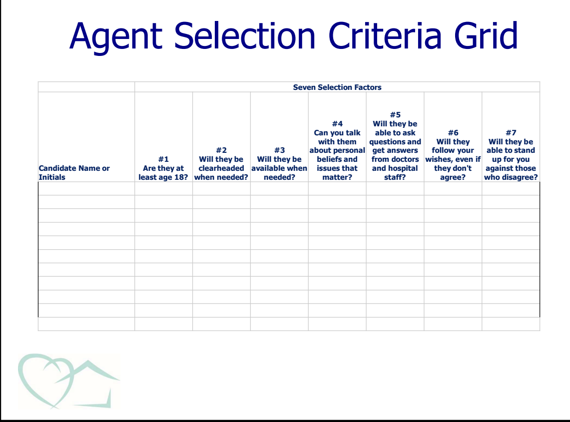
a. Domestic partner
b. Parents
c. Oldest sibling
d. Best friend
e. None of the above

Legal Lingo

- **Principal** = The person signing the advance directive naming others to make decisions for them.
- **Agent** = A person named to make decisions under an advance directive.

Mr. Wrong

Agent Selection Criteria Grid



	Seven Selection Factors						
Candidate Name or Initials	#1 Are they at least age 18?	#2 Will they be clearheaded when needed?	#3 Will they be available when needed?	#4 Can you talk with them about personal beliefs and issues that matter?	#5 Will they be able to ask questions and get answers from doctors and hospital staff?	#6 Will they follow your wishes, even if they don't agree?	#7 Will they be able to stand up for you against those who disagree?

Criterion #1

Are they at least age 18?

Criterion #2

Will they be clearheaded when needed?

Criterion #3

Will they be available when needed?

Criterion #4

Can you talk with them about personal beliefs and issues that matter?

Criterion #5

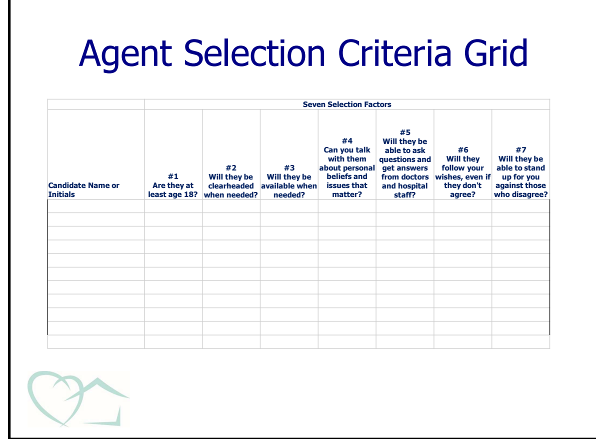
Will they be able to ask questions and get answers from doctors and hospital staff?

Criterion #6

Will they follow your wishes, even if they don't agree?

Criterion #7

Will they be able to stand up for you against those who disagree?



Agent Selection Criteria Grid

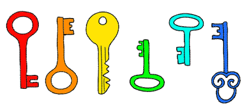
Candidate Name or Initials	Seven Selection Factors						
	#1 Are they at least age 18?	#2 Will they be clearheaded when needed?	#3 Will they be available when needed?	#4 Can you talk with them about personal beliefs and issues that matter?	#5 Will they be able to ask questions and get answers from doctors and hospital staff?	#6 Will they follow your wishes, even if they don't agree?	#7 Will they be able to stand up for you against those who disagree?

