The mission of Hospice and Palliative Care of St. Lawrence Valley is to enhance the quality of life through compassionate care for people affected by advanced illness and grief.

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Hospice and Palliative Care of St. Lawrence Valley, Inc.
6805 US Hwy 11
Potsdam, NY 13676
Tel. (315) 265-3105
Fax (315) 265-0323
Email: info@hospiceslv.org

Office Hours
8:00 - 4:30 p.m.
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Improving Dying in America
By Brian Gardam
Executive Director

Recent studies have reported disappointing results for the efforts to improve care at the end of life. Although most people would prefer to die at home, most people in America are still dying in the hospital. People are experiencing unacceptable pain levels in the last year of life. The US ranked ninth in a “Quality of Death Index”, using such measures as the availability of hospice and end-of-life training for health care professionals.

It is some comfort that our results at Hospice and Palliative Care of St. Lawrence Valley are better. Very few of our patients who receive care at home are admitted to the hospital. Families give us high scores for controlling pain and other symptoms. And 40% of people in St. Lawrence County receive hospice care in the last year of life, compared to 26% in New York as a whole.

But there is obviously much more to be done, both locally and nationally. Last fall, the Institute of Medicine issued a landmark report entitled Dying in America: Improving Quality and Honoring Individual Preferences at the End of Life. Here are some of its key findings:

• People nearing the end of life experience too many transitions between providers that fragment care and increase the burden on patients and families. (Through our Home Support Program, we work with local hospitals for years to improve transitions of care and readmissions).

• Demand for family caregiving is increasing, and the types of tasks performed by family caregivers are expanding from personal care and household tasks to include medical and nursing tasks, such as medication management. (Our Caregiver Support Program addresses the needs of family caregivers, even before the patient is on hospice).

• Palliative care is associated with a higher quality of life, including better understanding and communication, access to home care, emotional and spiritual support, well-being and dignity, care at time of death, and lighter symptom burden. Some evidence suggests that, on average, palliative care and hospice patients may live longer than similarly ill patients who do not receive such care. (Our community-based Palliative Care Program focuses on the medical and social issues of progressive illness, and enables patients to transition to hospice care when appropriate.)

• Although professional guidelines and expert advice increasingly encourage oncologists, cardiologists, and other disease-oriented specialists to counsel patients about palliative care, widespread adoption of timely referral to palliative care appears slow. (Current efforts at health system reform in New York will reward providers for making more timely referrals to palliative care, and we have presented programs to increase the palliative care knowledge of staff in physician practices.)

• Most people nearing the end of life are not physically, mentally, or cognitively able to make their own decisions about care. The majority of these patients will receive acute hospital care from physicians who do not know them. Therefore, advance care planning is essential to ensure that patients receive care reflecting their values, goals, and preferences. (We have long advocated advanced care directives, and our Palliative Care Program providers are championing use of the electronic Medical Orders for Life Sustaining Treatment – eMOLST form – so that physicians have ready access to knowledge of the patient’s wishes).

Continued on page 5
Quality Assessment and Performance Improvement

By Nina Nuwer, LMSW
Director of Quality Improvement and Information Services

Quality Assessment and Performance Improvement (QAPI) activities in 2014 continued to focus on improving the care provided to Hospice patients and compliance with new Medicare for Quality Reporting. While some new performance improvement projects were started in 2014, several projects started in 2013 were continued in 2014.

Documentation of pain management, an area that Hospice and Palliative Care of St. Lawrence Valley has been monitoring on a monthly basis for the last four years, continued in 2014. As pain and symptom management are the foundation upon which hospice is based, we will continue to monitor and track pain control on a regular basis. The requirement for staff to follow up on any reported or observed exacerbations of pain continues and its importance is underscored through the inclusion of the pain measure in staff evaluation. At year-end 2014, we had achieved 85% compliance.

