2018 ANNUAL REPORT

HOSPICE & Palliative Care
Oneida, Herkimer and Eastern Madison Counties

A.I.M. PALLIATIVE CARE
Advanced Illness Management
Oneida, Herkimer and Eastern Madison Counties

Quality, Compassionate, Care
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## COMPARISON OF PALLIATIVE CARE TO HOSPICE CARE

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<thead>
<tr>
<th>PALLIATIVE CARE</th>
<th>HOSPICE CARE</th>
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<tr>
<td>Patient has a serious or advanced illness. Care is aimed at managing distressing symptoms and improving quality of life.</td>
<td>Patient must have a terminal diagnosis with a physician’s prognosis of six months or less to live, if the disease runs its normal course. Care is aimed at managing distressing symptoms and improving quality of life.</td>
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<tr>
<td>Does not require a physician’s prognosis of six months or less to live.</td>
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<td>Covered by Medicare Part B or Medicaid.</td>
<td>Covered by Medicare and Medicaid.</td>
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<td>Covered by some private insurances.</td>
<td>Covered by most private insurances.</td>
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<td>Patient may simultaneously continue with life-prolonging or curative treatments. Payment for these treatments is authorized by patient’s health plan.</td>
<td>Not eligible for hospice services if patient is seeking life-prolonging or curative treatments.</td>
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<td>Provides supportive services that are elected by the patient. These may include medical, nursing, social work, spiritual, bereavement, and volunteer. Payment for these is authorized by the patient’s health plan and/or private pay.</td>
<td>Includes these supportive services: medical, nursing, social work, spiritual, bereavement, and volunteer. Services are included in the hospice per diem rate.</td>
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<td>May continue to see multiple physicians as authorized by the patient’s health plan.</td>
<td>Patient chooses one primary physician who coordinates care with hospice and with other physicians as well.</td>
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<td>Medications, treatments, supplies, and equipment are authorized by patient’s health plan, or private pay by patient.</td>
<td>Includes medications, treatments, supplies, and equipment that are related to the terminal illness and are in the patient’s plan of care.</td>
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<td>24-hour RN on-call phone service available. Fees apply for visits.</td>
<td>Includes 24-hour RN on-call service, with visits as needed.</td>
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<td>Covered services are on a per diem or fee-for-service rate as authorized by the patient’s health plan, or private pay. A sliding fee scale may apply.</td>
<td>All services related to the terminal illness and pre-approved by hospice are included and covered in the per diem rate. A sliding fee scale may apply if paying privately.</td>
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Dear Friends,

As we look back on 2018, it was a year filled with successes and challenges. Our Board of Directors, Development Council, leadership, staff, volunteers and donors worked in close collaboration with our focus on the strategic pillars we developed in 2017: finance, quality, people, growth and service.

Over the years we have grown by hiring, training and retaining hospice and palliative care experts who embrace our mission and have dedicated their careers to providing individualized care to those we serve. We are also extremely proud of our volunteers who support our organization in so many ways by sharing their time and talents with us. We would be remiss if we did not mention our donors who lend their monetary support to our organization through, memorial gifts, legacies, grants and sponsorships. These heartfelt gifts recognizing the care we provide means so much to the nurses, social workers, spiritual care coordinator, bereavement counselors and volunteers who provide bedside and bereavement care. Every day we are blessed by donors who support our organization because of the outstanding care we have provided to their families, friends and neighbors.

An area where we continue to face challenges is the length of stay of our patients and hospice utilization in the catchment area that we serve. In 2018, 47% of our patients were on service for 7 days or less, yet a patient can be on hospice services for up to six months or longer if the disease continues to progress. In 2017 New York State ranked 49 out of 51 in the country in hospice utilization. Oneida County ranked 61 out of 62, Herkimer County ranked 50 out of 62 and Madison County 48 out of 62. We are committed to improving these numbers but we need everyone’s help to do so. Many people have a fear that if they come on to hospice services that they are giving up hope when in actuality many patients have a better quality of life when their pain and symptoms are controlled and their emotional and spiritual needs are met. Healthcare professionals sometimes have difficulty sharing with a patient that treatments are no longer benefitting them which results in patients coming to us very late in their disease process. You can help by dispelling misconceptions about hospice with your own friends and family and by making your end-of-life wishes known to your family.