Please Don't Name Co-Agents

- Co-Agents: giving two or more Agents equal power to decide.
- Means all have to agree or the decision won't be made.
- Better = name in sequence

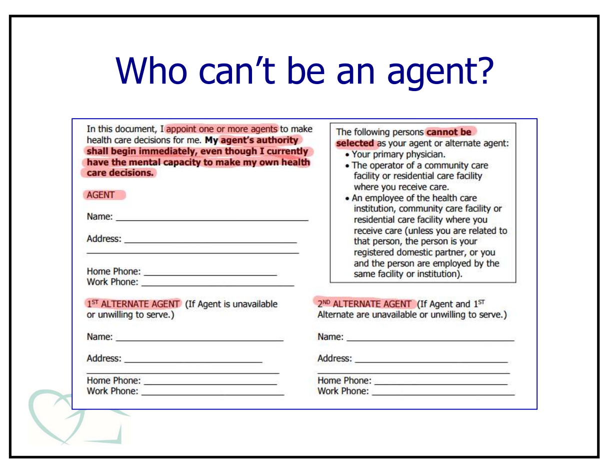
Key #2

Document Properly



Make it Official

Make your selection official by naming your Agent(s) in your Power of Attorney for Health Care (sample in your handouts)



Who can't be an agent?

In this document, I appoint one or more agents to make health care decisions for me. **My agent's authority shall begin immediately, even though I currently have the mental capacity to make my own health care decisions.**

AGENT

Name: ______

Address: ______

______

Home Phone: ______
Work Phone: ______

The following persons **cannot be selected** as your agent or alternate agent:

- Your primary physician.
- The operator of a community care facility or residential care facility where you receive care.
- An employee of the health care institution, community care facility or residential care facility where you receive care (unless you are related to that person, the person is your registered domestic partner, or you and the person are employed by the same facility or institution).

1ST ALTERNATE AGENT (If Agent is unavailable or unwilling to serve.)

Name: ______

Address: ______

______

Home Phone: ______
Work Phone: ______

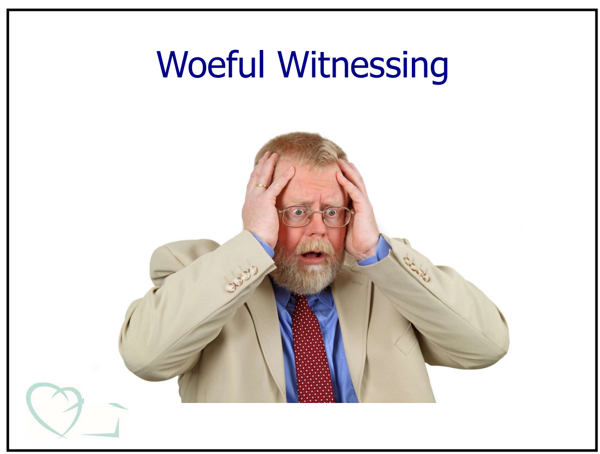
2ND ALTERNATE AGENT (If Agent and 1ST Alternate are unavailable or unwilling to serve.)

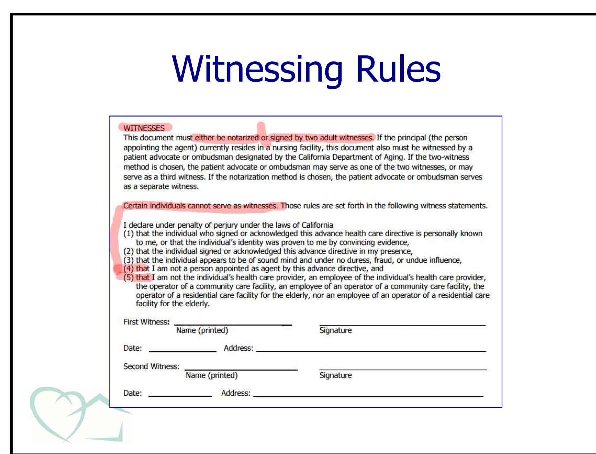
Name: ______

Address: ______

______

Home Phone: ______
Work Phone: ______





WITNESSES
This document must either be notarized or signed by two adult witnesses. If the principal (the person appointing the agent) currently resides in a nursing facility, this document also must be witnessed by a patient advocate or ombudsman designated by the California Department of Aging. If the two-witness method is chosen, the patient advocate or ombudsman may serve as one of the two witnesses, or may serve as a third witness. If the notarization method is chosen, the patient advocate or ombudsman serves as a separate witness.

