Service Category Definition - DSHS State Services
September 1, 2017 - August 31, 2018

Local Service Category:	**Hospice Services**
Amount Available**:**	**To be determined**
Unit Cost	
Budget Requirements or Restrictions:	Maximum 10% of budget for Administrative Cost
DSHS Service Category Definition:	Provision of Hospice Care provided by licensed hospice care providers to clients in the terminal stages of illness, in a home or other residential setting, including a non-acute-care section of a hospital that has been designated and staffed to provide hospice care for terminal patients. Hospice services include, but are not limited to, the palliation and management of the terminal illness and conditions related to the terminal illness. Allowable Ryan White/State Services funded services are: • Room • Board • Nursing care • Mental health counseling, to include bereavement counseling • Physician services • Palliative therapeutics Ryan White/State Service funds may not be used for funeral, burial, cremation, or related expenses. Funds may not be used for nutritional services, durable medical equipment and medical supplies or case management services.
Local Service Category Definition:	Hospice services encompass palliative care for terminally ill clients and support services for clients and their families. Services are provided by a licensed nurse and/or physical therapist. Additionally, unlicensed personnel may deliver services under the delegation of a licensed nurse or physical therapist, to a client or a client's family as part of a coordinated program. A physician must certify that a patient is terminal, defined under Medicaid hospice regulations as having a life expectancy of 6 months or less. Services must include but are not limited to medical and nursing care, palliative care, and psychosocial support for the patient, as well as a mechanism for bereavement referral for surviving family members. Counseling services provided in the context of hospice care must be consistent with the (Ryan White) definition of mental health counseling. Palliative therapies must be consistent with those covered under respective State Medicaid Program.
Target Population (age, gender, geographic, race, ethnicity, etc.):	Individuals with AIDS residing in the Houston HIV Service Delivery (HSDA).

Services to be Provided:	Services must include but are not limited to medical and nursing care, palliative care, psychosocial support and spiritual guidance for the patient, as well as a mechanism for bereavement referral for surviving family members. Counseling services provided in the context of hospice care must be consistent with the (Ryan White) definition of mental health counseling. Palliative therapies must be consistent with those covered under respective State Medicaid Program. Allowable Ryan White/State Services funded services are: • Room • Board • Nursing care • Mental health counseling, to include bereavement counseling • Physician services • Palliative therapeutics Services NOT allowed under this category: • HIV medications under hospice care unless paid for by the client. • Medical care for acute conditions or acute exacerbations of chronic conditions other than HIV for potentially Medicaid eligible residents. • Funeral, burial, cremation, or related expenses. • Nutritional services. • Durable medical equipment and medical supplies. • Case management services.
Service Unit Definition(s):	A unit of service is defined as one (1) twenty-four (24) hour day of hospice services that includes a full range of physical and psychological support to HIV patients in the final stages of AIDS.
Financial Eligibility:	Income at or below 300% Federal Poverty Guidelines.
Client Eligibility:	Individuals with an AIDS diagnosis and certified by his or her physician that the individual's prognosis is for a life expectancy of six (6) months or less if the terminal illness runs its normal course
Agency Requirements:	Agency/provider is a licensed hospital/facility and maintains a valid State license with a residential AIDS Hospice designation, or is certified as a Special Care Facility with Hospice designation. Provider must inform Administrative Agency regarding issue of long term care facilities denying admission for people living with HIV based on inability to provide appropriate level of skilled nursing care. Services must be provided by a medically directed interdisciplinary team, qualified in treating individual requiring hospice services. Staff will refer Medicaid/Medicare eligible clients to a Hospice Provider for medical, support, and palliative care. Staff will document an attempt has been made to place Medicaid/Medicare eligible clients in another facility prior to admission.

Staff Requirements:	All hospice care staff who provide direct-care services and who require licensure or certification, must be properly licensed or certified by the State of Texas.
Special Requirements:	These services must be: • Available 24 hours a day, seven days a week, during the last stages of illness, during death, and during bereavement; • Provided by a medically directed interdisciplinary team; • Provided in nursing home, residential unit, or inpatient unit according to need. These services do not include inpatient care normally provided in a licensed hospital to a terminally ill person who has not elected to be a hospice client. • Residents seeking care for hospice at Agency must first seek care from other facilities and denial must be documented in the resident's chart. Must comply with the Houston EMA/HSDA Standards of Care. The agency must comply with **the DSHS Hospice Standards of Care**. The agency must have policies and procedures in place that comply with the standards ***prior*** to delivery of the service.

FY 2019 RWPC "How to Best Meet the Need" Decision Process

Step in Process: **Council**		Date: **06/14/18**
Recommendations:	Approved: Y_____ No: _____ Approved With Changes:_____	If approved with changes list changes below:
1.		
2.		
3.		

Step in Process: **Steering Committee**		Date: **06/07/18**
Recommendations:	Approved: Y_____ No: _____ Approved With Changes:_____	If approved with changes list changes below:
1.		
2.		
3.		

Step in Process: **Quality Improvement Committee**		Date: **05/15/18**
Recommendations:	Approved: Y_____ No: _____ Approved With Changes:_____	If approved with changes list changes below:
1.		
2.		
3.		

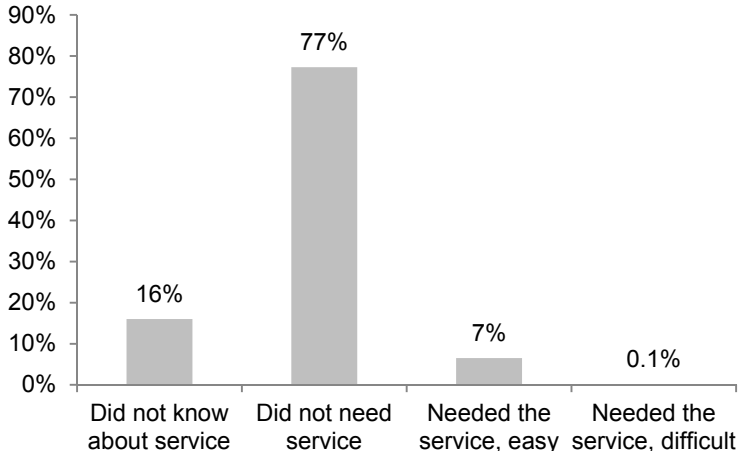
Step in Process: **HTBMN Workgroup**	Date: **04/25/18**
Recommendations:	Financial Eligibility:
1.	
2.	
3.	

HOSPICE

Hospice is end-of-life care for persons living with HIV (PLWH) who are in a terminal stage of illness (defined as a life expectancy of 6 months or less). This includes room, board, nursing care, mental health counseling, physician services, and palliative care.

(**Graph 1**) In the 2016 Houston HIV Care Services Needs Assessment, 7% of participants indicated a need for *hospice* in the past 12 months. 7% reported the service was easy to access, and 0.1% reported difficulty. 16% stated that they did not know the service was available.

GRAPH 1-Hospice, 2016



(**Table 1**) When barriers to *hospice* were reported, the only barrier type identified was education and awareness (lack of knowledge about the availability the service)

TABLE 1- Reported Barrier Type for Hospice, 2016

	No.	%
1. Education and Awareness (EA)	2	100%
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(**Table 2 and Table 3**) Need and access to services can be analyzed for needs assessment participants according to demographic and other characteristics, revealing the presence of any potential disparities in access to services. For *hospice*, this analysis shows the following:

- More males than females found the service accessible.
- More other/multiracial PLWH found the service accessible than other race/ethnicities.
- More PLWHA age 50+ found the service accessible than other age groups.
- No PLWH in special populations found the service difficult to access compared to all participants.