A performance improvement project on insuring that depression and anxiety symptoms were addressed per our patients wishes continued into 2014. Interventions were developed to improve collaboration between the interdisciplinary team members, so that all instances of anxiety or depression were followed up by the appropriate staff member. By June of 2014, our results were at 90% or higher in both areas.

As a response to a family caregiver’s letter following his loved one’s death, we developed a “Bridge to Bereavement” performance improvement project to identify ways to help families transition from the hospice program, in which there is a high degree of staff involvement and presence in the home, to the bereavement program. The project committee included representatives from nursing, social work, volunteers, home health aides, and administrative staff, and resulted in a series of staff in-services, change in agency protocols, and a heightened awareness of professional boundary issues. The in-services will be offered to staff on an annual basis. By year-end 2014, there had been no further correspondence from families with concerns about the transition from hospice to bereavement, and the project was completed.

In July, 2014, Medicare regulations became effective, requiring the reporting of a set of nine quality indicators, called the Hospice Item Set (HIS). These quality indicators include assessment and treatment of pain and dyspnea, a bowel regimen when a narcotic pain medication is ordered, and discussion of the patient/family wishes regarding cardiopulmonary resuscitation, other life-prolonging treatments, hospitalizations and spiritual concerns. We started tracking these measures in January 2014, to be prepared for reporting in July. By year end, 6 of 9 indicators had documented results above 90%, one indicator scored in the 80% range, and only 2 were below 80%. Results are shared with staff on both a group basis and an individual basis as an educational tool.

Hospice achieved Level Four in the Hospice-Veterans Partnership program, in 2014. The purpose of the partnership is to increase veterans’ access to end-of-life care. As part of the Level Four designation, hospices must have a performance improvement project based on questions specific to veterans on the Family Evaluation of Hospice Services survey. This survey goes out to all families hospice has served. Based on the results of the survey, we chose “Staff listened to patient’s stories related to military experience (always),” with a goal of raising the percentage from 50% to 75%. Although YTD results are lower than our goal, October and November started an upward trend in our data, with results of 100% for both months. We will continue to monitor veteran’s results in 2015.

As 2014 drew to a close, we began to prepare for the new Medicare patient survey requirements which will be effective in the second quarter of 2015. We also began an in-depth review of other patient database software to determine if productivity, efficiency and accuracy may be improved through the use of other software systems. These two projects will be major areas of focus for 2015.

On the Cover...

Pictured are several Healing Stones created by Hospice staff and volunteers. Stones are available at the Hospice Center for individuals who visit to receive counseling and support following the loss of a friend or loved one. Creating Healing Stones is also used as an activity in schools and groups to assist in the grieving process. The stones provide emotional support and healthy coping by helping the individual identify a word that offers them support. When creating and holding their stone, they are encouraged to be empowered by the hope and strength the word provides. It can offer time for reflection in a group or privately. Just as grief is unique to each person who experiences it, the stones have a unique meaning and impact to each person who holds them.
The Family Support Services department includes the disciplines of social work, bereavement, community education, caregiver support, spiritual care and volunteers. In 2014 we said good-bye to social workers Christina Snell and Coreen Bohl as they moved on to other opportunities. Scott Blankenship, LCSW-R, joined the department as the social work clinical supervisor and Palliative Care Social Worker. Community Educator, Nancy Vosbrink, and Bereavement Coordinator, Kay DePerno, successfully obtained Certifications in Thanatology from the Association of Death Education and Counseling.

Caregiver Support
Nancy Vosbrink continued to develop the caregiver program in 2014. The First Annual Caring for the Caregiver Event was held on June 5th to showcase the new Caregiver Program. Twenty-five individual caregivers attended, visiting the 18 agencies who provided essential information to assist them in carrying out their important role. The response from all was very positive with many asking about a date for next year’s fair. Caregiver resource materials were developed and distributed to fair attendees. This information will be updated in conjunction with the annual Caregiver Event. Caregivers participating in the fall education series received a binder with information on a variety of topics including self-care, family communication and navigating the health care system.

