

## WHAT YOU SHOULD KNOW

### Q: What is Palliative Care?

- Palliative care has also been known as “Comfort Care”.
- Palliative care is medical care that tries to keep patients with serious medical illnesses comfortable.
- Palliative care tries to help patients with their worries, fears and stress as well as any pain or other physical problem they may have.
- Palliative care can be started at any time in the patient’s illness, even when there is still hope for a cure.
- Palliative care can be provided by most, if not all, doctors, physician assistants, nurse practitioners, and nurses.
- Palliative care can be done in many places (including General Population, OHU, CTC or hospital) depending on a patient’s illness and their medical needs at that time.

### Q: What is Hospice?

- Hospice care also tries to keep patients comfortable as they die.
- Hospice care is usually used when a person has six months or less to live.
- Hospice care is given by a team made up of doctors, nurses, social workers, and chaplains who work together to keep the patient comfortable.
- Hospice care tries to help the patient deal with any “unfinished business”. If the patient wants to get in touch with family or wants religious support the hospice team can usually help.
- In CDCR hospice care is offered at CMF for men, and hospice-like comfort care is offered at CCWF for women.
- Most of the time your Primary Care doctor or cancer doctor will ask you if you are interested in the hospice program when the time is right.
- You are welcome to ask your doctor about hospice care at any time if you have questions.

### Q: Do you have to have cancer to be accepted into hospice?

- No, persons with many types of illnesses (such as heart failure, liver disease, COPD, dementia, kidney failure) are allowed into hospice.

### Q: Do you have to be in hospice to be considered for Compassionate Release or Medical Parole?

- No, these programs are different and it does not matter if you are in hospice.

### Q: What is advance care planning?

- Thinking ahead about what kind of medical care you want as you get sicker.
- The kind of medical treatment you want usually depends on what is important to you.
- Talking about your wishes with loved ones and your doctors and nurses will help make sure that your wishes are followed.
- Writing down your wishes in an “Advance Directive” form is another way to be sure they will be followed.
  - It’s important to remember that...
    - Your wishes can be changed any time.
    - Advance care planning is done over time and your wishes may change as your health changes.
    - It is best to think about what you want before you get really sick

### Q: What is an Advance Directive?

- Advance directives are papers that allow you to write your wishes about end of life care.
- They allow you to say what you want so that family, friends, doctors and nurses will know for sure what you want if you can no longer speak for yourself.
- In CDCR we use CDCR Form 7421 Advance Directive for Health Care .
- You may request an CDCR Form 7421 at anytime, even when you are young and perfectly healthy.
- The Form 7421 Advance Directive allows you to:
  - Name someone to speak for you when you can no longer speak for yourself (called a surrogate/agent)
  - Say what your wishes are (e.g. “I don’t want CPR or a breathing machine”, “feeding tube ok”)

## WHAT YOU SHOULD KNOW

### Q: What is a Health Care Surrogate/Agent?

- A health care surrogate (also called an agent) is a person that you pick to make health care choices for you when you cannot speak for yourself.
- The health care surrogate is very important.

### What a Health Care Surrogate Can Do (*once you can longer speak for yourself*)

- Talk with your doctor about your medical problems and agree to start or stop medical treatments including: medicines, tests, CPR, breathing machines (ventilators), feeding tubes
- Tell others about your end of life wishes and make sure they are followed

### Choosing a Health Care Surrogate:

A health care surrogate is often a family member, but does not need to be. He/she should be someone who:

- you can trust;
- will be able to talk with your family
- is willing to do the job
- knows about what you want

Your Health Care Surrogate cannot be your doctor or other medical provider.

### Q: What is a DNR order?

- A do not resuscitate (DNR) order is another way you ask that your wishes are followed.
- DNR is a request not to have cardiopulmonary resuscitation (CPR) if your heart stops or if you stop breathing.
- In most cases doctors and nurses will try to revive all patients if their hearts stop or if they stop breathing by doing CPR unless the patient has asked not to have this done.
- Unfortunately when a person has a serious or terminal illness CPR does not usually work and trying it can cause the person more pain and only slow their dying.
- In CDCR a POLST form (see below) is filled out by a clinician to record whether or not a patient wants or does not want CPR to be tried as well as other medical treatment

### Q: What is a POLST?

- POLST is short for Physician's Orders for Life Sustaining Treatment.
- This is a form that is used by all hospitals in California (and other states).
- In CDCR POLST Form 7385 is used to document a patient's wishes about end of life care.
- The POLST allows a patient to say:
  - Try CPR or Do Not Try CPR (Allow Natural Death)
  - I want comfort care only or I want full treatment (or something in between).
  - I want a feeding tube tried or I don't want a feeding tube tried.
- If you are seriously ill, especially if you have been in the hospital, your doctor should talk with you about filling out a POLST.
- If your doctor has not asked about your wishes, you should bring it up yourself so that any questions you have can be answered and your wishes can be written down and followed.