HealthcareFirst announced the recipients of its 2018 Hospice Honors at the National Hospice and Palliative Care Organization (NHPCO) Conference. The prestigious Hospice Honors Program recognizes hospices providing the highest quality of care from the caregivers’ point of view. Hospice & Palliative Care received Elite Status for 2018. Elite Status honors hospices scoring above the HealthcareFirst national average on 100% of the evaluated questions. Our drive to the highest quality of patient care is a top priority. This hard work as you can see has distinguished us as a leader in the industry, as we continue to exceed national scores. The changing environment in healthcare is a daily reminder of the challenges facing Hospice & Palliative Care. It is more important than ever for hospice providers to demonstrate quality care and to add value to our referring partners.

On August 14, 2018 we were proud to represent Hospice & Palliative Care at the Observer Dispatch’s Best of the Best Awards ceremony among our peers that took place at Wildcat Field House at SUNY Polytechnic Institute. In total, 128 different businesses from the Mohawk Valley were represented in a multitude of categories. We were honored to be voted the number one homecare agency by our community.

On the human resources front we are pleased to report that we have hired a full-time Nurse Practitioner to lead our Advanced Illness Management (A.I.M.) Palliative Care Program. This service truly compliments our hospice program. There are many individuals in Oneida, Herkimer and Madison Counties who are frequently admitted to the hospital with an advanced and progressive disease who can benefit from the special care we provide. Like Hospice patients, in addition to pain and other physical symptoms of their illness, these patients are often coping with emotional, social and spiritual distress. The AIM Program is not hospice care rather it is palliative care which focuses on the relief of symptoms related to the disease. The goal of the program is to improve the quality of life by aligning the patient’s goals of care and treatment and is intended to be an extra layer of support in navigating life with a chronic illness. Most services are offered through in-person visits at the patient’s home.

Our Board of Directors and Leadership developed a comprehensive three-year Strategic Plan with input from staff, volunteers and community members. Our plan includes launching a telehealth program to better serve our patients in a whole new way, offering an online volunteer training program for individuals who would like to volunteer but prefer an online course to a traditional six-week in person class, investing in our employee engagement and retention, expanding our A.I.M. Palliative Care Program and investigating how we market and brand our services to make them more accessible to all who need and want them.

We are confident that Hospice & Palliative Care will continue to grow in new and innovative ways to serve our community. We have been truly blessed by the overwhelming support we have received over the last forty-one years from patients and families, healthcare professionals, our staff, volunteers, businesses, foundations and donors. We hope you will consider being an ambassador for our organization and spread the word about all of the valuable services we have to offer, when people need it most.

Warm regards,

Steven Brown, DM FACHE (R)  
Hospice Board President

Shannon Cayea  
Chief Executive Officer

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Hospice Board President

Shannon Cayea  
Chief Executive Officer
Caring for Patients and Families
When Hospice & Palliative Care was founded in 1977, almost every patient we provided care to had a cancer diagnosis. Today, we serve patients from newborn to over 100 years old with any end stage illness. In 2018 we served 6 patients under the age of 17 as well as 6 patients over 100 years old. Our professionally trained staff are respected and trusted by those we serve and we are privileged to be welcomed into their lives. In 2018, patients came on to hospice services with the following diagnoses:

**2018 Primary Diagnoses**
- Cancer – 47%
- Lung/ Respiratory - 15%
- Heart/ Circulatory – 12%
- Other - 10%
- Dementia/ Alzheimer’s Disease - 8%
- Stroke - 3%
- Liver/ Digestive - 4%
- Motor Neuron – 1%

**Quality Achievements**
Hospice & Palliative Care received Hospice Honors Elite Status for the 2nd year in a row from HEALTHCAREfirst. HEALTHCAREfirst announced the recipients of its 2019 Hospice Honors at the National Hospice and Palliative Care Organization’s Leadership & Advocacy Conference. The Prestigious Hospice Honors program recognizes hospices providing quality of care from the caregivers’ point of view. Based on feedback from caregivers themselves, the Hospice Honors recognizes agencies who truly stand out based on level of care and commitment displayed to their patients and their caregivers.
Keeping our patients safe, and comfortable wherever the patient calls home is the hallmark of our quality of care. The Centers for Medicare Services (CMS) requires all Hospices to send out a survey to obtain feedback from the patient’s caregiver. Hospice & Palliative Care scored high in a number of categories and exceeded the national average in many categories. These ratings are published on the Hospice Compare Website https://medicare.gov/hospicecompare.