TABLE 2-Hospice, by Demographic Categories, 2016

	Sex		Race/ethnicity				Age		
Experience with the Service	Male	Female	White	Black	Hispanic	Other	18-24	25-49	50+
Did not know about service	16%	17%	10%	16%	20%	0%	21%	18%	12%
Did not need service	77%	77%	84%	75%	74%	13%	75%	77%	78%
Needed, easy to access	7%	6%	6%	8%	5%	87%	4%	5%	11%
Needed, difficult to access	0%	0%	0%	0%	0%	0%	0%	0%	0%

TABLE 3- Hospice, by Selected Special Populations, 2016

Experience with the Service	Unstably Housed[a]	MSM[b]	Out of Care[c]	Recently Released[d]	Rural[e]	Transgender[f]
Did not know about service	20%	13%	50%	21%	15%	14%
Did not need service	74%	80%	50%	74%	79%	77%
Needed, easy to access	6%	7%	0%	5%	6%	9%
Needed, difficult to access	0%	0%	0%	0%	0%	0%

[a]Persons reporting housing instability [b]Men who have sex with men [c]Persons with no evidence of HIV care for 12 mo.
[d]Persons released from incarceration in the past 12 mo. [e]Non-Houston/Harris County residents [f]Persons with discordant sex assigned at birth and current gender

HOSPICE SERVICES
2017 CHART REVIEW REPORT

PREFACE

DSHS Monitoring Requirements

The Texas Department of State Health Services (DSHS) contracts with The Houston Regional HIV/AIDS Resource Group, Inc. (TRG) to ensure that Ryan White Part B and State of Texas HIV Services funding is utilized to provide in accordance to negotiated Priorities and Allocations for the designated Health Service Delivery Area (HSDA). In Houston, the HDSA is a ten-county area including the following counties: Austin, Chambers, Colorado, Fort Bend, Harris, Liberty, Montgomery, Walker, Waller, and Wharton. As part of its General Provisions for Grant Agreements, DSHS also requires that TRG ensures that all Subgrantees comply with statutes and rules, perform client financial assessments, and delivery service in a manner consistent with established protocols and standards.

As part of those requirements, TRG is required to perform annual quality compliance reviews on all Subgrantees. Quality Compliance Reviews focus on issues of administrative, clinical, consumer involvement, data management, fiscal, programmatic and quality management nature. Administrative review examines Subgrantee operating systems including, but not limited to, non-discrimination, personnel management and Board of Directors. Clinical review includes review of clinical service provision in the framework of established protocols, procedures, standards and guidelines. Consumer involvement review examines the Subgrantee's frame work for gather client feedback and resolving client problems. Data management review examines the Subgrantee's collection of required data elements, service encounter data, and supporting documentation. Fiscal review examines the documentation to support billed units as well as the Subgrantee's fiscal management and control systems. Programmatic review examines non-clinical service provision in the framework of established protocols, procedures, standards and guidelines. Quality management review ensures that each Subgrantee has systems in place to address the mandate for a continuous quality management program.

QM Component of Monitoring

As a result of quality compliance reviews, the Subgrantee receives a list of findings that must be address. The Subgrantee is required to submit an improvement plan to bring the area of the finding into compliance. This plan is monitored as part of the Subgrantee's overall quality management monitoring. Additional follow-up reviews may occur (depending on the nature of the finding) to ensure that the improvement plan is being effectively implemented.

Scope of Funding

TRG contracts one Subgrantee to provide hospice services in the Houston HSDA.

INTRODUCTION

Description of Service

Hospice services encompass palliative care for terminally ill clients and support services for clients and their families. Services are provided by a licensed nurse and/or physical therapist. Additionally, unlicensed personnel may deliver services under the delegation of a licensed nurse or physical therapist, to a client or a client's family as part of a coordinated program. A physician must certify that a patient is terminal, defined under Medicaid hospice regulations as having a life expectancy of 6 months or less.

Services must include but are not limited to medical and nursing care, palliative care, and psychosocial support for the patient, as well as a mechanism for bereavement referral for surviving family members. Counseling services provided in the context of hospice care must be consistent with the (Ryan White) definition of mental health counseling. Palliative therapies must be consistent with those covered under respective State Medicaid Program.

Tool Development

The TRG Hospice Review tool is based upon the established local and DSHS standards of care.

Chart Review Process

All charts were reviewed by Bachelors-degree registered nurse experienced in treatment, management, and clinical operations in HIV of over 10 years. The collected data for each site was recorded directly into a preformatted computerized database. The data collected during this process is to be used for service improvement.

File Sample Selection Process

File sample was selected from a population of 51 who accessed hospice services in the measurement year. The records of 38 clients were reviewed, representing 75% of the unduplicated population. The demographic makeup of the provider was used as a key to file sample pull.

NOTE: DSHS changed the file sample percentage which will result in a lower number of files being reviewed in 2017.

Demographics- Hospice

2016 Annual

Total UDC: 38 Total New: 33

Age	Number of Clients	% of Total
Client's age as of the end of the reporting period		
Less than 2 years	0	0.00%
02 - 12 years	0	0.00%
13 - 24 years	0	0.00%
25 - 44 years	16	42.11%
45 - 64 years	22	57.89%
65 years or older	0	0.00%
Unknown	0	0.00%
	38	100.00%
Gender	**Number of Clients**	**% of Total**
"Other" and "Refused" are counted as "Unknown"		
Female	9	23.68%
Male	29	76.32%
Transgender FTM	0	0.00%
Transgender MTF	0	0.00%
Unknown	0	0.00%
	38	100.00%
Race/ Ethnicity	**Number of Clients**	**% of Total**
Includes Multi-Racial Clients		
White	9	23.68%
Black	20	52.63%
Hispanic	8	21.05%
Asian	1	2.63%
Hawaiian/Pacific Islander	0	0.00%
Indian/Alaskan Native	0	4.00%
Unknown	0	0.00%
	38	100.00%

From 01/01/16 - 12/31/16

2017 Annual

Total UDC: 51 Total New: 39

Age	Number of Clients	% of Total
Client's age as of the end of the reporting period		
Less than 2 years	0	0.00%
02 - 12 years	0	0.00%
13 - 24 years	1	1.96%
25 - 44 years	17	33.33%
45 - 64 years	30	58.82%
65 years or older	3	5.88%
Unknown		0.00%
	51	100.00%
Gender	**Number of Clients**	**% of Total**
"Other" and "Refused" are counted as "Unknown"		
Female	9	17.65%
Male	42	82.35%
Transgender FTM	0	0.00%
Transgender MTF	0	0.00%
Unknown	0	0.00%
	51	100.00%
Race/ Ethnicity	**Number of Clients**	**% of Total**
Includes Multi-Racial Clients		
White	19	37.25%
Black	24	47.06%
Hispanic	8	15.69%
Asian	0	2.63%
Hawaiian/Pacific Islander	0	0.00%
Indian/Alaskan Native	0	0.00%
Unknown	0	0.00%
	51	100.00%

From 01/01/17 - 12/31/17

RESULTS OF REVIEW

ADMISSION ORDERS AND ASSESSMENT

Percentage of client records that have a Hospice Certificate Letter in the chart

	Yes	No	N/A
Client records that evidenced a Hospice Certificate Letter.	38	0	-
Clients in hospice services that were reviewed.	38	38	-
Rate	**100%**	**0%**	-

Percentage of client records that have admission orders

	Yes	No	N/A
Client records that showed evidence of an admission order.	38	0	-
Clients in hospice services that were reviewed.	38	38	-
Rate	**100%**	**0%**	-

Percentage of client records that had a Comprehensive Assessment completed within 48 hours

	Yes	No	N/A
Client records that evidenced a completed Comprehensive Assessment within 48 hours.	38	0	-
Clients in hospice services that were reviewed.	38	38	-
Rate	**100%**	**0%**	-

Percentage of HIV-positive client records that showed assessment for pain at each shift

	Yes	No	N/A
Client records that showed evidence of a pain assessment at each shift.	38	0	-
Clients in hospice services that were reviewed.	38	38	-
Rate	**100%**	**0%**	-

Percentage of client records that have symptom management orders

	Yes	No	N/A
Client records that evidenced symptom management orders.	38	0	-
Clients in hospice services that were reviewed.	38	38	-
Rate	**100%**	**0%**	-

CARE PLAN, UPDATES AND MULTIDICPLINARY TEAM (MDT) DOCUMENTAITON

Percentage of client records that have a completed initial plan of care within 7 days of admission.

