

# SAN FRANCISCO PALLIATIVE CARE TASK FORCE

## ISSUE BRIEF #2

### SURVEY FINDINGS

At the first San Francisco Palliative Care Task Force meeting held May 29, 2014, members were asked for their Task Force outcome ideas—subsequently organized into seven issue areas: Delivery of Quality Palliative Care Services; Systems: Healthcare, Social Service; Community Education/Engagement/Awareness; Financing; Need for New and Innovative Services; Policy; and, Serving Marginalized/Disenfranchised Communities.<sup>1</sup> Members also identified a list of potential Task Force deliverables; three emerged that matched the Task Force project timeframe and available resources:

1. Create an inventory of current San Francisco palliative care services across the continuum; survey Task Force members about the palliative care services they provide or know others provide.
  2. Develop priority short- and long-term strategic recommendations to respond to San Francisco's current and future palliative care needs.
  3. Clarify a target population for receipt of palliative care services in San Francisco.
- \*\* Online surveys were selected as the primary Task Force tool for collecting information relevant to these deliverables.

Task Force Survey #1 was developed in response to these suggested deliverables and sent to members. Section I of the survey collected data from members about palliative care services and supports provided by their organizations, and others—to develop an inventory of San Francisco palliative care services. Section II asked members to list challenges providing palliative care services and supports in the seven issue areas used to organized Task Force outcome ideas—to provide context for the subsequent development of Task Force short-and long-term strategic recommendations. Section II asked members to select a Task Force palliative care target population option—to clarify a palliative care target population for receipt of services.

Nearly all Task Force members completed Task Force Survey#1; the following is an overview of the survey by section, and a discussion of relevant findings.

### **Section I: Palliative Care Services and Supports Provided by Organizations**

Members submitted data on the palliative care services and supports their organization provides, or is planning to provide (see Table 1 for the list of palliative care service and supports

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<sup>1</sup> Note: creating an inventory of San Francisco palliative care services also emerged as an issue area; however, it was not included in the survey section addressing challenges, because it was selected as a Task Force deliverable.

presented in the survey), and listed organizations providing palliative care services and supports not represented on the Task Force in this section. Additional space was provided for members to describe their services and list other services they provide. Members also reported the availability of services provided (weekdays, Saturday, Sunday) and the appropriate contact information (name of organization/department, phone, e-mail). Information collected in this section will be compiled and presented in an inventory of San Francisco palliative care services and supports that will be made available to members of the Task Force, other health and community-based providers, and, as appropriate, members of the public in September 2014.

Because this is the first step in collecting inventory information, at the second Task Force meeting on June 19, 2014, members will be asked if additional fields need to be added to the profile of organizations providing palliative care services and supports, and for feedback on the optimal inventory format (e.g., an at-a-glance matrix or detailed organizational profiles). Efforts will be made to research, identify, and include other San Francisco health and community-based social service providers providing palliative care services and supports in the inventory.