Certain individuals cannot serve as witnesses. Those rules are set forth in the following witness statements.

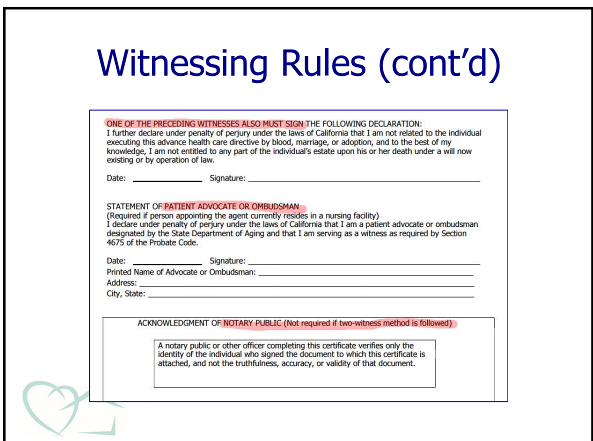
I declare under penalty of perjury under the laws of California
(1) that the individual who signed or acknowledged this advance health care directive is personally known to me, or that the individual's identity was proven to me by convincing evidence,
(2) that the individual signed or acknowledged this advance directive in my presence,
(3) that the individual appears to be of sound mind and under no duress, fraud, or undue influence,
(4) that I am not a person appointed as agent by this advance directive, and
(5) that I am not the individual's health care provider, an employee of the individual's health care provider, the operator of a community care facility, an employee of an operator of a community care facility, the operator of a residential care facility for the elderly, nor an employee of an operator of a residential care facility for the elderly.

First Witness: ____________ Name (printed) ____________ Signature

Date: ________ Address: ____________

Second Witness: ____________ Name (printed) ____________ Signature

Date: ________ Address: ____________



ONE OF THE PRECEDING WITNESSES ALSO MUST SIGN THE FOLLOWING DECLARATION:
I further declare under penalty of perjury under the laws of California that I am not related to the individual executing this advance health care directive by blood, marriage, or adoption, and to the best of my knowledge, I am not entitled to any part of the individual's estate upon his or her death under a will now existing or by operation of law.

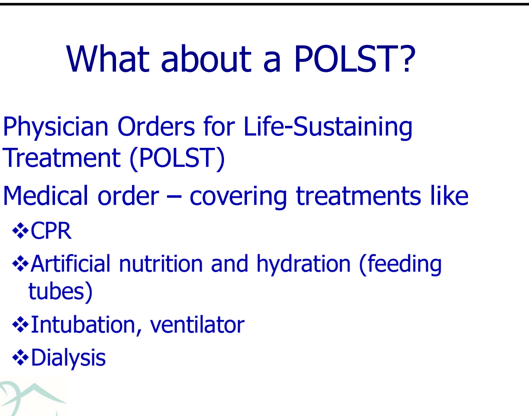
Date: ________ Signature: ____________

STATEMENT OF PATIENT ADVOCATE OR OMBUDSMAN
(Required if person appointing the agent currently resides in a nursing facility)
I declare under penalty of perjury under the laws of California that I am a patient advocate or ombudsman designated by the State Department of Aging and that I am serving as a witness as required by Section 4675 of the Probate Code.