	Yes	No	N/A
Client records that evidence a completed initial plan of care within 7 days of admission	38	0	-
Clients in hospice services that were reviewed.	38	38	-
Rate	**100%**	**0%**	-

Percentage of client records that have a completed plan of care reviewed and/or updated at least monthly.

	Yes	No	N/A
Client records that evidenced a completed plan of care that was updated at least monthly.	21	0	17
Clients in hospice services that were reviewed.	21	21	38
Rate	**100%**	**0%**	**45%**

Percentage of client records that showed weekly updates to the MDT care plan

	Yes	No	N/A
Client records that showed evidence of weekly updates to the MDT.	38	0	-
Clients in hospice services that were reviewed.	38	38	-
Rate	**100%**	**0%**	-

SERVICES

Percentage of client records that evidenced daily nurse's notes

	Yes	No	N/A
Number of client records that evidenced daily nursing documentation.	38	0	-
Clients in oral health services that were reviewed.	38	38	-
Rate	**100%**	**0%**	-

Percentage of client records that had bereavement care plans

	Yes	No	N/A
Client records that showed evidence of bereavement care plans.	37	0	1
Clients in oral health services that were reviewed.	37	37	38
Rate	**100%**	**0%**	3%

Percentage of client records that had dietary counseling

	Yes	No	N/A
Number of client records that evidenced dietary counseling	1	0	37
Clients in oral health services that were reviewed.	1	1	38
Rate	**100%**	**0%**	97%

Percentage of client records that had spiritual counseling

	Yes	No	N/A
Client records that evidenced spiritual counseling.	38	0	-
Clients in oral health services that were reviewed.	38	38	-
Rate	**100%**	**0%**	-

Percentage of client records that had pain management needs assessed each shift

	Yes	No	N/A
Number of client records that evidence a pain assessment each shift	38	0	-
Clients in oral health services that were reviewed.	38	38	-
Rate	**100%**	**0%**	-

FAMILY SUPPORT

Percentage of client records that showed end of life support services were given to the family.

	Yes	No	N/A
Client records that showed evidence of support services being offered to the family.	38	0	-
Clients in hospice services that were reviewed.	38	38	-
Rate	**100%**	**0%**	-

HOMELESSNESS

Percentage of client records that show the client was homeless on admission

	Yes	No	N/A
Client records that showed evidence of homeless on admission.	3	35	-
Clients in hospice services that were reviewed.	38	38	-

Rate	**8%**	**92%**	-

SUBSTANCE ABUSE

Percentage of client records that showed the client had active substance abuse on admission.

	Yes	No	N/A
Client records that evidenced active substance abuse on admission.	3	35	-
Clients in hospice services that were reviewed.	38	38	-
Rate	**8%**	**92%**	-

PSYCHIATRIC ILLNESS

Percentage of client records that showed the client had active psychiatric illness on admission (excluding depression).

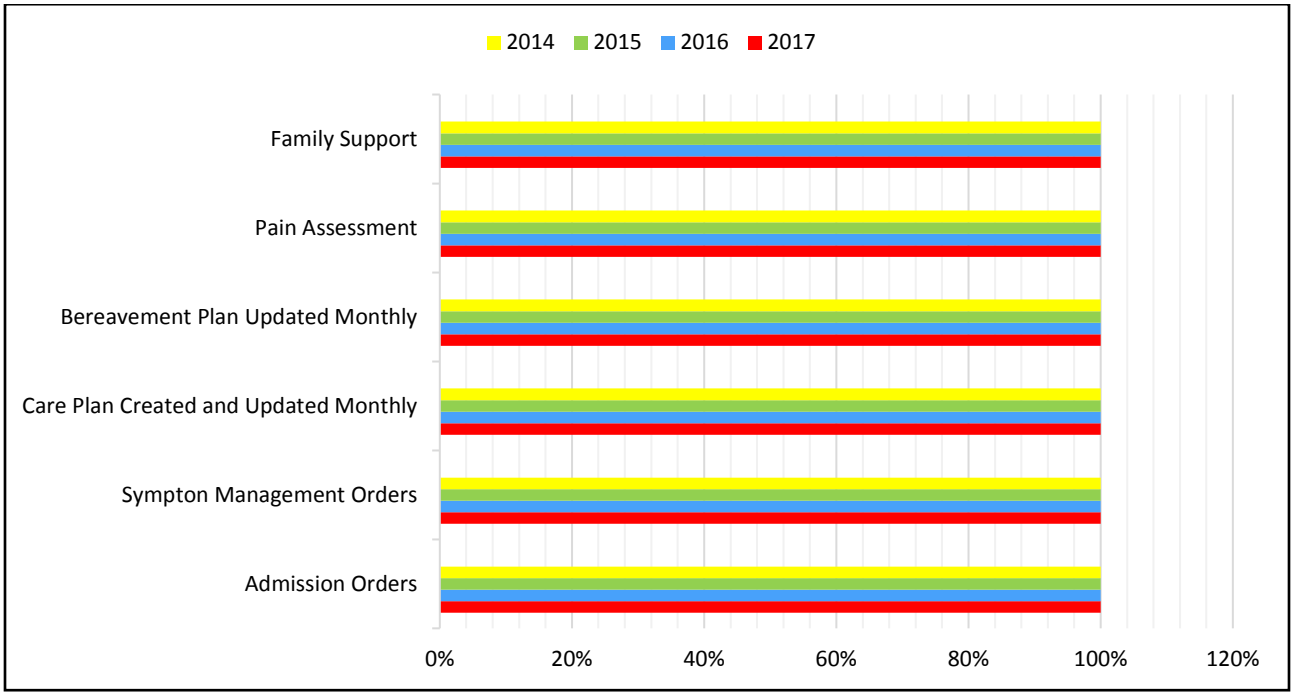
	Yes	No	N/A
Number of client records that evidenced active psychiatric illness	3	35	-
Clients in hospice services that were reviewed.	38	38	-
Rate	**8%**	**92%**	-

DISCHARGE

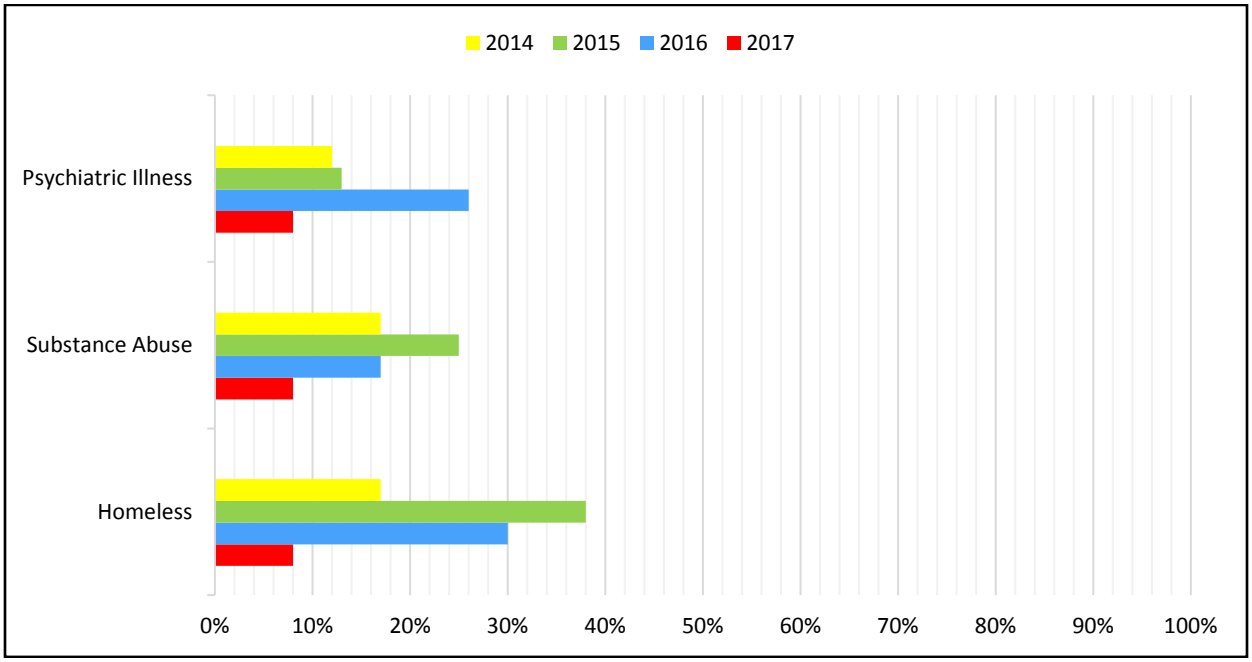
Percentage of client records that showed completed discharge documentation