Table 1. Palliative Care Services and Supports Presented in the Survey

<ul style="list-style-type: none"> <li>PC Medical Services*: Hospital</li> </ul>	<ul style="list-style-type: none"> <li>PC Pharmacy Support</li> </ul>	<ul style="list-style-type: none"> <li>Financial Coverage for PC (Insurance)</li> </ul>
<ul style="list-style-type: none"> <li>PC Medical Services: LTC/SNF/Rehab**</li> </ul>	<ul style="list-style-type: none"> <li>PC Psychologist/Psychiatrist</li> </ul>	<ul style="list-style-type: none"> <li>Housing Support</li> </ul>
<ul style="list-style-type: none"> <li>PC Medical Services*: Outpatient/Clinic</li> </ul>	<ul style="list-style-type: none"> <li>Caregiver/Family Support</li> </ul>	<ul style="list-style-type: none"> <li>Artist Support</li> </ul>
<ul style="list-style-type: none"> <li>PC Medical Services*: Community Medical Providers</li> </ul>	<ul style="list-style-type: none"> <li>Therapy/Counseling/Support Groups</li> </ul>	<ul style="list-style-type: none"> <li>Home/Building Modifications-Architecture</li> </ul>
<ul style="list-style-type: none"> <li>PC Medical Services*: Home</li> </ul>	<ul style="list-style-type: none"> <li>Bereavement Services</li> </ul>	<ul style="list-style-type: none"> <li>Legal/Advocacy Support</li> </ul>
<ul style="list-style-type: none"> <li>Residential Care</li> </ul>	<ul style="list-style-type: none"> <li>Advance Care Planning</li> </ul>	<ul style="list-style-type: none"> <li>Health Care Interpreter/Language Capabilities</li> </ul>
<ul style="list-style-type: none"> <li>Hospice Care</li> </ul>	<ul style="list-style-type: none"> <li>Direct Care Worker Support</li> </ul>	<ul style="list-style-type: none"> <li>Special Population Support</li> </ul>
<ul style="list-style-type: none"> <li>PC Social Work Support</li> </ul>	<ul style="list-style-type: none"> <li>Volunteer Caregiver Support</li> </ul>	
<ul style="list-style-type: none"> <li>PC Chaplain/ Spiritual Support</li> </ul>	<ul style="list-style-type: none"> <li>Transportation</li> </ul>	

\*PC Medical services = a trained palliative care specialist working with an interdisciplinary team

\*\* LTC = Long-Term Care Facilities; SNF = Skilled Nursing Facilities; Rehab= Rehabilitation

## **Section II: Challenges Providing Palliative Care Services and Supports**

In Section II, members reported challenges to providing palliative care in seven issue areas: Delivery of Quality Palliative Care Services; Systems: Healthcare, Social Service; Community Education/Engagement/Awareness; Financing; Need for New and Innovative Services; Policy; and, Serving Marginalized/Disenfranchised Communities. Tables 2 -8 list these challenges alongside members Task Force outcome ideas, from the first Task Force meeting, for each issue

area, to provide a contextual framework for the later development of Task Force short-and long-term palliative care recommendations. Under each table heading is a general description of the issue area presented.

**Table 2. Delivery of Quality Palliative Care Services**

*Addresses the structure and processes of palliative care: including the training, education, and oversight of palliative care team members; the physical, psychological, psychiatric, social spiritual/religious, cultural, and ethical aspects of care; adequate funding/insurance; and accessibility.*

<i><b>Issue Area Outcome Ideas</b></i>	<i><b>Challenges</b></i>
<ul style="list-style-type: none"> <li>• Define palliative care—what it is; what services it provides.</li> <li>• Increase the palliative care workforce.</li> <li>• Create processes to ensure collaboration and quality.</li> <li>• Educate professionals and caregivers.</li> <li>• Address the palliative care needs of the “direct care” workforce.</li> <li>• Assure that spiritual care is integrated into palliative care services and is not conflated with psychological care or cultural competence.</li> <li>• Engage primary care providers in "primary palliative care," so that the need for specialists is used efficiently.</li> </ul>	<ul style="list-style-type: none"> <li>• Credible quality metrics are still hard to develop and collect. We need to establish appropriate measurements, quality benchmarks, standards, and monitor outcomes across populations and settings.</li> <li>• Recognize that the shortage of trained palliative care specialists is a barrier to the expansion of palliative care services; palliative care needs to be included in all health care training—across the continuum, not limited to the specialty of palliative care.</li> <li>• Limited public awareness and ability of individuals to access services; coordination among agencies; coordination within agencies.</li> <li>• Funding is a big problem and the lack of seamless insurance coverage, e.g., the insurance gaps in paying for room and board in Residential Care Facilities for the Elderly, and, lack of community-based palliative care options.</li> <li>• Lack of culturally competent providers to serve limited English Proficiency (LEP) patients—language capabilities/ethnicity of staff—and special needs communities.</li> <li>• Confusion around palliative care chaplains, and the role religion/spirituality plays as a critical component of quality palliative care services and support for patients.</li> </ul>

**Table 3. Systems: Healthcare/Social Service**

*Addresses the health care system and the social service system, their infrastructures, and how each organizes, communicates, delivers, funds, and coordinates care and services for the populations they serve.*