Date: ________ Signature: ____________
Printed Name of Advocate or Ombudsman: ____________
Address: ____________
City, State: ____________

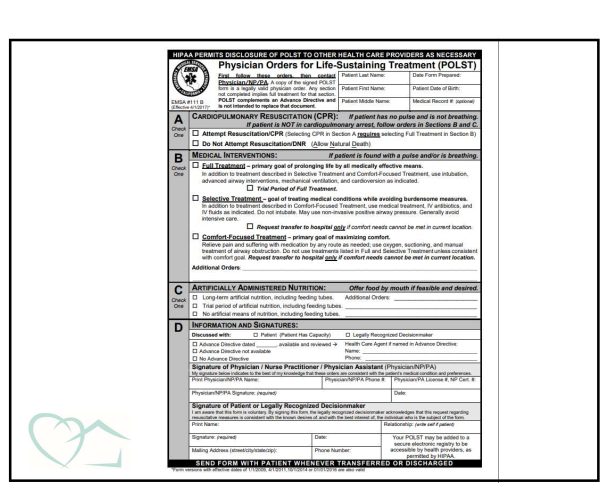
ACKNOWLEDGMENT OF NOTARY PUBLIC (Not required if two-witness method is followed)

A notary public or other officer completing this certificate verifies only the identity of the individual who signed the document to which this certificate is attached, and not the truthfulness, accuracy, or validity of that document.



What about a POLST? (cont'd)

- Signed by patient (or surrogate) and MD
- When should it be done?
  - Person is seriously ill or frail and MD wouldn't be surprised if person died within a year
- NNNY (not now, not you)



HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

Physician Orders for Life-Sustaining Treatment (POLST)

EMSA #111 B (Effective 4/1/2017)*

First follow these orders, then contact Physician/NP/PA. A copy of the signed POLST form is a legally valid physician order. Any section not completed implies full treatment for that section. **POLST complements an Advance Directive and is not intended to replace that document.**

Patient Last Name:	Date Form Prepared:
Patient First Name:	Patient Date of Birth:
Patient Middle Name:	Medical Record #: *(optional)*

A (Check One) **CARDIOPULMONARY RESUSCITATION (CPR):** *If patient has no pulse and is not breathing. If patient is NOT in cardiopulmonary arrest, follow orders in Sections B and C.*
☐ **Attempt Resuscitation/CPR** (Selecting CPR in Section A requires selecting Full Treatment in Section B)
☐ **Do Not Attempt Resuscitation/DNR** (Allow Natural Death)

B (Check One) **MEDICAL INTERVENTIONS:** *If patient is found with a pulse and/or is breathing.*
☐ **Full Treatment – primary goal of prolonging life by all medically effective means.**
In addition to treatment described in Selective Treatment and Comfort-Focused Treatment, use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.
☐ ***Trial Period of Full Treatment.***
☐ **Selective Treatment – goal of treating medical conditions while avoiding burdensome measures.**
In addition to treatment described in Comfort-Focused Treatment, use medical treatment, IV antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.
☐ ***Request transfer to hospital only*** *if comfort needs cannot be met in current location.*
☐ **Comfort-Focused Treatment – primary goal of maximizing comfort.**
Relieve pain and suffering with medication by any route as needed; use oxygen, suctioning, and manual treatment of airway obstruction. Do not use treatments listed in Full and Selective Treatment unless consistent with comfort goal. ***Request transfer to hospital only if comfort needs cannot be met in current location.***
Additional Orders: ____________

C (Check One) **ARTIFICIALLY ADMINISTERED NUTRITION:** *Offer food by mouth if feasible and desired.*
☐ Long-term artificial nutrition, including feeding tubes. Additional Orders: ________
☐ Trial period of artificial nutrition, including feeding tubes.
☐ No artificial means of nutrition, including feeding tubes.

D **INFORMATION AND SIGNATURES:**
Discussed with: ☐ Patient (Patient Has Capacity) ☐ Legally Recognized Decisionmaker
☐ Advance Directive dated ______, available and reviewed → Health Care Agent if named in Advance Directive:
☐ Advance Directive not available Name: ________
☐ No Advance Directive Phone: ________

Signature of Physician / Nurse Practitioner / Physician Assistant (Physician/NP/PA)
My signature below indicates to the best of my knowledge that these orders are consistent with the patient's medical condition and preferences.