	Yes	No	N/A
Client records that evidenced completed discharge documentation.	38	0	-
Clients in hospice services that were reviewed.	38	38	-
Rate	**100%**	**0%**	-

HISTORICAL DATA



COMORBIDITY DATA



CONCLUSION

The review showed that Hospice Care continue to be delivered at a very high standard. All fifteen Standard of Care data elements were scored at 100% compliance, including care plan, symptom management and family support. Of the client records reviewed, 8% (3) of records indicated the client was homeless on admission. This is a significant decrease from 30% in 2016. Additionally, 8% (3) of records reviewed showed evidence that the client had active substance abuse on admission (decrease from 17% in 2015); 8% (3) of records reviewed showed evidence of active psychiatric illness on admission (excluding depression). This is a decrease from 26% in 2016. Demographically, the client's served in the age bracket 45 and up, is increasing with 15 (60%) clients in 2015, 22 (58%) clients in 2016 and 33 (65%) clients in 2017.

National Hospice and Palliative Care Organization

NATIONAL HOSPICE AND PALLIATIVE CARE ORGANIZATION

FACTS AND FIGURES

HOSPICE CARE IN AMERICA

2017 EDITION

TABLE OF CONTENTS

INTRODUCTION

About This Report

NHPCO Facts and Figures: Hospice Care in America provides an annual overview of hospice care delivery. This overview provides specific information on:

- Hospice patient characteristics
- Location and level of care
- Medicare hospice spending
- Hospice provider characteristics
- Volunteer and bereavement services

Currently, most hospice patients have their costs covered by Medicare, through the Medicare Hospice Benefit. The findings in this report reflect only those patients who received care in 2016 through the Medicare Hospice Benefit and the hospices certified by the Centers for Medicare and Medicaid Services (CMS) to care for them.

What is hospice care?

Considered the model for quality compassionate care for people facing a life-limiting illness, hospice provides expert medical care, pain management, and emotional and spiritual support expressly tailored to the patient's needs and wishes. Support is provided to the patient's family as well.

Hospice focuses on caring, not curing. In most cases, care is provided in the patient's home but may also be provided in freestanding hospice facilities, hospitals, and nursing homes and other long-term care facilities. Hospice services are available to patients with any terminal illness or of any age, religion, or race.

How is hospice care delivered?

Typically, a family member serves as the primary caregiver and, when appropriate, helps make decisions for the terminally ill individual. Members of the hospice staff make regular visits to assess the patient and provide additional care or other services. Hospice staff is on-call 24 hours a day, seven days a week.

The hospice team develops a care plan that meets each patient's individual needs for pain management and symptom control. This interdisciplinary team, as illustrated in Figure 1, usually consists of the patient's personal physician, hospice physician or medical director, nurses, hospice aides, social workers, bereavement counselors, clergy or other spiritual counselors, trained volunteers, and speech, physical, and occupational therapists, if needed.

FIGURE 1. INTERDISCIPLINARY TEAM

What services are provided?

The interdisciplinary hospice team:

- Manages the patient's pain and other symptoms
- Assists the patient and family members with the emotional, psychosocial, and spiritual aspects of dying
- Provides medications and medical equipment
- Instructs the family on how to care for the patient
- Provides grief support and counseling
- Makes short-term inpatient care available when pain or symptoms become too difficult to manage at home, or the caregiver needs respite time
- Delivers special services like speech and physical therapy when needed
- Provides grief support and counseling to surviving family and friends

Location of Care

The majority of hospice care is provided in the place the patient calls home. In addition to private residences, this includes nursing homes and residential facilities. Hospice care may also be provided in freestanding hospice facilities and hospitals (see Levels of Care).

Levels of Care

Hospice patients may require differing intensities of care during the course of their disease. While hospice patients may be admitted at any level of care, changes in their status may require a change in their level of care.

The Medicare Hospice Benefit affords patients four levels of care to meet their clinical needs: Routine Home Care, General Inpatient Care, Continuous Home Care, and Inpatient Respite Care. Payment for each covers all aspects of the patient's care related to the terminal illness, including all services delivered by the interdisciplinary team, medications, medical equipment and supplies.

- Routine Hospice Care (RHC) is the most common level of hospice care. With this type of care, an individual has elected to receive hospice care at their residence.
- General Inpatient Care (GIP) is provided for pain control or other acute symptom management that cannot feasibly be provided in any other setting. GIP begins when other efforts to manage symptoms are not sufficient. GIP can be provided in a Medicare certified hospital, hospice inpatient facility, or nursing facility that has a registered nurse available 24 hours a day to provide direct patient care.
- Continuous Home Care (CHC) is care provided for between 8 and 24 hours a day to manage pain and other acute medical symptoms. CHC services must be predominately nursing care, supplemented with caregiver and hospice aide services and are intended to maintain the terminally ill patient at home during a pain or symptom crisis.
- Inpatient Respite Care (IRC) is available to provide temporary relief to the patient's primary caregiver. Respite care can be provided in a hospital, hospice facility, or a long term care facility that has sufficient 24 hour nursing personnel present.

Volunteer Services

The U.S. hospice movement was founded by volunteers and continues to play an important and valuable role in hospice care and operations. Moreover, hospice is unique in that it is the only provider with Medicare Conditions of Participation (CoPs) requiring volunteers to provide at least 5% of total patient care hours. Hospice volunteers provide service in three general areas:

- Spending time with patients and families ("direct support")
- Providing clerical and other services that support patient care and clinical services ("clinical support")
- Engaging in a variety of activities such as fundraising, outreach and education, and serving on a board of directors ("general support")

Bereavement Services

Counseling or grief support for the patient and loved ones is an essential part of hospice care. After the patient's death, bereavement support is offered to families for at least one year. These services can take a variety of forms, including telephone calls, visits, written materials about grieving, and support groups. Individual counseling may be offered by the hospice or the hospice may make a referral to a community resource. Some hospices also provide bereavement services to the community at large.

WHO RECEIVES HOSPICE CARE

How many Medicare beneficiaries received hospice care in 2016?

1.43 million Medicare beneficiaries were enrolled in hospice care for one day or more in 2016*. This includes patients who:

- Died while enrolled in hospice
- Were enrolled in hospice in 2015 and continued to receive care in 2016
- Left hospice care alive during 2016 (live discharges)

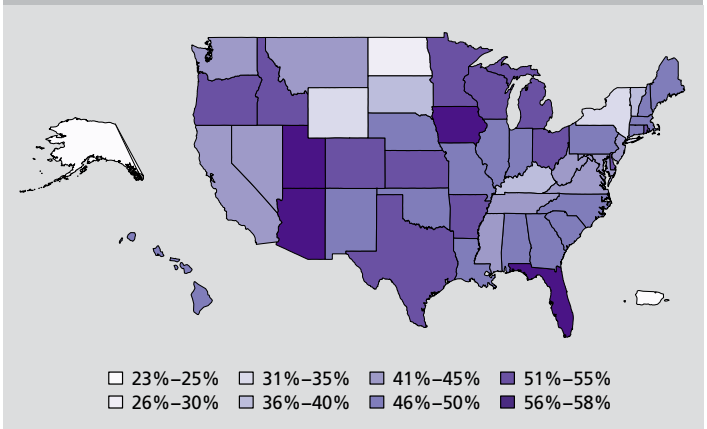
**includes all states, Washington D.C., and Puerto Rico.*

What proportion of Medicare decedents were served by hospice in 2016?