**Quality Highlights**

91% of the family caregivers would recommend our Hospice to another person
90% of the family caregivers rated the quality of our patient care at a 9 or 10 on a 10-point scale
98% of family caregivers said they received the right amount of emotional support

**Hospice Social Workers Assist Patients and Families with Access to Resources**

In hospice care, the social worker is a vital member of the team whose role is to advocate for the needs of their patients and families. Their insight, support and recommendation can vastly improve the experience of the patient and their family. Hospice & Palliative Care social workers are great advocates for patients. There are many facets that impact a patient’s life. Our social workers get to know patients and what their goals and wishes are. This information is then able to be communicated to the interdisciplinary team as well as the patient's family by the social workers to ensure the patient’s voice is heard. Hospice social workers are licensed master social workers (LMSW's) who annually educate themselves in end-of-life care through continuing education credits. Hospice social workers have been working on updating resources that are given out to patients and families in order to provide them with the most up-to-date community resources. Because our patients needs are usually not limited to what Hospice & Palliative Care can provide, our social workers are constantly working with outside resources and agencies to ensure their patients’ needs are met. Our social workers are able to create and maintain positive relationships with agencies in the community.

All three of our social workers have met the social work supervision requirements, which began in 2015, to apply for clinical licensure to become Licensed Clinical Social Workers (LCSW's). By the end of 2019 we hope to have all of our social workers hold this LCSW title.

**Hospice Volunteers Share their Time and Talents**

The Hospice & Palliative Care Volunteer Department provides a variety of services. Some examples are patient and family volunteers, office support, as well as outreach, and many more. The Volunteer Department works with each individual volunteer to match them with the best volunteer opportunity for them based on personalities, geographic location, as well as preferences. Patient and family volunteers offer companionship and a supportive presence to meet the needs of the patient and/or family. The Volunteer Coordinator interviews each patient and or family with the goal of learning more about their interests to relay to the volunteer. Examples may be interests in music, reading, or crafts that volunteers are able to assist with during visits. Hospice & Palliative Care also utilizes volunteers for office support such as data entry or reception coverage. Each volunteer completes an initial comprehensive training with annual education thereafter. Volunteers are valuable members of our team.

In 2018, The Volunteer Department began to research alternative options for volunteer training. As we provide services spreading over three counties, online training was researched as an option to provide potential volunteers with the ability to complete training at any time during the year from their own home in hopes of recruiting more people who may have otherwise not been able to attend the in-person training. The Volunteer Department is looking forward to introducing the online training option in 2019.
**Bringing Spirituality to Patients**

The Spiritual Care Coordinator provides spiritual and emotional support for Hospice patients and their families. In this integral role, the Spiritual Care Coordinator acts as a mentor to patients and families who request such support. The Spiritual Care Coordinator is Hospice’s link to the faith community and the community at large regarding the spiritual needs of patients and their families during their end-of-life journey. The Spiritual Care Coordinator maintains available contacts with the local faith community. The Spiritual Care Coordinator also provides support to staff and volunteers.

*Anthony Fragapane, Hospice’s Spiritual Care Coordinator, states,*

“it is a privilege to be able to serve in a capacity to bring hope to the end-of-life journey for our patients and their families as well as serve with such talented administrators, nurses, social workers, home care staff, volunteers and the entire team here at Hospice. It has been humbling for me to be a part of the patient’s spiritual journey at the end of their life.”

**Bereavement Assists with Healing**

Hospice bereavement counselors provide grief support to our patients’ families for 13 months after the death of their loved one. They provide one-to-one counseling, home visits, phone support and group counseling. Community education is also provided to businesses, schools, service organizations, and community agencies on how to best support their staff and clients through the grief process. Our bereavement counselors speak on local television and radio programs providing education on grief and promoting our bereavement groups.

We have a bereavement services phone line which allows us to offer education and referrals to bereaved in the community who call throughout the year looking for resources and support. Community members join our hospice families in attending our bereavement groups, which are offered throughout the year in various parts of the counties we serve. Our groups are well attended and this year we have had to institute waiting lists. Groups are offered for Spousal Loss, Adult Parental Loss, Young Widows, and Brave Hearts. Brave Hearts helps children ages 6-12 deal with loss and grief through art therapy, gardening, and expressing their feelings. Our Brave Hearts reunion now brings past attendees back for a gardening project in which they see the daffodils they have planted in bloom. Our annual Grief and the Holidays program in the fall is attended by 60-80 people and is much appreciated by the bereaved at this difficult time of the year.

Our bereavement volunteers call our hospice families 3, 6, and 12 months after the death of their loved ones to give them an outlet to support their grief; they are an invaluable part of our bereavement support and refer families back to our bereavement counselors when they determine that family members are in need of professional counseling.

