



Planning For Your Future

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HDSA Northern California Chapter Convention

HDSA Center of Excellence @ UC Davis Health

May 20, 2017



Topics of Discussion

- Advance Care Planning
- Financial Planning
 - Long Term Care Insurance
 - Government Benefits
- Community Resources

Purpose of Future Planning

- To ensure that you are treated and cared for according to your values, wishes and beliefs
- Ease the burden on loved ones from having to make difficult decisions without knowing what you would want
- Prevent unnecessary stress, frustration and feelings of guilt



ADVANCE CARE PLANNING

Advance Care Planning

- Process of discussing, preparing and documenting your wishes and preferences as related to your future medical care
 - Advance Health Care Directive
 - Physicians Order for Life Sustaining Treatment (POLST)
 - Living Will
- This will be an **ONGOING** process.
- Can often times be difficult to discuss, but it is necessary!

Topics to Consider

- Medical Preferences:
 - Pain management
 - Artificial nutrition and hydration
 - Intubation
 - Resuscitation
 - Dialysis
 - Antibiotics
 - Medication
 - Surgery
 - Treatments you would NOT want

Topics to Consider (cont.)

- Where do you want to be cared for
 - Home
 - Community
- What is important to you at the end of life?
 - Having friends/family visit often
 - Being pain free
 - Dignity and Quality of Life
 - Having closure
 - Religious/Spiritual Preferences

Topics to Consider (cont.)

- Who do you TRUST to make decisions and follow your wishes if you cannot communicate them yourself?
 - Spouse
 - Children
 - Friend
- Financial Decisions -- how will your care be funded?
 - Long term care insurance
 - Government benefits

Topics to Consider (cont.)

- After death preferences
 - Body, brain or organ donation
 - Burial/cremation
 - Funeral/Memorial/Life Celebration

Tips to Starting the Discussions

- Confront and understand any fears you might have associated with death, end of life
- Start discussions by talking about a recent death or something you saw on t.v./movie
- Speak openly and honestly about your beliefs, values, hopes and fears
- Ask questions about what to expect in regards to your current health condition
- Research the care options, support and available resources in your area

Gathering Information

- May involve discussions of any questions, concerns, preferences with:
 - Loves ones (trusted family, friends, children, etc)
 - Physicians
 - Social worker
 - Lawyer
 - Financial advisor
 - Religious/spiritual advisor

Documentation

- Living Will
- Advance Health Care Directive
 - Intensity of Care Form
- Physician Order for Life Sustaining Treatment (POLST)
- Pre-Hospital Do Not Resuscitate Form
- Medic-Alert Bracelet with medical conditions and DNR status (if determined)

Documentation Resources

- Advance Health Care Directive
 - California Hospital Association
 - www.calhospital.org/publications/free-resources/forms-handouts
- POLST
 - Coalition for Compassionate Care
 - www.finalchoices.org/polst.php
- Pre-Hospital DNR Form
 - California Emergency Medical Services Authority
 - www.emsa.ca.gov/personnel/DNR_faq.asp
- Medic Alert Bracelet
 - www.medicalert.org

Choosing a Power of Attorney

- Power of Attorney for Health Care
- Health Care Agent/Surrogate/Proxy

Choosing a Durable Power of Attorney (cont.)

- Consider selecting person(s) who is:
 - 18 years or older
 - Responsible
 - Trustworthy (will carry out your wishes as expressed)
 - Shares your values and beliefs about medical care and dying
 - Willing to accept responsibility and be available to make difficult decisions

Power of Attorney Responsibilities

- Make any medical decisions when you cannot
 - Including consent to start, continue or withdrawal care/treatment.
- Interpret and define your documented wishes
- Rehabilitation and Placement Decisions
- Apply for medical benefits
- Donation of body, brain, organs

When does POA become effective?