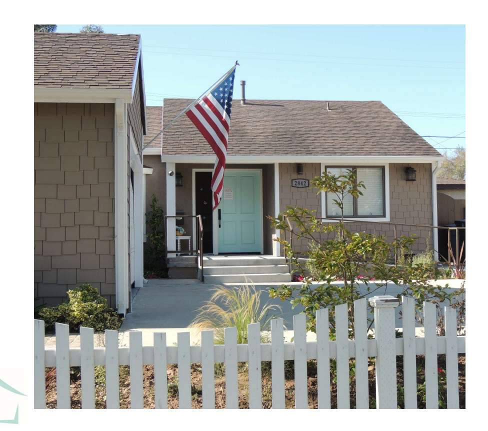
Print Physician/NP/PA Name:	Physician/NP/PA Phone #:	Physician/PA License #, NP Cert. #:
Physician/NP/PA Signature: *(required)*		Date:

Signature of Patient or Legally Recognized Decisionmaker
I am aware that this form is voluntary. By signing this form, the legally recognized decisionmaker acknowledges that this request regarding resuscitative measures is consistent with the known desires of, and with the best interest of, the individual who is the subject of the form.

Print Name:		Relationship: *(write self if patient)*
Signature: *(required)*	Date:	Your POLST may be added to a secure electronic registry to be accessible by health providers, as permitted by HIPAA.
Mailing Address (street/city/state/zip):	Phone Number:	

SEND FORM WITH PATIENT WHENEVER TRANSFERRED OR DISCHARGED

*Form versions with effective dates of 1/1/2009, 4/1/2011, 10/1/2014 or 01/01/2016 are also valid



About Caring House

- Part of the movement to improve the end-of-life experience for men and women and families in America
  - Dr. Atul Gawande – Boston, *Being Mortal and The Checklist Manifesto*
  - Dr. Ira Byock – Torrance, The Providence Institute for Human Caring

About Caring House

- A warm five-bedroom home in a residential neighborhood.
- Licensed by CA Dept of Social Services as an RCFE with full hospice waivers
- An IRC 501(c)(3) nonprofit
- Revenues are from sliding scale payments by residents/families and from donations

Kind words . . .

". . . I can't imagine what it would have been like for us to have been in any other setting, including her own home where we had tried so valiantly to keep her.

I truly wish we had entrusted her to your care sooner.

The incredible love and caring and calm bright feeling at Caring House are just a blessing to anyone caring for a loved one who is suffering. Not to mention how professional and knowledgeable everyone is.

Everyone cared for mom and for us in the most giving of ways! Thank you again for your kindness."

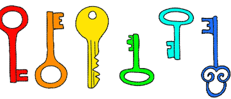
-- Delia Cotter, daughter of Delia Gondar

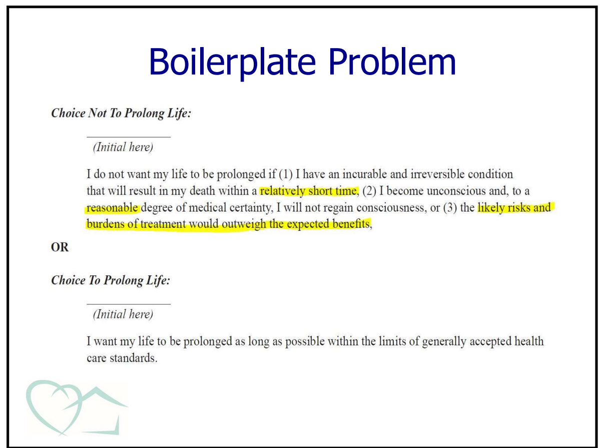
About Caring House (more)

- 2,600+ days of Peace at the End for our residents and families since opening in 2016

