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## Advance Care Planning (ACP) in Prison or Jail: Resources for Correctional Clinicians and Patients During COVID-19

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**Version 1**

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Please visit <https://amend.us/covid> for additional information and to ensure that you are referencing our most up-to-date recommendations.

Amend at UCSF is a health-focused correctional culture change program led by experts in medicine (geriatrics, infectious diseases, family medicine), public health, and correctional health and policy.

**Advance care planning** (ACP) is a *process* that supports adults **at any age or stage of health** to understand and share their *personal values, life goals, and preferences* regarding future medical care.

**What are incarcerated patients' rights with respect to advance care planning?**

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Incarcerated patients are legally entitled to adequate medical care under the Eighth Amendment, which includes access to advance care planning. Incarcerated patients retain the right to make their own medical decisions, including decisions regarding advance care planning.

### Why engage in Advance Care Planning (ACP)?

- Engagement in ACP is associated with improved patient and family experiences with health care near the end of life and greater concordance (agreement) between patient wishes and the health care they receive.
- In the setting of COVID-19, advance care planning and understanding people's wishes for medical care is critical. Up to 20% of patients with COVID-19 will require acute hospitalization, and 5-10% will require Intensive Care Unit (ICU) admission. Certain populations are at particularly high risk of mortality; among persons over age 80, mortality is estimated at 10-20%.

### What are key barriers to Advance Care Planning?

- Many health care professionals are not trained to have ACP discussions
- Primary care providers report insufficient time to engage in ACP during routine visits
- Electronic medical records do not always clearly delineate where and how to document ACP



### **What are some of the unique barriers to Advance Care Planning in prisons and jails?**

- Some patients are more likely to mistrust healthcare providers in the correctional setting
- Some incarcerated patients fear dying in the correctional setting rather than in the outside world, which can greatly influence their medical decisions when facing serious illness
- Incarceration prevents people from easily accessing the social supports (friends and family) many non-incarcerated people rely on when making their health care plans

### **Advance Care Planning in Prison and Jail**

Due to increased risk of morbidity (serious debilitating illness) and mortality due to COVID-19, all health care professionals should ensure that their patients who are incarcerated have had discussions about ACP. Fortunately, numerous high quality resources exist to guide clinicians in these discussions.

### **RECOMMENDATIONS FOR CORRECTIONAL HEALTH CARE PROVIDERS:**

#### **1. Familiarize yourself with advance care planning documents developed for COVID-19**

- We recommend the outpatient conversation guide developed by **Prepare for Your Care** (<https://prepareforyourcare.org/>), a website dedicated to helping patients with low health literacy engage in the advance care planning process. These free documents include language that any clinician, from any discipline, including peer counselors, can use to start advance care planning conversations.
  - See the [outpatient conversation guide](#) included on page 5 of this document (modified for the correctional setting), or online at:  
<https://prepareforyourcare.org/content/default/common/documents/PREPARE-Simple-ACP-Scripts-English.docx>
- Watch a 4-minute [advance care planning video](#) specific to COVID-19 created by Vital Talk at <https://vimeo.com/402742301>. **Vital Talk** is a nonprofit focused on improving clinicians' communication skills.
- Consider reading [Vital Talk's COVID Ready Communication Playbook](#) for more in-depth communication skills and techniques you can utilize during COVID-19  
<https://www.vitaltalk.org/guides/covid-19-communication-skills/>

#### **2. Establish and document a surrogate medical decision maker for your patient**

- Explain that a good surrogate decision maker is someone who they trust to follow their wishes. Your patient should tell their surrogate they have been chosen for this role. Ask for several forms of contact information and identify an alternate surrogate if possible.
- Establish where ACP information will be documented in your institution's medical record.
  - i. ACP information should be centrally located and easy to find.
  - ii. Some providers create a problem on the problem list called "Advance Care Planning" and document their patients' wishes and surrogate medical decision maker / Durable Power of Attorney (DPOA) information there.

#### **3. If your patient wants more information about any aspect of advance care planning, use materials from the Prepare for Your Care website**

- If your patient or their loved ones have computer access, encourage them to visit the [Prepare for Your Care](#) website at <https://prepareforyourcare.org/>
- If no computer access, print out [pamphlets for your patients](#) (in English or Spanish, available at <https://prepareforyourcare.org/pamphlet>), as useful conversation starters
- Prepare For Your Care also contains easy-to-read advance directives that are legally valid in all 50 states in English and Spanish



4. **If your patient is transferred to the hospital, be sure to send their ACP information with them, including their surrogate medical decision maker's contact information.**
- Remind the receiving healthcare provider that many incarcerated patients are mistrustful of correctional clinicians and their ACP should likely be re-addressed upon arrival.
  - Provide written contact information for the surrogate decision maker(s).
  - Provide a copy of an advance directive, if applicable.

**IN SUMMARY:**

The infographic features the AMEND logo (CHANGING CORRECTIONAL CULTURE) in the top left. The title 'Advance Care Planning Recommendations for Incarcerated Patients' is centered at the top in a large, bold, dark blue font. Below the title are four dark blue rectangular boxes, each containing a white icon and a text description:

- Review ACP conversation guide**: Icon of a document with a checklist.
- Establish and document patient's surrogate medical decision maker**: Icon of a person with a checkmark and an 'X' above their head.
- Offer Prepare for Your Care materials**: Icon of a computer monitor displaying a webpage.
- If patient is transferred to hospital, convey ACP information**: Icon of a hospital building with a cross on top.