A Caregiver Education Program and Support Group was developed to address the needs of caregivers in the community. The support group was offered on a trial basis in the fall addressing topics such as: Taking Care of the Caregiver: Information on Self-care and Stress Management; Navigating Changing Health Care Needs: Tools for tracking and managing Health care changes; and Alzheimer’s and Dementia: Coping as a Caregiver. Groups were well attended and demonstrated a need for the service to continue. In 2015, caregiver support groups will be offered the second Thursday of every month at the Hospice Center. Groups are free of charge and open to any caregiver. A Hospice affiliation is not required.

Bereavement Services
Mary Jones and Kay DePerno presented a workshop “When Grief Comes to School: Lesson Plans for Grief Support Groups in Schools” in May at the annual meeting of the Hospice and Palliative Care Association of New York State in Albany. Kay DePerno traveled to Colorado in September to participate in a four day workshop on the grief of suicide at the Center for Loss. There were a number of schools coping with suicide loss in 2014. A six week grief support group for those who experienced the grief of suicide will be offered in 2015.

St. Lawrence-Lewis BOCES contracted with Hospice Bereavement Services to provide support and education to schools experiencing the death of a student or teacher. The program, developed by hospice bereavement staff, has provided support to nearly every school district in St. Lawrence County over the last 18 years.

The Grief during the Holiday series, offered monthly November – January experienced record attendance. Participants learned about strategies to cope during the holidays and rituals of remembrance.

Volunteer Services
Volunteer Coordinator, Jennifer Brailsford, developed the volunteer aspect of the We Honor Veterans program, offering training, volunteer job duties and veteran to veteran assignments. With the help of long time flower donor, Maryann Catarfors, Jennifer instituted the summer flower delivery program to hospice patients residing in the Potsdam and Canton areas. Maryann gathers bouquets from her garden at home and delivers them to the Hospice office each week. She describes her work as a “privilege to share the beauties of mother nature with someone one last time.”

We Honor Veterans Program
This year, the agency completed the final requirements to submit our Level 4 application the National Hospice and Palliative Care Organization’s program. This involved a variety of steps around updated policies, performance improvement and community partnering. We were the second Hospice in New York State to achieve this highest level offered. We have continued hosting the Hospice Veteran Partnership of the North Country. This partnership has enhanced relationships with several agencies and groups supplying veteran services to recognize, honor and thank our Hospice Patients for their service. During the year we completed 45 Veteran Pinning Ceremonies for Hospice patients. There has been significant positive feedback for this program from patient family members, volunteers and staff.

Camp Healing Hearts
June 2015

Camp Healing Hearts will take place on Friday, June 26th, 2015. The one day grief camp is a fun filled day of activities for children, ages 5-17 (grouped by age) who have experienced the death of a family member or a close friend. Trained counselors will lead activities designed to help campers begin to understand what grief is and learn positive ways to cope. This year’s camp theme is A Day at the Carnival and is sure to be a positive, enjoyable experience for everyone! There is no cost to attend. If you have any questions or would like to register for camp contact:

Kay DePerno at Hospice:
(315) 265-3105
kdeperno@hospiceslv.org/slc
Since being founded by volunteers more than 30 years ago, donors have been the cornerstone in helping Hospice provide excellent comfort care for our patients. In 2014, Hospice staff cared for more than 500 patients and donors, in turn, supported the organization generously. Donors who gave to the Annual Appeal and those who gave in memory of their loved ones provided more than $263,000 in support of the care provided to community members. Those who left gifts to Hospice in their wills contributed significantly to the financial stability of the organization.

Many supporters attended fundraising events sponsored by Hospice such as Swim a Mile for Hospice and Tastes of Autumn, or pledged support through our Annual Radiothon for Hospice hosted by Community Broadcaster and Stephens Media Group. In 2014 Lou Williams, owner of The Gran View in Ogdensburg graciously welcomed Hospice volunteers to put on the first ever Tastes on the River. Many dedicated community members also organize events like the Community Bank Golf Tournament, the Hospice Motorcycle Run (which celebrated its 15th anniversary in 2014), the Bob Law Memorial Golf Tournament, Parishville AMVETS Ladies Auxiliary Walk/Run and many other activities. These special events raised more than $100,000 for Hospice care in our county.