Of all Medicare decedents in 2016, 48% received one day or more of hospice care *and* were enrolled in hospice at the time of death.

As illustrated in Figure 2, the proportion of Medicare decedents enrolled in hospice at the time of death varied across states from a low of 23% (PR) to a high of 58% (UT).

FIGURE 2. GEOGRAPHIC VARIATION IN THE PROPORTION OF MEDICARE DECEDENTS WHO DIED WHILE RECEIVING HOSPICE CARE IN 2016



What are the characteristics of Medicare beneficiaries who received hospice care in 2016?

Patient Gender

In 2016 more than half of hospice Medicare beneficiaries were female.

Female	58.6 %
Male	41.4 %

Patient Age

In 2016 about 64% of Medicare hospice patients were 80 years of age or older.

TABLE 1. PERCENTAGE OF PATIENTS BY AGE

Age Category (Years)	Percentage
< 65	5.3 %
65 - 69	7.7 %
70 - 74	10.0 %
75 - 79	12.8 %
80 - 84	16.7 %
> 84	47.5 %

*Patient Race**

In 2016 a substantial majority of Medicare hospice patients were Caucasian.

TABLE 2. PERCENTAGE OF PATIENTS BY RACE*

Race	Percentage
Caucasian	86.5 %
African American	8.3 %
Hispanic	2.1 %
Asian	1.2 %
Other	1.0 %
Native American	0.4 %
Unknown	0.4 %

** Categories correspond to those used by CMS in the Hospice Limited Data Set*

TABLE 3. DEATH/SERVICE RATIO BY RACE*

Race	Percentage
Caucasian	48.9 %
African American	35.6 %
Hispanic	37.4 %
Asian	31.7 %
Other	36.2 %
Native American	32.9 %
Unknown	34.3 %

**Percentage of Medicare decedents who died under hospice care by race.*

Principal Diagnosis

The principal hospice diagnosis is the diagnosis that has been determined to be the most contributory to the patient's terminal prognosis. In 2016 more Medicare hospice patients had a principal diagnosis of cancer than any other disease.

TABLE 4. PERCENTAGE OF PATIENTS BY PRINCIPAL DIAGNOSIS

Principal Diagnosis	Percentage
Cancer	27.2 %
Cardiac and Circulatory	18.7 %
Dementia	18.0 %
Respiratory	11.0 %
Stroke	9.5 %
Other	15.6 %

HOW MUCH CARE IS RECEIVED?

*Length of Service**

The average length of service (ALOS) for Medicare patients enrolled in hospice in 2016 was 71 days. The median length of service (MLOS) was 24 days.

** LOS calculation is based on the total days of care for patients who received care in 2016. Days of care have been combined for patients who had multiple episodes of care in 2016. Days of care occurring in other years are not included.*

*Days of Care**

In 2016 hospice patients received a total of 101 million days of care paid for by Medicare.

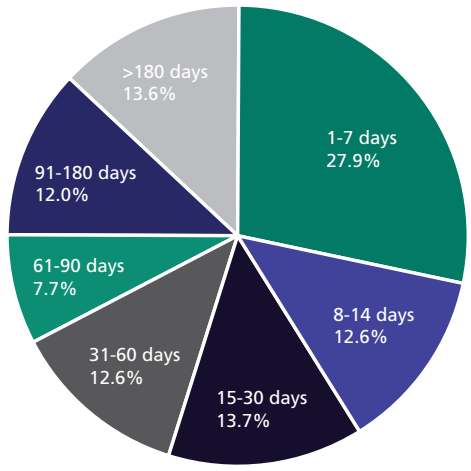
In 2016, a greater proportion of Medicare patients (27.9%) were enrolled in hospice a total of seven days or fewer compared to all other length of service categories.

TABLE 5. DAYS OF CARE CATEGORIES BY PERCENTAGE OF PATIENTS*

Total Days of Care	Percentage of Patients
1 – 7	27.9 %
8 – 14	12.6 %
15 – 30	13.7 %
31 – 60	12.6 %
61 – 90	7.7 %
91 – 180	12.0 %
> 180	13.6 %

**These values are computed using only days of care that occurred in 2016. Days of care occuring in other years are not included. Days of care have been combined for patients who had multiple episodes of care in 2016.*

FIGURE 3. PROPORTION OF PATIENTS BY DAYS OF CARE IN 2016



In 2016 over half (54.2%) of patients were enrolled in hospice for 30 or fewer days.

TABLE 6. DAYS OF CARE OVER MULTIPLE YEARS BY PERCENTAGE OF PATIENTS*

Total Days of Care	Percentage of Patients
1-60	61.6 %
61-180	18.3 %
181-365	10.7 %
>365	9.4 %

**These values are computed using all days of care that occurred in 2016 and, for patients who received care in 2014 and 2015 as well as in 2016, days of care from those years are also included.*

Patients with a principal diagnosis of dementia had the largest number of days of care on average in 2016.

TABLE 7. DAYS OF CARE BY PRINCIPAL DIAGNOSIS*

Principal Diagnosis	Mean # Days of Care	Median # Days of Care
Cancer	46 days	19 days
Cardiac and Circulatory	79 days	30 days
Dementia	104 days	54 days
Respiratory	71 days	21 days
Stroke	77 days	22 days
Other	62 days	16 days

**These values are computed using only days of care that occurred in 2016. Days of care have been combined for patients who had multiple episodes of care in 2016. Days of care occurring in other years are not included.*

Deaths

In 2016 1.04 million Medicare beneficiaries died while enrolled in hospice care. Close to half of the deaths occurred in a home and almost a third in nursing facilities.

TABLE 8. LOCATION OF DEATHS

Location of Death	Percentage
Home	44.6 %
Nursing Facility*	32.8 %
Hospice Inpatient Facility	14.6 %
Acute Care Hospital	7.4 %
Other	0.7 %

** Includes skilled nursing facilities, nursing facilities, assisted living facilities, and RHC days in a hospice inpatient facility.*

Discharges and Transfers

In 2016, live discharges comprised 16.8% of all Medicare hospice discharges.

TABLE 9. DISCHARGES BY TYPE OF DISCHARGE*

Type of Discharge	Percentage
Deaths	83.2 %
Live Discharges - Patient Initiated	
Transfers (change in hospice provider)	2.1 %
Revocations	6.4 %
Live Discharges - Hospice Initiated	
No longer terminally ill	6.6 %
Moved out of service area	1.3 %
Discharged for cause	0.3 %

**Calculations are based on total number of discharges which includes patients who were discharged more than one time in 2016.*

Level of Care

In 2016 the vast majority of days of care were at the Routine Homecare (RHC) level.

TABLE 10. LEVEL OF CARE BY PERCENTAGE OF DAYS OF CARE

Level of Care	Percentage of Days of Care
Routine Home Care (RHC)	98.0 %
Continuous Home Care (CHC)	0.2 %
Inpatient Respite Care (IRC)	0.3 %
General Inpatient Care (GIP)	1.5 %

RHC by Location of Care

56.5% of RHC days of care occurred in a private residence, 42.5% in a nursing facility and 1.0% in a hospice inpatient facility, an acute care hospital, or an unspecified location.

Location of Care

In 2016 most of days of care were provided at a private residence.

TABLE 11. LOCATION OF CARE BY PERCENTAGE OF DAYS OF CARE*

Location	Percentage of Days of Care
Home	55.6 %
Nursing Facility*	41.9 %
Hospice Inpatient Facility	1.3 %
Acute Care Hospital	0.5 %
Other	0.8 %

** Includes skilled nursing facilities, nursing facilities, assisted living facilities, and RHC days in a hospice inpatient facility.*

HOW DOES MEDICARE PAY FOR HOSPICE?