In 2018, we worked to develop our online resources for bereavement and also developed a series of mailings about specific bereavement issues to supplement our five bereavement mailings. Topics include Changes in Family Dynamics Following a Death, Grief and Guilt, Understanding the Grief Process, Grieving the Difficult Relationship, How to Help a Child Through Grief, and 30 other topics. Our website now has a section devoted to bereavement which lists internet resources to support grief, frequently asked questions about grief, and lists our bereavement groups.

Last May we welcomed Tracey Clark, MHC, NCC as a full-time bereavement counselor. Our two full time bereavement counselors and one half time bereavement counselor hold master’s degrees and work together to support our hospice families, community bereaved, and hospice staff.
STATEMENT OF FINANCIAL POSITION

REVENUE AND SUPPORT

Patient Care Reimbursement
Medicare/Medicaid/Other Insurance (88.2%) $5,262,249

Public Support
Contributions/Grants (6%) $381,006
Investment Income (1.4%) $82,446
Fundraising Income (4.3%) $257,032
Other Income (.1%) $2,126

TOTAL REVENUE AND SUPPORT: $5,984,859

Operating Expenses
Program Services (86%) $5,160,458
Administration, General and Fundraising (14%) $788,913

TOTAL EXPENSE: $5,949,371

Patients Served from 2012-2018
HOSPICE MAKES A DIFFERENCE

Together We Made A Difference in 2018

Hospice & Palliative Care appreciates the generosity of donors, staff members, volunteers, board members, and community partners who have invested in the hospice mission to provide end-of-life care in Oneida, Herkimer and Eastern Madison counties.

- 796 PATIENTS AND THEIR FAMILIES RECEIVED HOSPICE CARE AND SERVICES.
- 113,819 hours were provided to patients and their families by the interdisciplinary team.
- 25,264 visits were made by our interdisciplinary team including: Physicians, Nurses, Certified Home-Health Aides, Social Workers, Bereavement Counselors and Spiritual Care Coordinators.
- 25,189 miles were driven by volunteers who provided services to our patients and their families.
- $139,148 is the cost of savings provided by our volunteers for their services to our patients and families.
- 115 volunteers provided 4,932 hours of service to our patients and their families.
- Less than 3% of Hospice’s patients went back to the hospital.
- Over 100 veterans were honored through our We Honor Veterans program.

“I will always remember you fondly. You were there for us when we needed you. You made a very bad time for us bearable. Your calmness and compassion was very comforting to my sister and I when we really needed it. I thank you from the bottom of my heart for what you did for us and what I am sure you have done for others as well.” – The family of Rosabel

“To all the wonderful people that work at Hospice & Palliative Care. With great gratitude I would like to acknowledge everyone, for what you do each and every day. It was a tough year in our family, we lost Judi (mother, wife, sister) in May 2018 then in Nov 2018 we lost John (father, brother, friend). With that said we could have never done this on our own, without the help of your top notch team. Everyone just did what needed to be done, with professionalism, compassion and dignity. So thank you to everyone, for your empathy and help during our most difficult times.” – The Family of Judi and John
“My mother loved life and lived it her way. Her wish was to come home. So we are so grateful to Hospice for all your wonderful services that this could happen for her. Please know you all are so very special in our hearts. – The family of Patricia

“I cannot thank you enough for the care that Thomas received. It was not only caring but personal. He really liked to joke with the girls and always said they were nice! You were really wonderful to us. The family and I really appreciate all your calls to me.”
– The mother of Thomas

“There are no words to tell you all how thankful we were for your caring services. My mother was so happy to have you helping and caring for her. Every person who came to our home or we spoke to on the phone were all so professional, kind and caring! We could not have gotten through this without you!” – A mother’s family

“My mother was on hospice for about 10 days. I want to thank you for admitting her and taking such good care of her while she was there. I know that she enjoyed the care, the food, the baths, and the attention that the nurses and other staff provided. And while the family visited her there we felt very welcome and comfortable. I also appreciated how you worked to communicate with our family and help guide us through the process. Her final hours and moments were peaceful and comfortable because of the nurses on duty, and we will always cherish that. Thank you for all that you do.” – Nancy’s Son & Family
OUR SPECIAL EVENTS

Thank you to all of our sponsors and to everyone in the community who attended and contributed to our 2018 Events! The funds raised helped us continue to fulfill our mission of providing quality, compassionate, end-of-life care to patients throughout our service area as well as comprehensive bereavement programs to support their loved ones. We are pleased that we were able to increase attendance at several events in 2018 and look forward to achieving even greater success in the year ahead.

Claudia Jasinski
Development Council President