A COMPASS IN UNCHARTED WATERS
NAVIGATING YOUR FUTURE WITH CYSTIC FIBROSIS

Meg Dvorak, LCSW
Adult Cystic Fibrosis Social Worker
Stanford Healthcare
• 35% of CF adults are college graduates vs 27% gen US population
• 2/3 CF adults are students or working
Apply for a CF scholarship!
The number of pregnancies among women with CF has steadily increased since the 90’s—in 2013, a total of 257 women with CF were pregnant in the US. There are approx. 40 CF adults at Stanford who are parents. Many insurance companies are covering some costs of fertility tx.

www.resolve.org
Website dedicated to infertility information, resources, and support
PRINCIPLES IN PLANNING FOR CAREER

• Protect access to affordable insurance through employment
• Select employers covered by civil rights and other employment laws
• Select employment opportunities with flexible work schedules
• Assess appropriateness of work environment
WORK CESSATION

- Provides a significant part of a person’s identity
- Provides a sense of value and achievement
- Camaraderie/social aspects
- Work helps keep a routine and a “normal life” outside CF, Keeps people going
- CF becomes the full time job
- Conflicting emotions
- Financial concerns—how can afford this??
- Planning for transition to disability
- Guilt over “not financially contributing”
Maintaining Insurance

- Employer health plan through self, spouse, or DP
- Disabled adult on parents’ insurance
- GHPP
- Medi-cal and/or Medicare through disability
- Regular Medi-cal through income
- Covered California  (Stanford contact Kevin Woods—650-724-5750)
  - Blue Shield PPO and EPO
  - HealthNet EPO
  - Valley Health HMO
  - Anthem Blue Cross HMO, PPO, EPO
    - Only the hospital is in-network.
    - Physician services out of network
SSI and SSDI - both use same medical criteria

- FEV1 <50% in past year
- 3 hospitalizations or 6 MD interventions
- Home IVs every 6 mos
- Treatment burden min. 3-4 hours

CF Social Security Project

- 90% cases decided within 30-90 days (average is 178 days)
- 100% success rate for most 1st time applicants (vs 5%)
- Can help with medical reviews

New rules proposed summer 2015

Pressure to reduce # of people receiving benefits

More scrutiny of applicants and benefit recipients

New ABLE Act for 2015
CF LEGAL INFORMATION HOTLINE
A VALUABLE RESOURCE

- Provides free and confidential information on the laws that protect people with CF. Since 1998 over 35,000 calls received from people with CF, their family members and their CF care team members
- Provides representation for people with CF applying for SSI/SSDI
- Sponsored by funding from the CF Foundation
- Call 1-800-622-0385
TAKING CARE OF YOURSELF

- Establish care with a good PMD
- Recognize and understand your mental health needs
- Treatment and administrative burden
- Get help
  - Talk to your social worker
  - Explore the many self care options available

Quittner et al, Thorax 2014; 69:12 1067-1068
CFRI’s Partners in Living Initiative
A Holistic Approach to Life with Cystic Fibrosis

Mindfulness Based Stress Reduction Class for the CF Community

A 9-week online class led by Dr. Julie Desch, which combines body awareness, mindfulness meditation and hatha yoga to help those touched by cystic fibrosis to address anxiety, depression, chronic pain, and stress.

Beginning on Sunday, April 12, sessions will be held from 4:00 – 6:00 PST.

Sessions are open to those diagnosed with CF, as well as caregivers. Week seven will feature a six-hour online “mini-retreat.” The final class session will be held on Sunday, June 7.

Participants will need a computer with access to the internet, headphone (or earbuds) with a microphone, and a Skype account (optional but encouraged).

The $75 registration fee covers the MBSR workbook, 8 class sessions, and the online retreat.*

For more information or to register, call 650.404.9975, or click on this flyer.

* Due to unforeseen costs, the registration fee is $75 (not the previously listed $50). We are grateful to Vertex for supporting this program, which would otherwise require a $450 registration fee.
Advance Care Planning

- Care planning is a process of structured discussion and documentation woven into the regular process of care.
- **Planning** is essential, should occur early in course of illness.
- Should be open, honest, and sensitive to family and cultural issues.
- The **goal** is to ensure best care for patients and their and family’s wishes will be respected.
- Decision making around transplant w/u and listing.
PALLIATIVE CARE MODEL

- **SOCIAL**
  - Advance care planning, referrals for community support, caregiver support

- **PSYCHOLOGICAL**
  - Symptoms, treatment side effects

- **PHYSICAL**
  - Coping and emotional support for you and your family, sexuality and body image, mood

- **SPIRITUAL**
  - Your faith and general spiritual beliefs, supporting meaning and purpose in your life, as defined by you
My Health Care Wishes

The California Medical Association’s

Advance Health Care Directive Kit

For more information on Advance Health Care Directives, see www.cmanet.org

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Your Right to Make Health Care Decisions
Physician Orders for Life-Sustaining Treatment (POLST)

First follow these orders, then contact physician. This is a Physician Order Sheet based on the person’s current medical condition and wishes. Any section not completed implies full treatment for that section. A copy of the signed POLST form is legal and valid. POLST complements an Advance Directive and is not intended to replace that document. Everyone shall be treated with dignity and respect.

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

A  CARDIOPULMONARY RESUSCITATION (CPR):  If person has no pulse and is not breathing. When NOT in cardopulmonary 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  MEDICAL INTERVENTIONS:  If person has pulse and/or is breathing.