Medicare paid hospice providers a total of 16.9 billion dollars for care provided in 2016.

Spending per Patient

The average spending per Medicare hospice patient was $11,820.00.

TABLE 12. MEDICARE SPENDING PER HOSPICE PATIENT

First Quartile	Median	Third Quartile
$1,904.00	$5,384.00	$16,110.00

Spending by Days of Care

In 2016 just under half of Medicare spending for hospice care was for patients who received 180 or fewer days of care.

TABLE 13. MEDICARE SPENDING BY DAYS OF CARE

Total Days of Care*	Percentage of 2016 Medicare Payments for 2016
1-60	19.2 %
61-180	25.1 %
181-365	26.5 %
>365	29.2 %

**Includes days of care that occurred in 2014 and 2015 as well as 2016.*

Spending by Diagnosis

In 2016 close to 25% of Medicare hospice spending was for patients with a principal diagnosis of dementia.

TABLE 14. MEDICARE HOSPICE SPENDING BY PRINCIPAL DIAGNOSIS

Principal Diagnosis	Percentage of Medicare Payments
Cancer	19.6 %
Cardiac and Circulatory	20.2 %
Dementia	24.9 %
Respiratory	10.9 %
Stroke	10.4 %
Other	14.0 %

Spending by Level of Care

In 2016 the vast majority of Medicare spending for hospice care was for care at the Routine Home Care level.

TABLE 15. MEDICARE SPENDING BY LEVEL OF CARE

Level of Care	Percentage of Medicare Payments
Routine Home Care	92.3 %
Continuous Home Care	1.3 %
Respite Care	0.3 %
General Inpatient Care	6.1 %

WHO PROVIDES CARE?

How many hospices were in operation in 2016?

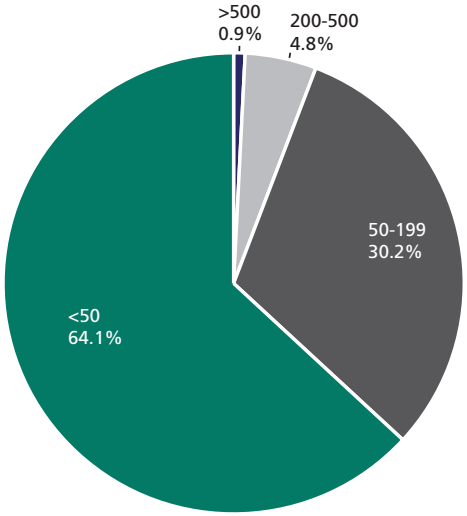
Over the course of 2016, there were 4,382 Medicare certified hospices in operation.

Hospice Size

One indicator of hospice size is average daily census (ADC) or the number of patients cared for by a hospice on average each day.

In 2016 the mean ADC was 63 and the median 31. The majority of hospices had an ADC of less than 50 patients.

FIGURE 4. AVERAGE DAILY CENSUS



Tax Status

62.5% of active Medicare Provider Numbers were assigned to hospice providers with for-profit tax status and 24.7% with not-for-profit status. Government-owned hospice providers comprised 12.8%.

Patient Volume

Admissions

In 2016 hospice providers performed a total 1.2 million unduplicated admissions* of Medicare hospice patients.

** Unduplicated admissions include patients who were part of the census at the end of 2015, carried over into 2016, discharged in 2016 and readmitted within the year.*

Volume of Deaths

In 2016 the highest number of hospice providers served 50 or fewer patients who died while enrolled in hospice care.

TABLE 16. VOLUME OF DEATHS

Total Deaths in 2016	Percentage of Hospice Providers
0 – 50	33.1 %
51 – 100	17.8 %
101 – 200	18.2 %
201 – 500	18.6 %
501 – 1000	8.1 %
>1000	4.1 %

Volunteers

In 2016 the majority of volunteer time was for direct patient care and the majority of volunteers were designated as direct care volunteers.

TABLE 17. VOLUNTEER TIME*

Type of Volunteer Sevice	Percentage of Volunteer Time
Direct Patient Care	42.7 %
Clinical Support	29.9 %
Non Clinical	27.4 %

**2015 and 2016 combined*

DATA SOURCES

The primary data source used for the findings in this report is CMS hospice claims data included in the hospice standard analytical file Limited Data Set (LDS). The NHPCO National Data Set (NDS) is the data source for the Volunteer and Bereavement statistics. The FY 2018 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements is the source for the Tax Status statistics.

Hospice Limited Data Set (LDS)

The hospice standard analytical file contains final action claims submitted by hospice providers. Once a beneficiary elects hospice, all hospice related claims are included in this file. Selected variables within the files are encrypted, blanked, or ranged.

The LDS file includes:

- the level of hospice care received (e.g., routine home care, inpatient respite care),
- terminal diagnosis (ICD-9/10 diagnosis),
- the days of service,
- reimbursement amounts,
- hospice provider number and beneficiary demographic information.

Federal Register 82: 36638

Aug. 4, 2017 (42CFR418)
"FY 2018 Hospice Wage Index and Payment Rate Update and Hospice Quality Reporting Requirements"

This document, prepared by CMS, contains certain descriptive information about hospice in 2016.

NHPCO National Data Set (NDS)

The NDS is a voluntary data collection initiative that gathers information on a wide range of hospice operations. NDS summary results provide useful information to hospices for defining strategic goals, setting operational targets, and improving care delivery.

SUGGESTED CITATION:
NHPCO Facts and Figures: Hospice Care in America. Alexandria, VA: National Hospice and Palliative Care Organization, March 2018.

QUESTIONS MAY BE DIRECTED TO:
National Hospice and Palliative Care Organization
Attention: Research
Phone: 703.837.1500
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www.nhpco.org

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Hospice History and Facts

Hospice facts

- Hospice care is a service, which may be provided at home, in a hospital, a nursing home, or in a facility specifically designated for such service.
- Hospice does not hasten or prolong death.
- Hospice care may be recommended for patients with a usually less than six-month life expectancy and an incurable illness for whom the focus of care is primarily comfort.
- The goal of hospice is to provide comfort, reduce suffering, and preserve patient dignity.
- A team consisting of doctors, nurses, social workers, clerics, volunteers, and therapists participate in the care of hospice patients.
- Medicare, Medicaid, and most private insurance carriers provide hospice benefits.

What is hospice care?

Hospice is a field of medicine that focuses on the comprehensive care of patients with terminal illnesses. Hospice need not be a place but rather a service that offers support, resources, and assistance to terminally ill patients and their families.

The main goal of hospice is to provide a peaceful, symptom-free, and dignified transition to death for patients whose diseases are advanced beyond a cure. The hope for a cure shifts to hope for a life free of suffering. The focus becomes quality of life rather than its length.

Hospice care is patient-centered medical care. A host of valuable services are offered to address every aspect of the patient's care as a whole. This is achieved by considering each individual's goals, values, beliefs, and rituals.

Why is hospice care important?

In many chronic and progressive conditions such as cancer, heart disease, or dementia, the natural disease process can ultimately reach an end stage. Most of the time, as a disease progresses to an advanced stage, its symptoms become more intolerable and difficult to control. As a result, an end-stage condition can significantly impair a person's functional status and quality of life.

At this point, often there is no further cure or treatment to control the progression of the disease. Furthermore, aggressive treatment may only offer little benefit while posing significant risk and jeopardizing the patient's quality of life.

In such late stages of diseases, hospice can offer help for patients and families. The use of the term "nothing left to do," is generally to be avoided by health care professionals. There may be nothing with curative potential to do, but there is always something to do that helps with symptoms or improves quality of life. There are many aspects of a patient's well-being that can be addressed. Hospice can play a key role in managing physical symptoms of a disease (palliative care) and supporting patients and families emotionally and spiritually.

Hospice care promotes open discussions about "the big picture" with patients and their loved ones. The disease process, prognosis, and realities are often important parts of these discussions. More importantly, the patient's wishes, values, and beliefs are taken into account and become the cornerstone of the hospice plan of care.