<i>Issue Area Outcome Ideas</i>	<i>Challenges</i>
<ul style="list-style-type: none"> <li>• Establish a navigation system to help patients access palliative care across the health and social service continuum.</li> <li>• Identify the nexus between two parallel streams in healthcare: complex case management under a medical model and palliative care.</li> <li>• Identify opportunities for support and collaboration between the medical model of palliative care and social supports.</li> <li>• Identify ways to decrease logistical suffering. (Logistical suffering refers to a breakdown in systems, or a system insufficiency, resulting in some form of suffering by all parties involved)</li> <li>• Provide seamless services across the continuum.</li> <li>• Collect more palliative care data from all organizations.</li> </ul>	<ul style="list-style-type: none"> <li>• Health care and social service delivery systems rules and regulations that pose financial challenges—for providers and patients.</li> <li>• The health care system and our culture emphasize the medical model rather than considering how lives and communities are impacted by serious illness; we may need a centralized office or department to coordinate [palliative] care and services rather than our current ad hoc system.</li> <li>• Current delivery system is fragmented—lack of information/data sharing across systems; the medical model and social-long term care model have different incentives and funding. Need to find a way to align both.</li> <li>• Limited integration of services and inter-agency care coordination; we need better coordination between hospital/ home and community—especially for homeless and underserved populations.</li> <li>• Poor communication of information [across systems] (e.g. advance directives, Physician Orders for Life Sustaining Treatment-POLST); unable to get IHSS services as quickly as needed for end-of-life care; and, limited palliative care options for homeless persons.</li> <li>• Difficulty coordinating.</li> <li>• Lack of reimbursement for services.</li> <li>• Address transportation for patients, e.g., to medical appointments.</li> </ul>

**Table 4. Community Education/Engagement/Awareness**

*Addresses opportunities to educate, engage, and increase public awareness about palliative care.*

<i><b>Issue Area Outcome Ideas</b></i>	<i><b>Challenges</b></i>
<ul style="list-style-type: none"> <li>• Educate and engage people about palliative care early, “up stream,” before they need palliative care, in language they understand.</li> <li>• Think creatively about how to educate and engage consumers, current educational opportunities about palliative care are inadequate—create a campaign to explain the content in a different context (consider promoting advance directives, end-of-life planning, POLST forms—especially for supportive housing clients).</li> <li>• Be a community that has an open conversation about treatment preferences.</li> <li>• Focus on educating the provider community, especially primary care providers, about palliative care. Assist primary care providers in their ability to communicate the difference between palliative care and hospice to patients.</li> <li>• Raise awareness and educate residents about palliative care with support from City and County of San Francisco.</li> </ul>	<ul style="list-style-type: none"> <li>• The public does not know what palliative care is, so they don’t ask for it. And, providers don't know what services exist. We need a clear message about palliative care (see LaCrosse, WI - exemplar palliative care community).</li> <li>• This is a huge challenge: people do not want to talk about end of life issues and serious illness, etc., under "normal" circumstances. How do we get people's attention? The language that's used to describe and explain palliative care is not accessible to the public; and, the language may be interpreted differently in different communities.</li> <li>• Primary care providers have not often adopted "primary palliative care" as part of their practice; and, the public has not been engaged in discussing their hopes and concerns related to serious illness and end-of-life care with their providers.</li> </ul>

**Table 5. Financing**

*Addresses the range of issues relevant to financing palliative care: federal policy, private insurers, financial reimbursement structures, regulations, etc.*

