

# Consumer Group Snapshot

## Persons Who Are Terminally Ill

Consumer Category:  
**With/At Risk of Health Conditions**



February 2007

<b>CONSUMER GROUP: Persons who are terminally ill</b>	
<b>DEFINITION</b>	<i>Terminal Illness:</i> A condition that is incurable and irreversible. <sup>1</sup>
<b>THE CONSUMERS</b>	See Attachment 1: Family of Services & Attachment 2: Consumer Matrix
<i>Stage One:</i> At Risk (Estimated Number/ Percent County Population)	<p>According to the Centers for Disease Control and Prevention (2005), individuals with chronic diseases often can have prolonged and eventually life-limiting courses of illness.<sup>2</sup> Chronic diseases—such as heart disease, stroke, cancer, and diabetes—are among the most prevalent, costly, and preventable of all health problems. Chronic diseases have generally accepted characteristics, although each characteristic may not be applicable to each disease; however, they usually last a long time, are generally non-infectious in origin, and are unlikely to be cured. Seven of ten Americans who die each year die of a chronic disease.</p> <p>AIDS is also a growing life-limiting illness.</p>
<i>Stage Two:</i> In Crisis (Estimated Number/ Percent County Population)	<p>Total Cuyahoga County population per the American Community Survey (2002): 1,348,871</p> <p>Individuals diagnosed with terminal illness, which is defined by Medicare Part A regulations as having “a medical prognosis that his or her life expectancy is 6 months or less.”<sup>3</sup></p> <p>In Cuyahoga County in 2002, 15,177 individuals died from all causes. 1.1 percent total county population (2002).<sup>4</sup></p> <p>From 2000-2002, 15,938 individuals died from diseases of the heart, 10,563 from cancers, 2,628 from cerebrovascular disease, 1,756 from chronic lower respiratory diseases, 1,232 from diabetes mellitus, 866 from Alzheimer’s disease, and 875 from kidney diseases.<sup>5</sup></p>
<i>Stage Three:</i> Post Death (Estimated Number/ Percent County Population)	The families of the 15,177 individuals who passed away in 2002.
<b>Age by Generation</b>	Persons of all ages can experience a terminal illness, although the probability increases with age.
<b>Risk Factors</b>	<p>Risk factors for acquiring a chronic disease include:</p> <ul style="list-style-type: none"> <li>• Cigarette smoking;</li> <li>• Binge drinking;</li> <li>• No leisure time physical activity;</li> <li>• No regular physical activity;</li> </ul>

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- Diet, including insufficient fruit and vegetable consumption;
- Obesity;
- Irresponsible sexual behavior;<sup>6</sup>
- Not accessing preventative care; and
- Genetics.

According to a recent study on barriers to accessing hospice services (Johnson, C.B. and Slaninka, S.C.,1999), risk factors for not accessing hospice services in a timely manner after having acquired a terminal illness include:

- Individual and family’s lack of knowledge about the role of hospice, ambivalence towards treatment options, and possible view that hospice provides inferior quality of care.<sup>7</sup>
- Health care providers’ lack of knowledge about the role of hospice or not making appropriate referrals to hospice due to reluctance to disclose, discuss, or acknowledge patient terminality, and access to hospice care being perceived as giving up on the patient.<sup>8</sup>
- Being of color.<sup>9</sup>
- Being a member of vulnerable population (children, long-term care residents, prison inmates, rural residents).<sup>10</sup>
- Lack of medical coverage.

Historic Trend Line

Per the National Center for Health Statistics and the Center for Disease Control. (2001):<sup>11</sup>  
Increasing number of individuals acquiring chronic diseases such as diabetes, heart disease, cerebrovascular disease, and Alzheimer’s disease; however, decline in rates have been seen for heart disease and cancer, the two leading causes of death which account for more than half of all deaths in the United States each year. Declines were also documented for stroke and chronic liver disease.