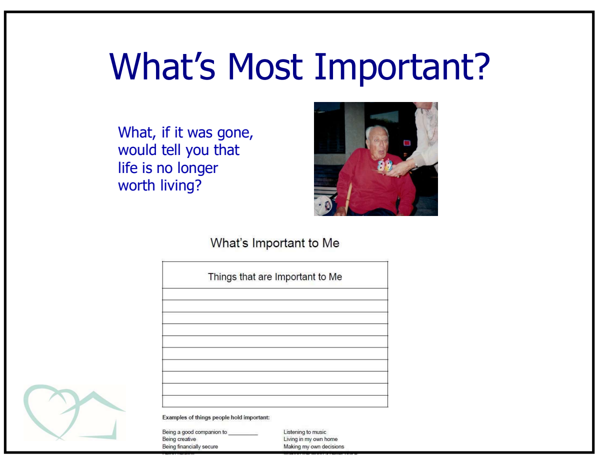
Key #3

Figure Out What Matters to You

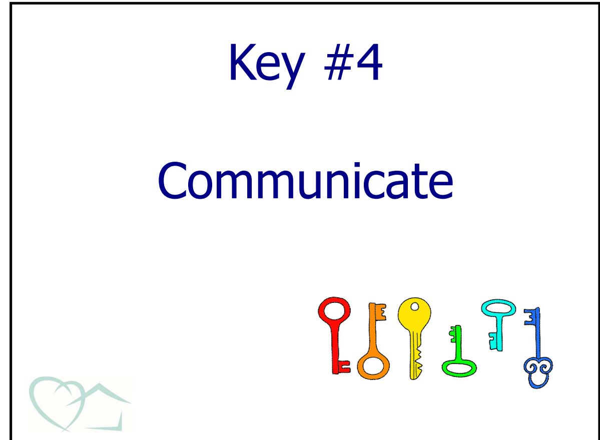




Boilerplate Problem
Choice Not To Prolong Life:
(Initial here)
I do not want my life to be prolonged if (1) I have an incurable and irreversible condition that will result in my death within a relatively short time, (2) I become unconscious and, to a reasonable degree of medical certainty, I will not regain consciousness, or (3) the likely risks and burdens of treatment would outweigh the expected benefits.
OR
Choice To Prolong Life:
(Initial here)
I want my life to be prolonged as long as possible within the limits of generally accepted health care standards.



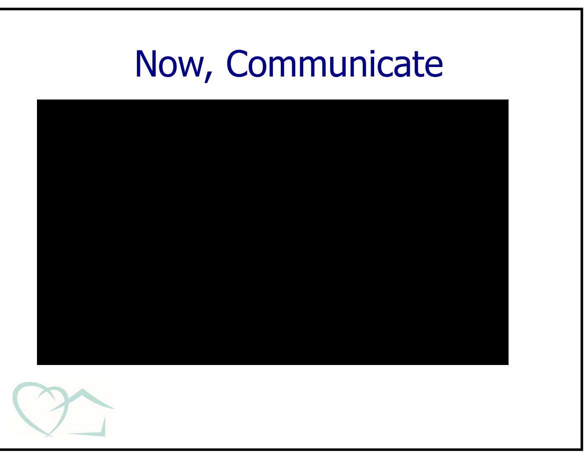
What's Most Important?
What, if it was gone, would tell you that life is no longer worth living?
What's Important to Me
Things that are Important to Me



Key #4
Communicate

"My Lawyer Did It"
WISHES

"My Lawyer Did It"



Now, Communicate

Now, Communicate (cont'd)

- Was this effective communication?
- What would have made it better?

Two monologues
do not equal
a dialogue

Five Things to Talk About

1. Here's what's important to me.
2. Can and will you help me?
3. What are the potential challenges for us?
4. Who else can help?
5. What can we do together to make this work out well?