<i><b>Issue Area Outcome Ideas</b></i>	<i><b>Challenges</b></i>
<ul style="list-style-type: none"> <li>• Design a seamless system of palliative care that is coordinated and supported by insurance (e.g., pays for inpatient and outpatient palliative care, and then when needed, hospice) to reduce the financial burden on patients.</li> <li>• Use capitation to finance comprehensive and seamless array of palliative care services—share risk (insurers and providers) on value-based contracting strategies.</li> <li>• Study the economic viability of reimbursing for integrated palliative care across health care settings; ensure that payers and providers are more in sync on payment issues.</li> <li>• Obtain information on San Francisco residents now insured under Covered California and Medi-Cal.</li> <li>• Determine the financial impact of current insurance policies that do not reimburse certain palliative care disciplines and activities, i.e., MSWs, chaplains, home visits, TeleMed.</li> <li>• Pay for ambulance transportation for palliative care wheelchair users and the non-ambulatory to get in/out of their homes.</li> <li>• Assess the viability of a "palliative care pilot" with health plans—ACO's (Accountable Care Organizations).</li> </ul>	<ul style="list-style-type: none"> <li>• Insurance coverage for comprehensive palliative care services is either limited or nonexistent across settings—hospital, home care, residential care, and hospice—how then to provide appropriate palliative care to a broad spectrum?</li> <li>• Federal funding cuts and static private sector finances have resulted in staff reductions, challenging all palliative care providers.</li> <li>• The biggest challenge: Medicare and now, Medi-Cal Managed Care. Both have regulations that are modeled after the Medicare Hospice Benefit that makes the provision of palliative care services upstream and not predicated on prognosis very challenging.</li> <li>• Providing 1:1 caregiver support in a home is expensive, and home-based care without other social support services can be isolating for patients without a social network.</li> <li>• It may be less a financial challenge than an attitudinal one—a major challenge is the adoption of a different perspective on financing palliative care. We need to encourage a different way of thinking by professionals, caregivers, providers, et al., about this issue. Such change may not cost a great deal of money, but is difficult to achieve.</li> <li>• Lack of data to support request for financing and to answer the question, "Who will pay for it?"</li> <li>• We have reimbursement limitations with current fee-for-service system and it is difficult to show return on investment; explore value and outcome based reimbursement.</li> </ul>

**Table 6. Need for New and Innovative Services**

*Addresses creative program opportunities to meet the palliative care needs of San Franciscan residents.*

<i><b>Issue Area Outcome Ideas</b></i>	<i><b>Challenges</b></i>
<ul style="list-style-type: none"> <li>• Establish a broad-based San Francisco palliative care consultation service.</li> <li>• Create a daycare for people with palliative care needs.</li> <li>• Provide transportation services to people with palliative care needs (e.g., cab vouchers).</li> </ul>	<ul style="list-style-type: none"> <li>• System design challenge is the greatest challenge: Without substantial investment (sustained financial support), we will be faced with designing more innovative—even out of the box solutions—using existing resources.</li> <li>• Time and money are the major challenges; also need more people with expertise.</li> <li>• Innovative programs will still need to be implemented in the context of current system regulations.</li> <li>• Palliative Care Day Programs need architectural support for bathing facilities, meals, recreational activities and as well as medication/treatment, psychosocial services and of course appropriate transportation for those who are not fully ambulatory; need for alternative community based care for persons with disability who have extensive activities of daily living (ADL) needs, such eating, bathing, dressing, etc., that are more custodial in nature than skilled, and chronic illnesses; need for volunteers who could provide companionship and support for the homebound.</li> <li>• Need hospice for homeless clients. Address end-of-life for individuals with behavioral health issues and substance use.</li> <li>• Unable to get support to start new initiatives without grant funding.</li> <li>• Need bridge programs to support patients who are not ready for hospice but who need palliative care. Need emergency department resources to connect patients with the community.</li> </ul>