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Amend COVID-19 Guidance & Tools developed by:

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Amend at UCSF fundamentally transforms culture inside prisons and jails to reduce their debilitating health effects. We provide a multi-year immersive program drawing on public health-oriented correctional practices from Norway and elsewhere to inspire changes in correctional cultures and create environments that can improve the health of people living and working in American correctional facilities.

Amend is currently focused on providing resources, expertise, and support to correctional systems confronting the global COVID-19 pandemic.

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## Appendix: ACP Planning Guidance from Prepare for Your Care (Modified Prison/Jail)

### Due to COVID-19, Advance Care Planning is Imperative

**Regardless of healthcare profession**, please address basic ACP during phone, video, or in person visits. Any ACP done now may save patients, families, and other providers from uncertainty and stress later on.

## What You Can Say:

### STEP 1: Ask About a Surrogate Decision Maker

“I wanted to take a moment to talk to you about advance care planning. This involves choosing an emergency contact and the medical care that is important to you.”

“First, I would like to ask if there is someone you trust to help make medical decisions for you if there ever came a time you could not speak for yourself?”

*If yes:* “That’s great. The next time you have a chance to communicate with them, tell them that you chose them for this role and what is important to you. That way they can be the best advocate and speak up for you if needed.”

“I will make sure I put this in your medical record. It is also important to keep their name and phone number written down wherever you keep important personal items.”

*If no:* “It is OK if you cannot think of someone right now. If someone comes to mind in the future, please let your medical providers know so we can put the information in your medical record.”

### STEP 2: Ask about Advance Directives

“Have you ever completed an advance directive? This is a legal form that lets you write down the name of your medical decision maker and your wishes for medical care.”

*If yes:* “That’s great. Do you remember what you wrote down? Do you still feel the same way? Do you know where this form is?”

“The most important part is to now share the information in this form with your medical provider, family, and friends. It is also important to bring a copy of the form with you if you need to go to the hospital. Please speak up and remind your provider to send a copy of the form with you if you are sent to the hospital. That way your family, friends, and medical providers will know what is most important to you.”

*If no:* “This is OK. A good place to start is a website called PREPAREforYourCare.org. It has simple information and advance directive forms for free and COVID-19 specific information and resources. You can get the website on a smartphone, a tablet, or a computer. That website again is PREPAREforYourCare.org. You can download the form to fill out on your computer or print to out. If you don’t have computer access, I can print out an advance directive for you, and you can review



it now, or take it back to your [dorm/cell] to review [if patient is allowed to bring papers to their housing unit]. I can also print out a pamphlet for you to read.”

*[Optional due to social distancing]:* “The forms sometimes need extra witnessing or a notary to be legal. If you fill out the form it is OK for now to just sign and date it. It is really important to share the information with your family and friends and medical providers as you are able. These conversations are the most important part. Remind your provider to send your form with you if you go to the hospital.”

### STEP 3: Document Patients' Wishes in the Medical Record

Learn and use your hospital's standard documenting practices that allow for the information to be in **a central location** so that other medical providers can find it when needed.

## If You have More Time

### Step 2a: Additional ACP Communication: *Focus values, not a menu/checkbox approach.*

“What is most important in your life and what brings you joy. Is it family, friends, pets or hobbies?”

*Ask about their own experiences to help shape their values.*

“Have you ever had your own experience with serious illness or a friend or family member who was very sick or dying? [Optional] Do you remember seeing someone on TV who was very sick or dying?”

When you think back, what do you think went well and what did not go well?  
If you were in these situations [again], what would you want for yourself?”

*Normalize the spectrum of peoples' preferences.*

“It can sometimes be helpful to think in general about what kind of medical care would be important to you. For example, some people feel that living as long as possible is the most important thing to them, no matter what their quality of life may be or the pain they may go through. Other people feel that there may be some health situations they know they would not want to go through, such as not being able to wake up from a coma or needing to be on machines to live. Have you thought about this before? What type of person are you?”

*Optional:* “People may feel very different about this now in their current health and in the future if they were to get very sick, such as if they were to get Coronavirus. Have you thought about this?”

“It is very important that you share this with your family, friends, and medical providers. If you have to come to the clinic or hospital you may be asked these questions again.”

### For additional COVID-specific communication see these resources:

- [CAPC](https://www.capc.org/toolkits/covid-19-response-resources/) (https://www.capc.org/toolkits/covid-19-response-resources/)
- [Vital Talk](https://www.vitaltalk.org/guides/covid-19-communication-skills/) (https://www.vitaltalk.org/guides/covid-19-communication-skills/)
- [Respecting Choices](https://respectingchoices.org/covid-19-resources/) (https://respectingchoices.org/covid-19-resources/)
- [Ariadne Labs](https://covid19.ariadnelabs.org/2020/04/15/serious-illness-care-program-covid-19-response-toolkit/) (https://covid19.ariadnelabs.org/2020/04/15/serious-illness-care-program-covid-19-response-toolkit/)