Per the National Hospice and Palliative Care Organization (n.d.):<sup>12</sup>  
There has been a significant increase in use of hospice care for all types of diseases (historically used mostly by cancer patients). The number of hospice programs and number of hospice patients has grown substantially in recent decades. In 1985, there were 1,545 hospice programs serving 158,000 patients; in 1994, there were 2,312 programs serving 340,000 patients; in 2000, there were 3,100 programs serving 700,000 patients; and in 2004, there were 3,650 programs serving 1,060,000 patients.

More than half a million people with AIDS have died in the USA.<sup>13</sup> There have been at least 39,000 new AIDS diagnoses each year since 1989. During the 1980s, there were rapid increases in the number of AIDS cases and deaths of people with AIDS. Cases peaked with the 1993 expansion of the case definition, and then declined. The

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	<p>most dramatic drops in both cases and deaths began in 1996, with the widespread use of combination antiretroviral therapy. The rate of decrease in AIDS diagnoses slowed in the late 1990s. After reaching a plateau, the number of diagnoses increased slightly each year from 2001 to 2004. There were an estimated 42,514 diagnoses in 2004. In total, an estimated 944,306 people have been diagnosed with AIDS.</p> <p>The number of deaths among people with AIDS remained relatively stable in the period 1999-2003, before dropping slightly to an estimated 15,798 deaths in 2004. Since the beginning of the epidemic, an estimated 529,113 people with AIDS have died in the USA.</p>
Influencing Factors Underlying Historic Trend Line (+/-)	<p>Per the Centers for Disease Control Foundation (2003):<sup>14</sup> Decline in cancer rates and mortality is attributed to decreased smoking, more effective screening, and earlier identification. Increases in number of individuals with other chronic diseases are attributable to increases in obesity and lack of activity, and to the aging of the population, which tends to get more chronic diseases. Mortality increased for the following leading causes of death: Alzheimer’s disease, kidney disease, hypertension, and Parkinson’s disease.</p> <p>Per the Hospice and Palliative Care Association of New York (n.d.):<sup>15</sup> Initiation of the Medicare hospice benefit in 1982 resulted in a substantial increase in programs providing and patients using hospice. In 1997, changes were made to the Medicare system, expanding hospice benefits that encouraged other terminally ill people (in addition to just those with cancer) to use hospice. National professional and community education and awareness campaigns about hospice have increased awareness of the service. Additionally, more people dying of chronic illness have contributed to increased use of hospice.</p>
Life Trajectory	Acquire terminal illness ⇒ Palliative (comfort) care provided in combination with or at the exclusion of curative care ⇒ Acceptance of death, appropriate closure for individual and family members, support for bereaved family after death
Consumer Impact Strategy	Facilitate access to quality-of-life and life-prolonging treatments, if patient desires. Initiate services early enough in life-limiting illness progression so that the benefits of comfort care, counseling and spiritual care, and bereavement can be realized.
Future Projection	Anticipate continued increase in number and rate of individuals with chronic disease that may lead to a terminal illness with aging of the baby boomer cohort; however, more effective management and treatment may decrease morbidity and mortality.