**Table 7. Policy**

*Addresses policies that directly or indirectly impact palliative care.*

<i><b>Issue Area Outcome Ideas</b></i>	<i><b>Challenges</b></i>
<ul style="list-style-type: none"><li>• Develop policies that expand home-based caregiver support services (i.e., in-home supportive services) for palliative care patients.</li></ul>	<ul style="list-style-type: none"><li>• No clear policy on palliative care currently.</li><li>• Governmental and insurance bureaucracies are the main challenges.</li><li>• Limited awareness of palliative care combined with the lack of political will and lack of palliative care metrics and applied methodology, negatively impact the development of effective palliative care policy.</li><li>• Developing and maintaining policy [palliative care] that is flexible for emerging realities in marketplace.</li><li>• Currently, eligibility for some services excludes those with continuing care needs [who may benefit from palliative care], e.g. persons with advanced cancer previously homeless whose condition stabilized, may no longer be covered for skilled nursing facility care and are shocked when discharge to the community is proposed.</li><li>• Main obstacle is the Medicare Hospice Benefit that is rigid in the determination of eligibility: less than six months prognosis and denial of curative or "aggressive" treatment.</li><li>• Challenge of hospice restrictions re: foregoing life-prolonging treatments</li><li>• Need more inclusive [palliative care] policies to address the needs of marginalized and disenfranchised communities.</li><li>• Need policies to address health care decision-making for underrepresented patients.</li></ul>



**Table 8. Serving Marginalized/Disenfranchised Communities**

*Addresses the unique and specific palliative care needs of marginalized and disenfranchised communities overlooked or not appropriately responded to by the health and social service delivery systems.*

<i><b>Issue Area Outcome Ideas</b></i>	<i><b>Challenges</b></i>
<ul style="list-style-type: none"> <li>• Identify opportunities to provide palliative care services to people who are disenfranchised, e.g., homeless, poor, undocumented, uninsured.</li> <li>• Research the palliative care needs of vulnerable populations.</li> </ul>	<ul style="list-style-type: none"> <li>• Reaching marginalized and disenfranchised communities is difficult due to inequities in education, health care access, and finances.</li> <li>• Addressing issues of disparity in health care will require building relationships and gaining trust of communities that have been marginalized—need to focus on palliative care education and awareness for disenfranchised communities.</li> <li>• Complexity of this population is not easy to manage or coordinate services for. Provider capacity may not be adequate.</li> <li>• Need to be able to clearly define and communicate palliative care in culturally appropriate manner; underserved and Limited English Proficiency (LEP) communities are NOT accessing palliative care currently. There is very limited care for these populations.</li> <li>• Financing is a huge issue for marginalized and disenfranchised communities. Note: possibly with the California Coordinated Care Initiative and the additional enrollment of these communities in insurance exchanges, coverage should be available to almost all.</li> <li>• Limited materials to provide education re: palliative care and hospice [for marginalized and disenfranchised communities]; limited access to interpreters, few providers who are culturally concordant.</li> <li>• Challenge: advanced directives and hospice beds for unrepresented patients.</li> </ul>

Once completed, the tables were analyzed to identify a subset of the issue areas that could be represented by Task Force member small workgroups—for the purpose of developing Task Force short- and long-term palliative care recommendations. Four emerged with the potential to cover all the issue areas presented: *Delivery of Quality Palliative Care Services (Quality)*,

*Systems: Healthcare/Social Service (Systems), Community Education /Engagement/ Awareness (Community Education) and Financing.* These areas were determined broad enough to include outcome ideas from the issue areas not selected, *Need for New and Innovative Services, Policy,* and *Serving Marginalized and Disenfranchised Communities.* Members will discuss the four workgroups at the next Task Force meeting before selecting one to work on that best represents their interests and expertise.

### **Section III: Palliative Care Target Population**

The final section of Task Force Survey #1 addressed the third deliverable for Task Force members: clarify a target population for receipt of palliative care services in San Francisco. Members were asked to choose one of three target population options (listed below with the rationale for each).

#### **Option #1**

- Patients at the moment of diagnosis of a serious illness.

Rationale: *This broader palliative care population ensures that a larger group of patients can experience improved quality of life through the relief of pain and other troubling symptoms, and meet patients' emotional, spiritual, and practical needs.*

#### **Option #2**

- Patients with serious life-threatening illnesses or conditions in their last year or two of life.

Rationale: *This narrower palliative care population definition allows for greater tracking of services and costs associated with palliative care in the last year or two of life, e.g., diagnoses, hospital admissions and length of stay, treatment interventions, hospice, etc.*

#### **Option #3**

- Other

Rationale: *This option was provided to allow for other palliative care target population definitions.*

Among survey respondents, 36 percent chose, *Patients at the moment of diagnosis of a serious illness*; 36 percent chose, *Patients with serious life-threatening illnesses or conditions in their last year or two of life*; 21 percent chose *Other*; and, 7 percent chose not to respond (see member narrative other responses below).