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## WHAT YOU SHOULD KNOW

### Myths About Death and Dying:

<p><b>"Death is too frightening to talk about"</b>  <b>"It's not normal to talk about death"</b></p>	<ul style="list-style-type: none"> <li>• In the United States death is often hidden away in the back rooms of hospitals. Many people do not like talking about death even though death is a normal part of life.</li> <li>• In the past grandparents died at home and children learned death was a normal part of life.</li> <li>• Thinking about dying can be scary, but often learning more of the facts can make it less scary.</li> <li>• Feel free to ask questions of your doctor or nurse.</li> </ul>
<p><b>"Dying is always painful"</b></p>	<ul style="list-style-type: none"> <li>• This is one of the most common myths about dying.</li> <li>• Many people die without having pain.</li> <li>• If pain does occur, it can usually be treated and the patient can be made comfortable.</li> </ul>
<p><b>"It is not legal to stop a treatment such as a breathing machine once it is started".</b></p>	<ul style="list-style-type: none"> <li>• This is not true.</li> <li>• In the early 1980's the courts said that there is no legal difference between stopping a treatment once it is started and never starting the treatment.</li> <li>• Patients or families can decide to <i>withhold</i> treatment that is not wanted (never start it).</li> <li>• Patients or families can decide to <i>withdraw</i> treatment that is no longer wanted (stop it).</li> </ul>
<p><b>"No matter what, the patient must continue to be fed and be given liquids during the dying process"</b></p>	<ul style="list-style-type: none"> <li>• There comes a time in some cases where giving the dying person food ( tube feeding) and liquids is no longer helpful and so these are stopped.</li> <li>• For persons at the end of their life stopping or not starting tube feeding and fluids is not painful.</li> <li>• In fact the opposite is true: giving tube feeding and liquids to dying persons can prolong their discomfort and prevent nature from taking its course.</li> <li>• The choice to withhold or stop tube feeding and/or liquids is made only when it is clear that using them would not help. This is never done without a lot of thought.</li> <li>• It is best to think about whether you would want tube feeding and discuss your wishes with your doctor and nurse before you are too ill to state your wishes</li> </ul>



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## WHAT YOU SHOULD DO

### MY END OF LIFE WISHES / VALUES

**Think about which of the following are important to you when you think about dying:**

physical comfort   
  relief of pain and distress   
  to die naturally  
 live as long as possible no matter what   
  other \_\_\_\_\_

**Which of the following are important to your quality of life?**

able to care for my physical needs   
  recognizing family & friends   
  making my own decisions  
 having a say about my care needs   
  receiving palliative (comfort) care & hospice  
 other \_\_\_\_\_

**Have you thought about whether you would want to have CPR done?**     use     don't use     not sure

**Have you thought about whether you would want a feeding tube?**     use     don't use     not sure

**Would you want to be kept alive by machines (ventilator) in the following cases?:**

- If my thinking functions were destroyed?     use     don't use     not sure
- If I were near death with a terminal illness?     use     don't use     not sure

**Are you a member of a religion?**     No     Yes    **If yes, is there a person you would want to help attend to your spiritual needs as death nears?** (Specific faith or congregation) \_\_\_\_\_

**If your medical team believes that your death is near is there a family member you would like to be told?** (Must be on CDCR Form 127) \_\_\_\_\_

**Following your death is there a family member you would like to be told?** (Must be on CDCR Form 127) \_\_\_\_\_

**Are there other things important for someone to know about you, in the event that you become unable to communicate or your death is near?**

**How do you feel about death and dying?** ( Have you had someone close to you die? Did that person's illness or medical treatment change your thinking about death and dying?)

**Note:** Complete and share this with your doctor, family, and caregivers.

### MY DIAGNOSIS/MEDICATIONS

It is important that you understand your medical conditions and ask your medical team any questions you have.

**My major health conditions:**

\_\_\_\_\_

\_\_\_\_\_

It is important to know what medications you are taking and why you are taking them.

**Questions about my medications:**

\_\_\_\_\_

\_\_\_\_\_



### ADVANCE DIRECTIVES

**Have you completed ?:**

**Advance Health Care Directive** (CDCR 7421)

If so, approximately when?

\_\_\_\_\_

Who did you chose to speak for you if you cannot speak for yourself? \_\_\_\_\_

\_\_\_\_\_

**POLST** (CDCR Form 7465)

If so, approximately when? \_\_\_\_\_