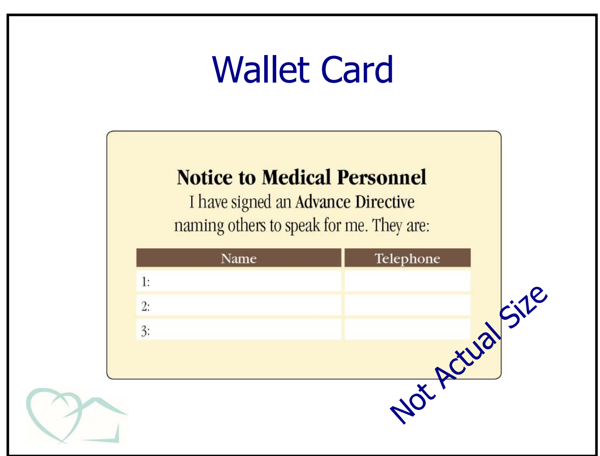
Icebreakers

1. "I need your help with something."
2. "Remember when [John] died? I'm thinking I want the same [or something different]."
3. "I was thinking about what happened to [Mary], and it made me realize . . ."

Reference: theconversationproject.org

Icebreakers - More

4. "Even though I'm okay right now, I'm worried that . . . . , and I want to be prepared."
5. "I need to think about the future. Will you help me?"
6. "I just answered some questions about how I want the end of my life to be. Can we talk about my answers? And what yours might be?"



Starfleet personnel
shall not interfere with
the internal development of
alien civilizations.

Agent's Prime Directive

1. Follow the Principal's wishes
2. If not known, follow the Principal's values and views
3. If not known, use Agent's best judgment and act in the Principal's best interests

Agent's Top Duties

1. Speak for and make care decisions for the Principal
2. Communicate with the Principal to learn wishes, values and views
3. Keep up to date

Agent Tasks

1. Regularly communicate with the Principal and others.
2. Get educated about how to do an awesome job.
3. Be available when needed.

Agent Tasks (cont'd)

4. Let the healthcare team know that you are the Agent.
5. Establish who will be the "MD Quarterback."
6. Ask questions until you have enough information.

Agent Tasks (cont'd)

7. Understand the context.

- Just getting started vs. ODTAA Syndrome
- Progressive illness? What stage?
- Exhaustion?
- Looking for a cure vs. Time for Peace

Agent Tasks (cont'd)

8. Set and revise Goals of Care.

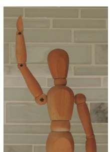
Goals of Care

Agent Tasks (cont'd)

9. Make decisions.

Two Hands Up?

- Question #1 -- Would the treatment be medically helpful?

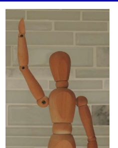


- Question #2 -- Would the Principal say "Yes" to the treatment?

Two Hands Up?

Pursue the treatment if

Don't pursue the treatment if

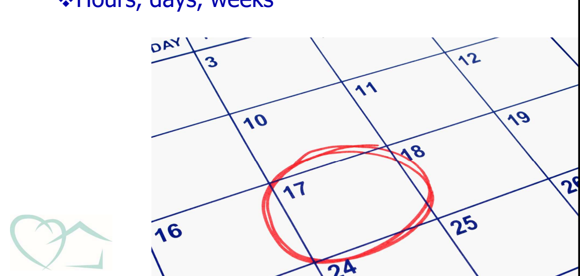


Agent Tasks (cont'd)

10. Set time limits

Time Limits are Crucial

- Set time limits
  - Hours, days, weeks



Agent Tasks (cont'd)

11. Stay on top of Discharge Planning

- Start discharge planning on or before the date of admission.
  - When move to the next level?
  - What services and equipment needed?
  - Where can services be provided?
  - Who will provide the care?

Discharge Planning (cont'd)

Role of Agent:

- ❖ Be proactive
- ❖ Obtain and review Written Discharge Plan
- ❖ Consider appealing the discharge order
  - ❖ Better to stay, or better to go?