#### **Other Responses:**

- *Issues around timing of death/how much time is left to live can be confusing. Seems better to have target population be something like the diagnosis of a life threatening illness.*
- *I do not feel this is an "either/or." If someone is diagnosed with a "serious illness" we do not know if it is their last year or two of life or not. I don't think these can be separated.*
- *Both are applicable.*

- *Would like to see definition include parts of both definitions. Don't want it to be restrictive, missing those who really need palliation, for example, those not dying but need symptom control.*
- *The former seems unworkable at this stage, but is the ultimate target.*
- *Hard to choose one. I see a combination. Not necessarily restricted to time prognosis or time of diagnosis. Wouldn't want to miss the people with intractable symptoms whose quality of life is unbearable, or heading that way. Maybe looking at defining how palliative care can make a difference and when. (Note: many people diagnosed with a serious illness don't have high "illness burden/distress" and likely would not benefit greatly from palliative care services; those that do have high illness burden/distress would benefit regardless of prognosis.)*

The results for this section—an even split between the first two options, and a range of comments reported in the “Other” option—highlight the need for a thoughtful Task Force discussion of the palliative care target population and selection of a general Task Force definition of palliative care, the latter to frame the palliative care provided to the target population. Below are three nationally respected palliative care definitions from the World Health Organization (WHO), the Centers for Medicare & Medicaid (CMS), and the Center to Advance Palliative Care (CAPC). Members are encouraged to review these definitions in light of the palliative care target population options; both will be discussed at the second Task Force meeting. Time permitting; a definition for each will be selected before members assemble in small workgroups to begin developing recommendations. Note: if more time is needed to reach consensus on these definitions, the discussion will be continued at the following Task Force meeting.

### **WHO Definition of Palliative Care**

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patients illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- Will enhance quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

## **CMS Definition of Palliative Care**

Palliative care” means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

## **CAPC Definition of Palliative Care**

Palliative care is specialized medical care for people with serious illnesses. It is focused on providing patients with relief from the symptoms, pain, and stress of a serious illness—whatever the diagnosis. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious illness and can be provided along with curative treatment.

Palliative care treats people suffering from serious and chronic illnesses including cancer, cardiac disease such as Congestive Heart Failure (CHF), Chronic Obstructive Pulmonary Disease (COPD), kidney failure, Alzheimer's, HIV/AIDS and Amyotrophic Lateral Sclerosis (ALS). Palliative care relieves the symptoms of these diseases, such as pain, shortness of breath, fatigue, constipation, nausea, loss of appetite and difficulty sleeping. It helps patients; gain the strength to carry on with daily life. It improves patients’ ability to tolerate medical treatments. And it helps patients’ have more control over their care by better understanding their choices for treatment options. The point of palliative care is to relieve suffering and provide the best possible quality of life for both the patient and their family.

Palliative care is a partnership of patient, medical specialists and family. Usually a team of experts, including palliative care doctors, nurses and social workers, provides this care and works together with patients’ own doctor. Chaplains, massage therapists, pharmacists, nutritionists and others may also be part of the palliative care team.

The palliative care team of specialists provides spends as much time as necessary with patients and families. The team supports patients and families every step of the way, not only by controlling patients’ symptoms, but also by helping patients understand their treatment options and goals. Working with patients’ doctor to provide an extra layer of support, the palliative care team provides:

- Time for close communication
- Expert management of pain and other symptoms
- Help navigating the healthcare system
- Guidance with difficult and complex treatment choices
- Emotional and spiritual support for patients and families

## **Conclusion**

Task Force members’ demonstrated their collective commitment to addressing San Francisco’s current and future palliative care needs with their timely and thoughtful survey responses. The next step for Task Force members is to review and discuss the survey findings at the June 19, 2014 Task Force meeting.