- Terms: Competency vs. Capacity
- POA is effective when a medical assessment has determined you do not have **CAPACITY** to make the decision

Important Reminders

- You may change your wishes and/or your Power of Attorney at any time
- To ensure your wishes are followed, make sure you have ongoing discussions and **DOCUMENT** what you want

Advance Care Planning Resources

- Family Caregiver Alliance
 - www.caregiver.org
- Caring Connections
 - www.caringinfo.org
- Coalition for Compassionate Care of California
 - www.finalchoices.org
- Center for Health Care Decisions
 - www.sacdecisions.org



FINANCIAL PLANNING

Financial Planning

- Long Term Care Insurance
- Government Benefits

- Other options:
 - Living Will & Special Needs Trust should be discussed with an Attorney in that field.

Facts

- Medical insurance such as Medicare, DO NOT provide Long Term Care benefits.
 - Most insurance covers a short term (100 day) stay at SNF for rehabilitation
- Medi-Cal or Long Term Care Insurance is the ONLY insurance that has a long term care benefit.

What Long Term Care Covers

- As with any insurance coverage and benefits will depend on the policy you purchased.
- Long Term Care Insurance can cover:
 - In-home assistance with Activities of Daily Living
 - (dressing, bathing, grooming, meal preparation, light housekeeping, etc)
 - Adult Day Health Care
 - Out of Home Placement
 - Skilled Nursing Facility or Assisted Living Facility

Costs (Monthly)

	Sacramento	San Francisco	Redding	Fresno	Stockton	Santa Cruz
Homemaker Services (In-Home Assistance)	\$4,195	\$4,624	\$4,099	\$3,432	\$3,442	\$4,385
Adult Day Health Care (ADHC)	\$1,690	\$1,733	\$1,950	\$1,650	N/A	\$3,467
Assisted Living Facility (Private 1 bedroom)	\$3,350	\$4,000	\$3,250	\$3,750	\$2,905	\$4,200
Skilled Nursing Facility (Semi-Private Room)	\$7,756	\$12,532	\$7,498	\$6,722	\$6,577	\$6,722
Skilled Nursing Facility (Private Room)	\$8,669	\$17,094	\$8,060	\$7,026	\$9,349	\$7,452

MONTHLY Costs of Long Term Care: Genworth Cost of Care Survey
[\(http://californialongtermcare.com/cost-of-care-survey/ \)](http://californialongtermcare.com/cost-of-care-survey/)

Long Term Care Insurance

- Should be purchased in early adulthood, when in good health.
 - Chronic conditions will likely exclude you from eligibility OR could significantly increase premiums.
- Make sure to discuss how much of the care will be covered and how do you file a claim for the benefits.
 - Maximum daily financial benefit
 - Maximum policy benefit

LTC Insurance Resources

- National Clearinghouse for Long Term Care Information
 - www.longtermcare.gov
- National Advisory Center for Long Term Care Insurance
 - www.longtermcareinsurance.org
- Health Insurance Counseling and Advocacy Program (HICAP)
 - www.cahealthadvocates.org
- California Partnership for Long Term Care
 - www.rureadyca.org
- California Department of Insurance
 - <http://www.insurance.ca.gov/0100-consumers/0060-information-guides/0050-health/ltc-rate-history-guide/index.cfm>



GOVERNMENT BENEFITS

Government Benefits

- California State Disability Insurance (SDI)
- Social Security Disability Insurance (SSDI)
- California Paid Family Leave Insurance Program (PFL)
- Family Medical Leave Act (FMLA)

California State disability insurance (sdi)

- Employment Development Department (EDD)
- **BENEFITS:**
 - Paid compensation for wages lost due to disability
- **ELIGIBILITY**
 - Employed prior to disability
 - Paid into SDI
 - Unable to work

Social Security Disability Insurance (SSDI)

- Social Security Administration
- **BENEFIT:**
 - Paid compensation for inability to work due to long term disability
- **ELIGIBILITY:**
 - Worked and paid Social Security taxes for enough years, with some having been paid in recent years.
 - Meet definition of “medically disabled”

California Paid Family Leave (PFL) Insurance Program

- Administered by EDD
- **BENEFIT:**
 - Paid time off to care for a loved one
 - Up to 6 weeks of leave in 12 month period
- **ELIGIBILITY**
 - Employed and covered by SDI
 - Exhausted vacation, sick or other paid time off

Family Medical Leave ACT (FMLA)

- US Dept of Labor's Employment Standards Administration, Wage & Hour Division
- **BENEFIT:**
 - Up to 12 weeks UNPAID time off during a 12 month period for specific or medical reasons.
- **ELIGIBILITY**
 - Employed by a covered employer
 - Worked in this job for 12 months.