Agent Tasks (cont'd)

12. Keep family informed.

13. Self care.

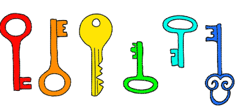
Success as an Agent

Success as an Agent is 75% preparation.

The other 75% is caring.

Key #6

Keep Up to Date



That's Old News

Entire World Rejoices in Downfall of Autocratic Militarism

THE DAILY TELEGRAM

VOL. XXIX, NO. 118 — LONG BEACH, CALIFORNIA, MONDAY AFTERNOON, NOVEMBER 11, 1918 — PRICE 2 CENTS

TEN PAGES

WORLD WAR IS OVER

Beaten Germany Accepts Armistice Terms and Hostilities Cease on All Fronts

MONS TAKEN BY BRITISH AS NEWS REACHES ARMY | ALL CROWNED HEADS OF EMPIRE BUSY ABDICATING

Kaiser, Crown Prince and Hindenburg Seek Refuge in Holland

"IT'S OVER BOYS"

WAS WORD SENT ALONG LINES BY CYCLISTS

WHEN PEACE CAME

LONDON, Nov. 11.—It is officially announced that the armistice with Germany was signed at 5 a.m. today and that hostilities ceased at 11 a.m. Prime Minister Lloyd George announced that the cessation of hostilities was effective at 11 a.m. on all fronts of Europe.

WASHINGTON, Nov. 11.—It was shortly before 3 o'clock this morning when President Wilson, roused from a deep slumber, walked to the door of his bedroom and received from a white house attendant, the official State department message that the great war had come to an end.

GIVE UP "DIVINE RIGHTS"

GERMANY IS BRANDED NOW AS BEATEN NATION

Hun Acknowledges Superiority of Allies —To America Goes Glory of Turning Tide of War

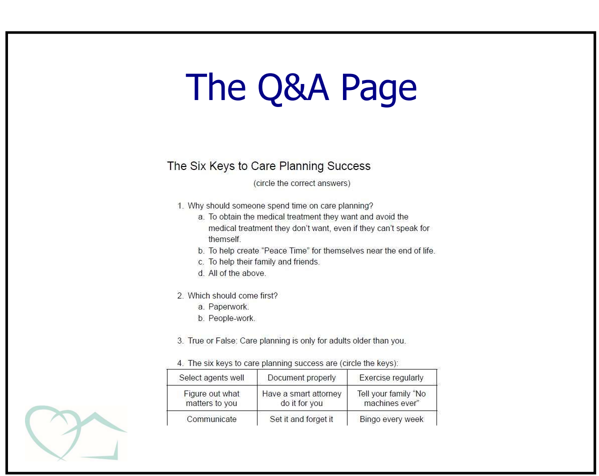
HOLLAND'S PROBLEM

ARMED IMPERIALISM COMPLETELY ENDED BY ACCEPTED ARMISTICE

President Wilson, in Address to Joint Congress, Outlines the Conditions Accepted by Germany Which Puts Into Discard the Illicit Ambitions of Prussian Autocracy and Starts Peace Which Will Satisfy World Desires.

ALL DRAFTING

The Q&A Page



The Six Keys to Care Planning Success

(circle the correct answers)

1. Why should someone spend time on care planning?
   a. To obtain the medical treatment they want and avoid the medical treatment they don't want, even if they can't speak for themself.
   b. To help create "Peace Time" for themselves near the end of life.
   c. To help their family and friends.
   d. All of the above.

2. Which should come first?
   a. Paperwork.
   b. People-work.

3. True or False: Care planning is only for adults older than you.

4. The six keys to care planning success are (circle the keys):

Select agents well	Document properly	Exercise regularly
Figure out what matters to you	Have a smart attorney do it for you	Tell your family "No machines ever"
Communicate	Set it and forget it	Bingo every week

Slides and handouts available at
peaceattheend.org
on the Care Planning page

SUPPORT
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