During each holiday season Hospice invites supporters to make gifts in memory of loved ones, most of whom have been cared for by Hospice. Their names are added to stars which decorate two Memory Trees at the Hospice office. In 2014, more than one thousand stars covered the trees and provided Hospice with a record amount of support.

It is truly humbling to witness the amount of community support that Hospice is shown throughout the year. This support serves as motivation to our staff to continue providing excellent care and gives us the ability to provide programming beyond what is covered by insurance.

Thank you all!

Improving Dying in America Continued

- Incentives under fee-for-service Medicare result in more use of services (hospital days, intensive care, emergency care), more transitions among care settings, and late enrollment in hospice, all of which jeopardize the quality of end-of-life care and add to its costs. In addition, payment silos contribute to fragmentation of care, hinder coordination across providers, and encourage inappropriate utilization. (Federal and state experiments with “value-based” reimbursement seek to reward providers for outcomes, not the number of services provided).

There is a lot of work to do to improve the quality of dying. We have made some important steps locally that are showing results. But improving the delivery of care, patient-provider communication, advanced care planning, professional education, and payment systems must guide our local and national agenda so we can be proud of the kind of end-of-life care this country provides.
By Gayle Hammers, RN
Director of Patient Care Services

The most noticeable change that took place in 2014 is the retirement of Sue Cappione, RN, after 25 years as the Director of Patient Care. Her dedication and loyalty to the agency, as well as the hospice philosophy, will be greatly missed. Her mantra “What does the patient want?” has been passed down and continues to be at the forefront of patient care services as we assist patients with self-determined life closure.

We have adapted our work practices as regulatory changes have occurred. Changes to Medicare Part D coverage of hospice medications had the biggest impact on the agency over the past year. The original regulation went into effect in April 2014 but was revised in July, thanks to hospice organizations and advocates across the nation. The revised regulation is much more manageable and allows our hospice to more effectively serve patients.

Hospice currently employs 9 fulltime primary care RNs as well as 9 per diem RNs. Jackie Donie joined the Maple Team as a primary RN in 2014. She lives in Massena and has extensive long term care experience including caring for patients at the end-of-life in skilled nursing facilities. We hired 3 per-diem RNs on the Pine Team; Ann Bonno, Jordyn Downing, and Paige McCrea. Hope Cameron and Vic Goodrow recently joined the Oak Team as per-diem RNs. Per diem staff are essential in assisting with coverage of on-call hours as well as vacations and sick leave. Sharon Bearce, RN CHPN retired after 11 years with Hospice. She was an End of Life Nursing Education Consortium (ELNEC) instructor, as well as a mentor to many and a blessing to all! We are also pleased to announce that Lucille D’Agostino RN, an 8 year employee and primary nurse, received her Bachelor’s in Nursing from SUNY Canton in December 2014.

Our patient care team would not be complete without the Direct Care Staff who are often with the patients more frequently than other staff. We currently employ 12 Licensed Practical Nurses (LPN) and 8 Home Health Aides (HHA). Anne Karlberg hired 3 new staff in 2014; Kayla Beaudin HHA, Tasha Bogrette HHA, and Tracy Donie LPN. Long time Hospice employee Jane Barr, HHA, came out of retirement to once again join our team.

Several of the patient care employees (RN, LPN, HHA) have expressed interest in becoming certified in Hospice and Palliative Care this year. Becoming certified is important in that it reinforces to patients, providers and the community that we are specialists in end-of-life care, making us a unique and valuable commodity in St. Lawrence County. Hospice continues to provide education to several health-related programs in the county, and provides a site for internships and job shadowing. Sharing our knowledge with others is of utmost importance to assist the community in fully understanding the mission of Hospice and Palliative Care of St. Lawrence Valley.