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<b>THE SAFETY NET:</b> Which of the 80 safety net core services are needed to empower consumers to positively alter their life trajectory?	
<i>Stage One: At Risk</i>	<p><b>Primary Services</b></p> <ul style="list-style-type: none"> <li>• Hospice Care (sometimes called pre-hospice)</li> </ul> <p><b>Access Services</b></p> <ul style="list-style-type: none"> <li>• Disease/Disability Information</li> <li>• Medical Expense Assistance</li> <li>• Medical Transportation</li> </ul> <p><b>Supportive Services</b></p> <ul style="list-style-type: none"> <li>• Senior Housing and Information and Referral</li> </ul>
<i>Stage Two: In Crisis</i>	<p><b>Primary Services</b></p> <ul style="list-style-type: none"> <li>• Hospice Care</li> </ul> <p><b>Access Services</b></p> <ul style="list-style-type: none"> <li>• Disease/Disability Information</li> <li>• Medical Expense Assistance</li> <li>• Medical Transportation</li> </ul> <p><b>Supportive Services</b></p> <ul style="list-style-type: none"> <li>• Case/Care Management</li> <li>• Home Delivered Meals</li> <li>• In-Home Assistance</li> </ul>
<i>Stage Three: Stabilized (patient) and post-death of terminally ill patient (family)</i>	<p><b>Primary Services</b></p> <ul style="list-style-type: none"> <li>• Hospice Care</li> </ul> <p><b>Access Services</b></p> <ul style="list-style-type: none"> <li>• Disease/Disability Information</li> </ul> <p><b>Supportive Services</b></p> <ul style="list-style-type: none"> <li>• Case/Care Management</li> <li>• General Counseling Service (Outpatient Mental Health Facilities)</li> <li>• Hospice Care (specifically Bereavement Counseling)</li> </ul>

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Intended or Unintended Philosophy Underlying Service Delivery (i.e., assumptions about what will work)

- *Historic philosophy:* Physician-directed, hospital-based care with all medical interventions possible in effort to cure patient.
- *Current philosophy* (Per the National Hospice and Palliative Care Organization, n.d.<sup>16</sup>): Care providers working as a cooperative team with terminally ill patient and his or her family with patient at center of decision making. Focus is on palliative treatment (or comfort care), pain management, and symptom control as opposed to medical interventions focused on curing the patient. A full suite of services is provided addressing the psychological, spiritual, and physical comfort of the patient.
- Treatment more often provided on an outpatient basis, and sometimes in the home.
- Intensity of services can be modified depending on state of illness, and continues after death of terminally ill patient in the form of bereavement support for the family. Supports can last days, weeks, months.
- Hospice services provided most often at home (though can be in a medical center, long term care facility, etc.). A National Hospice Foundation study found that 80 percent of individuals say they want to die in their homes, and 75 percent of hospice patients actually do die at home.

What Works

Preferred intervention is made at the point when the patient is known to be terminal.<sup>17</sup> Experts suggest that the greatest benefit of hospice services to the family is realized when there are actually several months of hospice involvement.

In 1997, the Robert Wood Johnson Foundation initiated the Last Acts campaign to improve end-of-life care.<sup>18</sup> A basis of the campaign was that experts and the public generally agree that the best end of life care treats the whole person – body, mind, and spirit. In 1997, Last Acts published its Precepts of Palliative Care, which describe for health professionals five areas that are key to delivering high-quality end-of-life care. In summary, these are:

- Respecting patient goals, preferences, and choices;
- Providing comprehensive caring;
- Utilizing the strengths of interdisciplinary resources;
- Acknowledging and addressing caregiver concerns; and
- Building systems and mechanisms of support.

Per another report produced by the Robert Wood Johnson Foundation looking at cancer care, providing palliative care and treatment at the same time are possible and even desirable.<sup>19</sup> Additionally, programs that “promoted excellence” had the following typical features:

- Ongoing communication among patients, families, and providers;
- Advanced care planning and patient-centered decision making that is iterative and reflective of patients' values and preferences;