HOW TO FILE FOR SSDI

Getting Started

- Decide how you are going to file
- Keep journal of the progression of your symptoms
- Print application forms
- Have all supporting information available

Medical disability definition

- The inability to engage in SGA because of medically determinable physical or mental impairment(s):
 - That can be expected to result in death
 - Has lasted and is expected to last longer than 12 months.

Medical disability evaluation criteria

- Are you working?
- Is your medical condition severe?
- Is your medical condition in the list of disabling impairments?
- Can you do the work you previously did?
- Can you do any other type of work?

Impairment evaluation criteria

11.17 Neurodegenerative disorders of the central nervous system, such as Huntington's disease, Friedreich's ataxia, and spinocerebellar degeneration, characterized by A or B:

- A. Disorganization of motor function in two extremities (see 11.00D1), resulting in an extreme limitation (see 11.00D2) in the ability to stand up from a seated position, balance while standing or walking, or use the upper extremities.

OR

- B. Marked limitation (see 11.00G2) in physical functioning (see 11.00G3a), and in one of the following:
 - 1. Understanding, remembering, or applying information (see 11.00G3b(i)); or
 - 2. Interacting with others (see 11.00G3b(ii)); or
 - 3. Concentrating, persisting, or maintaining pace (see 11.00G3b(iii)); or
 - 4. Adapting or managing oneself (see 11.00G3b(iv)).

Approval/denial of application

- Disability Determination Services (DDS)
 - Decide if your medical condition meets Social Security law
 - Will use medical evidence from your doctors, hospitals, clinics
- Notified via mail of decision

Resources

- www.ssa.gov
- 800-772-1213
- Local Social Security Office



COMMUNITY RESOURCES

Community Resources

- Support Groups
- Caregiving Assistance:
 - In Home Care Assistance Agencies
 - Adult Day Health Care
 - Skilled Nursing Facilities, Assisted Living or Board and Care
- Legal Assistance
- Transportation

Community Resources

- Del Oro Caregiver Resource Center
 - www.deloro.org
 - Education Classes; support groups; Respite for caregivers; short term counseling, legal consultation
- Huntington's Disease Society of America (HDSA)
 - www.hdsa.org
 - Education, Advocacy, Research
- HDSA Center of Excellence @ UC Davis
 - <https://www.ucdmc.ucdavis.edu/huntingtons/>

Community Resources (cont.)

- Senior Centers
 - http://www.careforcalifornia.net/list/11_ca_senior_centers.htm
 - Social activities, classes, support groups
- California Care Planning Council
 - <http://www.careforcalifornia.net/index.htm>
 - Extensive website with resources about aging, planning for the future, caregiving resources, etc.

So Now What???



PRACTICAL STEPS....

Gather Information

- Identify people you trust to be involved in your financial and medical care
- Gather all sources of documents already prepared and place together
 - Include both financial and medical
- Identify areas you feel are important to be discussed and documented
- Utilize community resources, get details about eligibility, costs, etc.

Organize

- Designate and file or binder to store all important documentation and resources
- Store in protected place, but one that is easily accessible
- Tell trusted family/friends where this information is located

Organize (cont.)

- Consider completing a Personal Health Record
 - Used to organize and have medical health information readily available
 - Can be completed using on-line software or notepad
 - Contains all necessary information about your health history and current medical treatments
 - Can assist with beginning the discussion about your medical preferences

Documentation

- Living Will & Trusts
- Advance Health Care Directive
- Physician Order for Life Sustaining Treatment (POLST)
- Medical Alert Bracelets
- Financial Power of Attorney

Conclusion

- Planning and communicating is an important step to ensuring that your loved ones know and understand your wishes
- It can ease worry, family conflict, burden, stress and frustration
- Community resources are available to help

Contact Information

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- QUESTIONS????