Hospice and palliative-care philosophy encourages these type of discussions with treating physicians early on in the course of a terminal disease. Patients can outline their preferences before they become too ill and incapable, thereby relieving some of the decision-making burden from family members. Advance care directives can be discussed and their completion facilitated in this setting.

What is the history of hospice?

Toward the end of the 19th century, hospices became designated places for the care of terminal patients in Ireland and England. The modern concept of hospice was later developed in England in 1967 by Dr. Cicely Saunders.

St. Christopher's hospice was the first hospice under the direction of Dr. Saunders. The philosophy of end-of-life care and the practice of hospice have since spread to many other countries around the world.

In the United States, hospice was originally run by volunteers who cared for dying patients. In the 1980s, Medicare authorized formal hospice care and Medicare hospice benefits became part of Medicare Part A. State-run insurances or Medicaid also offer hospice benefits, as do most private insurances.

Currently in the United States alone there are several thousands of hospice agencies. This branch of the medical field continues to grow as more people live longer with their chronic conditions. As a result, hospice can become a reasonable option for more patients during the disease progression.

In the early 1990s, hospice became an official medical subspecialty and physicians involved in the care of hospice patients could become board certified in hospice and palliative medicine.

What are the main goals of hospice care?

The end-of-life period is a sensitive part of everyone's life cycle. Psychosocial, financial, interpersonal, medical, and spiritual conflicts are all intertwined.

The main goal of hospice care is to reduce potentially unavoidable physical,

emotional, psychosocial, and spiritual suffering encountered by patients during the dying process.

As a result, medical care during this period is very delicate and needs to be individually tailored. End-of-life care requires detailed attention to each person's wishes, beliefs, values, social situation, and personal characteristics.

The complex care of hospice patients may include the following:

- Managing evolving medical issues (infections, medication management, pressure ulcers, hydration, nutrition, physical stages of dying)
- Treating physical symptoms (pain, shortness of breath, anxiety, nausea, vomiting, constipation, confusion, etc.)
- Counseling about the anxiety, uncertainty, grief, and fear associated with end of life and dying
- Rendering support to the patient, their families, and caregivers with the overwhelming physical and psychological stresses of a terminal illness
- Guiding patients and families through the difficult interpersonal and psychosocial issues and helping them with finding closure
- Paying attention to personal, religious, spiritual, and cultural values
- Assisting patients and families making their wishes known and also reaching financial closures (living will, trust, advance directive, funeral arrangements)
- Providing bereavement counseling to the mourning loved ones after the death of the patient

What are some misconceptions about hospice care?

Many misconceptions about hospice care still exist in the mind of the public and health-care professionals. For example, it is perceived that hospice is a physical location and it only treats pain in cancer patients.

The following are some of the true facts about hospice to clarify these misconceptions.

- Hospice care can be provided in many settings. It need not be only a physical place where patients go to die.
- Hospice is not only for cancer patients.
- Hospice does not deal only with pain management.
- Hospice does not hasten or prolong death.
- Hospice does not discriminate based on age, gender, race, or religion.
- Hospice does not participate in or encourage active euthanasia.
- Hospice does permit patients to see their regular physician.
- Hospice does allow patients to go to hospital if they choose.
- Hospice can be revoked at any time by patients or their families.
- Hospice can be provided for children with terminal disease.

What kinds of services does hospice care provide?

Services provided under hospice depend on the patient's needs and medical

condition. General services provided by hospice include

- routine medical assessment and evaluation by a physician,
- frequent nurse visits ranging between daily to weekly depending on patient's needs and condition,
- spiritual counseling,
- social worker evaluation,
- volunteer services.

Additional personnel, including dieticians, pharmacists, home health aids, and other therapists, can also be involved in the care of a patient under hospice.

Contribution from these team members is dictated by the needs and goals of the patient.

In regards to medications, hospice typically supplies medications that help with managing and controlling the symptoms of the underlying condition.

In addition, durable medical equipment and medical supplies are routinely provided and covered under hospice benefits. Wheelchairs, hospital beds, wound-care supplies, oxygen tanks, nutritional supplements, diapers, and urinary catheters are examples of some of the equipment often provided to patients by hospice.

Are hospice services available for children?

Most, but not all, hospices render care for pediatric patients with terminal illnesses. The care provided for children on hospice is generally even more delicate and complex because of

- challenges in communicating with children about their illness,
- children's perceptions about illness and death,
- difficulty assessing children's symptoms,
- unnatural and dramatic circumstance for parents,
- effects of a child's illness on other siblings and friends,
- uneasy social interactions with other children.

Hospices which provide pediatric care often use the expertise of counselors, therapists, and social workers trained in child psychology and communication.

Can hospice care be offered **at home**?

Yes, because hospice is a service which can be provided in many different settings. Its location to deliver care is based on each individual's preference. In fact, the majority of patients on hospice stay at their home or their usual residence (nursing homes or long-term care facilities) as they did prior to going on hospice.

Hospice care can be offered where the patient lives as long as the environment is safe, and the intensity of care does not overwhelm the patient and caregivers.

Occasionally, a patient may need to be moved to a nursing facility or another health-care setting if their home care becomes unachievable. This situation usually arises because of a need for higher level of personal care or uncontrolled symptoms requiring close monitoring by trained staff.

What are some medical conditions commonly referred to hospice?

Even though cancer remains one of the most common hospice diagnoses, many other terminal conditions are now very routinely referred to hospice.

Conditions other than cancer that are commonly referred to hospice are

- lung disease (chronic obstructive lung disease, COPD);
- heart disease, congestive heart failure;
- stroke;
- coma;
- advanced liver disease, cirrhosis;
- end-stage kidney disease;
- dementia (Alzheimer's or other types);
- advanced neurologic diseases (Parkinson's disease, ALS);
- human immunodeficiency virus (HIV)/AIDS.

In reality, no specific restrictions exist as to what conditions can be referred to hospice. Any disease that is deemed end stage is not reversible, and its further treatment poses more burden than benefit can be considered for referral to hospice.

How is referral to hospice made?

Referral to hospice is considered when a physician believes the patient's life expectancy is less than six months if the disease runs its natural course. Clinical guidelines are available to help clinicians with these determinations.

The option for hospice is then presented to the patient or their surrogate decision makers. If the patient's or their decision makers' goals and wishes are in line with hospice principles, then a formal referral can be made by the doctor.

Hospice staff meet with the patient and family to discuss hospice services. They evaluate the patient's medical condition, functional level, living situation, religious beliefs, and social support system. They determine long-term goals, wishes, and expectations of the patient and family members.

Once criteria for a terminal diagnosis are established and the patient and family consent to hospice care, a two-physician certification has to be signed certifying the terminal illness and appropriateness of hospice. The hospice certificate is typically signed by the referring physician and the hospice medical director.

How does hospice care work?

Hospice strives to optimize comfort and quality of the remaining life and to

preserve patient's dignity. The patient agrees to forego further treatment aimed at curing their disease. A comprehensive care plan consistent with the patient's goals and wishes is established.

Routine home visits from nurses, social workers, clergy, volunteers, caregivers, and home aids are provided. The frequency of these visits may vary considerably for each patient's individual situation. Hospice nurses visit the patient at least once or twice a week, but these visits can increase to as often as daily in a crisis situation. Other staff may also attend to the patient as frequently as the patient's care mandates.

For patients living in assisted-living facilities or nursing homes, collaborative hospice services are coordinated with the facility's own staff.

Hospice medical directors or other hospice contracted doctors are available to the hospice team by phone 24/7 to address any issues that may arise at any time with patients.

The patient's personal physician or primary-care physician can stay on as the attending physician if he or she chooses to. In these situations, the primary doctor can work in collaboration with the hospice team and the hospice medical director. If the primary-care physician decides not to follow the patient on hospice, then the hospice medical director acts as the patient's primary-care physician.