My hope is that this year of transition as the new Director of Patient Services will be as seamless as possible, with continuity in promoting our mission of enhancing the quality of life through compassionate care for people affected by advanced illness and grief.

Reflecting on the First Year of Palliative Care

Many years of planning and preparation came to fruition in 2014 as the Palliative Care program made the expansion of services to include patient consultations. Nurse Practitioner, Missy Heylen, CHPN, saw her first patient on February 5th. Since that time there have been 200 admissions to the Palliative Care program resulting in 525 visits. The majority of palliative care consultations were completed in the patient’s home. Patients and families have also received services in the palliative care office, local hospitals, and cancer treatment centers. The team works with each patient’s primary care provider to add an extra layer of support to reduce the impact of the illness and improve the quality of life for the patient and their family. Patients have been assisted with symptom management as well as advanced care planning and completion of advanced directives.

The team also includes Dr. Sandra McClory, Medical Director, Dr. Gary Berk, Susan Caldwell RN, Scott Blankenship LCSW, and Shelley Vebber, Office Assistant. Payment for palliative care services is primarily covered by Medicare Part B. It covers approximately 75% of our patient days and reimburses us for any visits made by the MD, NP and LCSW.

Palliative Care also includes the Home Support Program which contracts with local hospitals and provides 30 days of transitional care services once the patient is discharged from the hospital. The program provides education and support to patients who face challenges in managing their disease(s). In addition to home visits and phone calls, services offered include the Bosch Health Buddy, which is a telehealth unit with a variety of disease management programs. This enables the patient to learn self-monitoring of their disease with the support of the palliative care team.

In 2015, we hope to see our palliative care program grow even larger as we continue to provide education to providers and the community about this valuable community health resource for assisting patients in managing their chronic and/or terminal disease(s) even if they are still receiving curative treatment.
Hospice Care Around the County

Hospice care is a mobile service, with staff and volunteers driving to visit patients in their homes, nursing homes or hospitals. Within our service area of St. Lawrence County, care is provided by three teams: Maple, Oak and Pine, with all staff using the Hospice Center in Potsdam as their base.

The Pine team serves the largest geographic portion of the county and Maple, the smallest. In 2014, the Pine team also served the greatest number of patients. Hospice staff logged more than 310,557 miles in 2014 to provide care to 506 patients.

Oak Team
Ogdensburg Area
Average Daily Census 22
Patients Served 165
Days of Care 8,353
Miles driven 78,796

Maple Team
Massena Area
Average Daily Census 24
Patients served 130
Days of care 8,774
Miles driven 107,210

Pine Team
Canton, Potsdam and Gouverneur Areas
Average Daily Census 28
Patients served 211
Days of care 12,372
Miles driven 124,551

St. Lawrence County, NY

Patient Services Statistics

Hospice Average Daily Census

Hospice Patients Served by Diagnosis

Cancer
Non Can

2009 2010 2011 2012 2013 2014
Hospice Memorial Garden Reservation Form

I would like to memorialize/honor my loved one, ____________________, in the Garden with a gift to Hospice of $_________ for the following Garden feature(s) (select from list below): _________________________________

Name: ___________________________________________ Phone: ________________________________

Address_________________________________________________________________________________

2 1/4" Glass Medallion, $60  4" x 8" Memorial Paver, $125  12" x 12" Memorial Paver $500
Memorial Grove Tree, $1,500  24" x 24" Corporate Paver, $2,000

To Name the Hospice Memorial Garden in its Entirety, $50,000

When ordering a Glass Medallion or Memorial Paver, please print desired engraving below:

Glass medallions: 3 lines, up to 16 characters per line (inc. spaces). 4"x8" Pavers: 3 lines, up to 14 characters per line (inc. spaces). 12"x12" Paver: 6 lines, up to 15 characters per line (inc. spaces)

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Name on Credit Card ________________________________

Card Number___________________________________ Exp. Date______________________

Signature_____________________________________________________________________

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