☐ Comfort Measures Only  Relieve pain and suffering through the use of medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Transfer to hospital only if comfort needs cannot be met in current location.  
☐ Limited Additional Interventions  In addition to care described in Comfort Measures Only, use medical treatment, antibiotics, and IV fluids as indicated. Do not intubate. May use non-invasive positive airway pressure. Generally avoid intensive care.  
☐ Transfer to hospital only if comfort needs cannot be met in current location.  
☐ Full Treatment  In addition to care described in Comfort Measures Only and Limited Additional Interventions, use intubation, advanced airway interventions, mechanical ventilation, and defibrillation/cardioversion as indicated. Transfer to hospital if indicated. Includes intensive care.

Additional Orders:  

C  ARTIFICIALLY ADMINISTERED NUTRITION:  Offer food by mouth if feasible and desired.

☐ No artificial means of nutrition, including feeding tubes.  Additional Orders:  
☐ Trial period of artificial nutrition, including feeding tubes.  
☐ Long-term artificial nutrition, including feeding tubes.  

D  INFORMATION AND SIGNATURES:

Discussed with:  ☐ Patient (Patient Has Capacity)  ☐ Legally Recognized Decisionmaker  
☐ Advance Directive dated available and reviewed  
☐ Advance Directive not available  
☐ No Advance Directive  
Health Care Agent if named in Advance Directive:  
Name:  Phone:  

Signature of Physician
My signature below indicates to the best of my knowledge that these orders are consistent with the person’s medical condition and preferences.

Print Physician Name:  
Physician Phone Number:  
Physician License Number:  

Physician Signature:  (required)  Date:  

Signature of Patient or Legally Recognized Decisionmaker
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 this form.

Print Name:  
Relationship:  (write self if patient)  

Signature:  (required)  Date:  
Address:  
Daytime Phone Number:  
Evening Phone Number:  

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED
HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

<table>
<thead>
<tr>
<th>Patient Information</th>
<th>Date of Birth</th>
<th>Gender: M F</th>
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<table>
<thead>
<tr>
<th>Health Care Provider Assisting with Form Preparation</th>
<th>Phone Number:</th>
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<tbody>
<tr>
<td>Name:</td>
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<table>
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<tr>
<th>Additional Contact</th>
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Directions for Health Care Provider

Completing POLST
- Completing a POLST form is voluntary. California law requires that a POLST form be followed by health care providers, and provides immunity to those who comply in good faith. In the hospital setting, a patient will be assessed by a physician who will issue appropriate orders.
- POLST does not replace the Advance Directive. When available, review the Advance Directive and POLST form to ensure consistency, and update forms appropriately to resolve any conflicts.
- POLST must be completed by a health care provider based on patient preferences and medical indications.
- A legally recognized decisionmaker may include a court-appointed conservator or guardian, agent designated in an Advance Directive, orally designated surrogate, spouse, registered domestic partner, parent of a minor, closest available relative, or person whom the patient’s physician believes best knows what is in the patient’s best interest and will make decisions in accordance with the patient’s expressed wishes and values to the extent known.
- POLST must be signed by a physician and the patient or decisionmaker to be valid. Verbal orders are acceptable with follow-up signature by physician in accordance with facility/community policy.
- Certain medical conditions or treatments may prohibit a person from residing in a residential care facility for the elderly.
- If a translated form is used with patient or decisionmaker, attach it to the signed English POLST form.
- Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid. A copy should be retained in patient’s medical record, on Ultra Pink paper when possible.

Using POLST
- Any incomplete section of POLST implies full treatment for that section.

Section A:
- If found pulseless and not breathing, no defibrillator (including automated external defibrillators) or chest compressions should be used on a person who has chosen "Do Not Attempt Resuscitation."

Section B:
- When comfort cannot be achieved in the current setting, the person, including someone with "Comfort Measures Only," should be transferred to a setting able to provide comfort (e.g., treatment of a hip fracture).
- Non-invasive positive airway pressure includes continuous positive airway pressure (CPAP), bi-level positive airway pressure (BiPAP), and bag valve mask (BVM) assisted respirations.
- IV antibiotics and hydration generally are not "Comfort Measures."
- Treatment of dehydration prolongs life. If person desires IV fluids, indicate "Limited Intervention" or "Full Treatment."
- Depending on local EMS protocol, "Additional Orders" written in Section B may not be implemented by EMS personnel.

Reviewing POLST
It is recommended that POLST be reviewed periodically. Review is recommended when:
- The person is transferred from one care setting or care level to another, or
- There is a substantial change in the person’s health status, or
- The person’s treatment preferences change.

Modifying and Voiding POLST
- A patient with capacity can, at any time, request alternative treatment.
- A patient with capacity can, at any time, revoke a POLST by any means that indicates intent to revoke. It is recommended that revocation be documented by drawing a line through Sections A through D, writing "VOID" in large letters, and signing and dating this line.
- A legally recognized decisionmaker may request to modify the orders, in collaboration with the physician, based on the known desires of the individual or, if unknown, the individual’s best interests.

This form is approved by the California Emergency Medical Services Authority in cooperation with the statewide POLST Task Force. For more information or a copy of the form, visit www.caPOLST.org

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED
# POLST VS. ADVANCE HEALTHCARE DIRECTIVE

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- For seriously ill/frail, at any age
- Specific orders for *current* treatment
- Can be signed by decision maker

**AHCD**

- For anyone 18 and older
- General instructions for *future* treatment
- Appoints decision maker
Thank you! Any Questions??