Home visits by hospice doctors are sometimes necessary in cases of crisis or in situations where a physician's expertise is necessary in the care of the patient. Furthermore, since the beginning of 2011, Medicare has mandated more frequent doctor visits if a patient remains on hospice beyond six months. A face-to-face patient encounter is required every 60 days to justify continual hospice care.

Medications for treating pain and other symptoms, as well as medical supplies and equipment, are part of the care provided by hospice for their patients.

Generally, therapies that are thought to be a cure for the underlying hospice condition are not offered. For example, a patient who has a terminal cancer as their hospice diagnosis may not receive any further chemotherapy and radiation for a curative purpose while on hospice. However, if such a therapy is offered to relieve an intractable symptom (for a palliative reason), some hospices may agree to cover these costs.

Who is part of the hospice team?

At the very core of every hospice there are four required components: medical doctors, nurses, social workers, and chaplains.

In addition to these core components, essentially all hospices benefit from involvement of other support staff who make irreplaceable contributions to patient care and are vital to survival of hospice organizations. Contributions of these team members vary between hospices and depend on the plan of care of the patients.

Hospice volunteers are an integral part of the hospice team. They assist patients with meal preparation, running errands, companionship, basic needs around the house, and other projects to help the patient and the family. Certified home health aides are another important part of hospice care. Home aides are usually employed by hospice and help patients and families with personal care such as assistance with bathing, feeding, and other basic needs.

Hospices often utilize other ancillary staff including

- nurse assistants and LVN (licensed vocational nurses),
- dieticians or nutritionists,
- speech, physical, occupational therapists,
- bereavement counselors,
- respiratory therapists,
- pharmacists.

Less commonly, some hospices may utilize the expertise of acupuncturists, music therapists, massage therapists, psychologists, or art therapists if these services are thought to improve the patient's symptoms or overall quality of life.

Hospice patients are always (24 hours a day, seven days a week) under the care of the hospice medical directors through nurses and other hospice team members.

An essential component of hospice care is the interdisciplinary team (or IDT) meeting which takes place every two weeks. During the IDT, each patient's progress, active issues, and overall plan of care are thoroughly reviewed by the hospice medical directors, nurses, social workers, volunteers, chaplain, and other ancillary staff who are involved in the patient's care.

Because hospice care is centered around the patient as a whole, the recommendations and input from each team member in IDT contribute meaningfully to the overall plan of care.

What is respite care?

Respite care is a rest period provided for hospice patients' families or caregivers. In cases where a patient's caregiver (either family or private caregiver) has an emergency or simply needs to rest temporarily from the burden of caregiving responsibilities, respite care can be arranged.

During respite care, a hospice patient can be moved for a period of up to five days to a nursing home while caregivers can take a brief time off. This period allows the family or the caregiver to address their own issues or simply take a much needed rest. After the respite period, the patient can return home.

Who is eligible for hospice care?

As a general guideline, hospice is recommended to a patient with an incurable terminal disease with a life expectancy of six months or less if the disease were to

run its normal course.

Although this is the rule by which Medicare defines hospice eligibility, it is not always possible to predict whether an individual will live less than six months. Therefore, certain clinical criteria are in place for common hospice diagnoses. Physicians can use these guidelines to assess whether someone is a candidate for hospice referral.

In addition to disease specific criteria, there are also other general guidelines for hospice eligibility. These guidelines are based on the patient's functional status and physical signs and symptoms which can indicate advanced stages of a disease regardless of the diagnosis.

Even with these guidelines in place, many patients outlive the six-month period on hospice. If this happens, hospice can thoroughly reassess the overall condition of the patient and determine whether there are signs of ongoing clinical decline. They can then recertify the patient to remain on hospice if there is evidence of disease progression.

Sometimes, the disease may stabilize, or the patient's condition may show evidence of improvement during hospice care. In these situations, hospice will terminate hospice care and the patient can resume their routine health-insurance benefits which they had prior to the hospice enrollment.

Who pays for hospice care?

Medicare recipients are entitled to receive Medicare hospice benefits under Medicare Part A. Most state Medicaid programs also cover these services. The majority of private insurance carriers have hospice benefits as well.

How can people find and choose hospice care?

There are numerous choices for hospice care in every state, county, and city. The list of hospice companies for patients to choose from varies based on the location.

Although hospices typically offer the same basic requirements and focus on the comfort and quality of life, there is also some degree of flexibility and variation among different hospice agencies.

Your physicians or local hospitals may recommend a hospice for you. Most physicians are familiar with local hospice organizations and can refer patients or provide a list of what is available.

The following lists some general resources for people who are interested in more information about hospice in their local areas:

- Primary-care physician, specialists, or hospital doctor (hospitalist)
- Local hospitals and urgent-care centers
- Medical social workers

- Nursing homes or skilled nursing facilities
- State health department
- Health insurance carrier
- Local home health agencies
- Phonebook
- The Internet

What questions should people ask of hospice agencies?

Hospice frequently asked questions (FAQ)

1. Who pays for hospice?

Most people are concerned about the how the cost of hospice is covered. Medicare hospice benefit is a part of Medicare which would cover hospice care once a Medicare beneficiary is enrolled in hospice. Most other private insurance plans also carry their own hospice benefits.

2. Can I take my regular medications on hospice?

Many people want to know whether they should continue taking their regular medication while on hospice. This depends on the patient's goals, medical condition, prognosis, and the indication for these medications. In general, most medication can be continued as long as they do not interfere with patient's comfort and are not taken as a potential cure for the hospice qualifying condition. Most people prefer to take fewer pills. They can ask hospice which medications they can safely discontinue without an untoward reaction.

3. Can hospice help with my living situation?

Many people may have difficulty with having their loved ones die at home or simply are unable to provide the level of care that is needed. Hospice agencies often have relationships are local assisted-living facilities which can accommodate hospice patients, usually at an additional cost. Alternatively, sometimes Medicaid plans can cover some of the room and board cost at these rest homes.

4. Can hospice provide treatment for infections?

Many patients and families are concerned whether they can receive treatment for infections such as pneumonia or urine infection. Hospices are flexible in terms of their approach to treating reversible infections. Most, but not all, offer diagnostic tests and antibiotics. It is important to address these concerns during the initial hospice evaluation.

5. Is my own doctor allowed to see me on hospice?

Others want to know if they can still see their own regular physicians. As mentioned earlier, primary-care doctors can continue to follow their patients on

hospice and even make home visits.

6. Is it possible to go the hospital if I am on hospice?

Hospitalizations are covered if someone's symptoms are out of control despite routine hospice care at home. Patients can also be hospitalized for conditions unrelated to the hospice diagnosis. For example, if a patient with cancer suffers a fall and has a hip fracture, hospitalization may be required to fix the fracture. In this scenario, the patient's insurance usually covers the hospitalization in addition to the hospice benefits.

7. Other than medication and equipments, what other services does hospice offer?

Ancillary services such as nutritionists, therapists, and home health aides provide valuable services for hospice patients. The degree to which every hospice utilizes these services varies widely. Sometimes these additional interventions are important to patients and their families. Thus, it is advisable to discuss the availability of these services with the hospice representatives.

Where can a person find more information about hospice care?

A good starting point for people to find out more information about hospice care is their primary-care doctor's office or local clinics and hospitals.

Other than the resources listed previously, one can also search the Internet for more information or refer to the following:

- National Hospice and Palliative Care Organization
  http://www.nhpco.org/templates/1/homepage.cfm
- The National Association for Home Care and Hospice
  http://www.nahc.org
- National Institute of Health (NIH)
  http://www.nih.gov
- Hospice Medicine Foundation
  http://www.hospicemedicinefoundation.org
- American Academy of Hospice and Palliative Medicine
  http://www.aahpm.org/index.html
- Medicare publications and web site
  http://www.cms.gov
- State Medicaid publications

Medically reviewed by Jay B. Zatzkin, MD; American Board of Internal Medicine with subspecialty in Medical Oncology

REFERENCE:

National Hospice and Palliative Care Organization. "History of Hospice Care." Jan. 29, 2010.