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	<ul style="list-style-type: none"> <li>• Formal assessment and treatment of physical and psychosocial symptoms;</li> <li>• Care coordination (also known as case management) to streamline access to services and monitor quality care;</li> <li>• Spiritual care;</li> <li>• Anticipatory guidance in coping with illness and issues of life completion and life closure;</li> <li>• Crisis prevention and early crisis management;</li> <li>• Bereavement support;</li> <li>• An interdisciplinary team approach to care; and</li> <li>• 24/7 availability of a clinician knowledgeable about the case.</li> </ul> <p>Cultural competence is a leading practice in hospice. Research shows that ethnic minorities access hospice care significantly less often than Caucasians. In part, this has been attributed to the lack of cultural competence among hospice staff. In their efforts to provide culturally appropriate end-of-life care, hospices should have established intervention plans aimed at increasing cultural competence among hospice staff.<sup>20</sup></p>
What Doesn't Work	<ul style="list-style-type: none"> <li>• Uncoordinated, non-patient centered care.</li> <li>• A "one size fits all" model for end-of-life palliative. There are distinct patterns of function decline in the last year of life for different diseases that indicate the need for different approaches to palliative care. Different diseases have different trajectories, and even the same disease can be manifested in significantly different ways in different patients.</li> </ul>
Community-wide Strategies to Impact Life Trajectories	Enable access to treatment (transportation, expenses, etc.). Provide a) education for both potential patients and health care providers focusing on understanding hospice and on advance care planning, and b) outreach to racial and ethnic minorities that have traditionally not utilized hospice, thereby increasing access to and timeliness of hospice services.
First Call for Help	Between 2000 and 2004, there were 96 requests for services for those who were terminally ill. Of these, 4 (4 percent) were unmet, meaning that there was no agency to which to refer callers. See Attachment 3: First Call for Help for more detail. Note that referrals to hospices are more likely to be made by physicians than through First Call for Help.

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**RESOURCES**

Identified Resources 2003-04

Identified Terminally Ill Revenues		
As of 5/11/06		
	Community	UW*
Hospice Services	\$18,321,323	\$166,143
<b>Total</b>	<b>\$18,321,323</b>	<b>\$166,143</b>

\* UW revenues are included in community totals.

NOTE: This does not include all monies for this consumer group. Much of hospice service is covered by Medicare and private insurance, which are not included here. See Attachment 4 for details and Attachment 5 for Revenue Checklist.

Government Resource Trend Line

Increasing Medicaid and Medicare reimbursements. Decreasing Ryan White Title I reimbursements.

Future Direction of Government Funding

“In 2001, Medicare spending accounted for 17 percent of total national health expenditures. Total Medicare expenditures as a percentage of the total gross domestic product has also risen from 1.8 percent in 1990 to 2.4 percent in 2000, suggesting that the burden of financing this program has been increasing.<sup>21</sup> Medicare spending on hospice has grown dramatically from \$1.9 billion in 1995, to \$6.7 billion in 2004, and an estimated \$9.8 billion in 2006. The aging of the population will intensify this expenditure as a greater percentage of the population becomes eligible to retire, reducing Medicare income tax revenue, and a greater proportion of the population enters the Medicare program, increasing Medicare expenditures. Considerable concern is being expressed regarding the solvency of the Medicare program.”<sup>22</sup>

“The Centers for Medicaid and Medicare have over the past decade promoted the availability of the benefit of hospice care to providers and beneficiaries. In December 2003, Congress passed the Medicare Modernization Act of 2003. The hospice provisions were designed to improve access and make hospice care more available to patients and families earlier in their illnesses, including (a) an educational consult for patients who would be appropriate for hospice but have not yet been referred, (b) contracting for core or specialized nursing services, (c) nurse practitioners not employed by hospice to continue caring for patients under hospice, (d) a rural hospice demonstration project to evaluate care delivery.”<sup>23</sup>

“While access to hospice services has been made easier, trends in the reimbursement of hospice are of

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	<p>considerable concern. Medicare and Medicaid reimburse hospice providers at a per diem rate based on four levels of care in which all hospice services (including prescriptions, counseling, respite, home care visits, etc.) are to be absorbed. The per diem rate is intended to allow for variation over an average length of stay in a hospital. However, reimbursement rates were set approximately 20 years ago, and, while there have been some increases based on an index rate, they have not been modified to account for advances in technology, pharmacology, or other medical treatments which are now best practices in standards of palliative care. Additionally, trends in short hospice lengths of stay and a lack of increase in reimbursement rates are requiring providers to absorb more costs. As a Milliman, USA report states, “As the average length of hospice service shrinks, intensive service days required at the onset of hospice enrollment and during the last phase of a terminal illness comprise a higher percentage of days, resulting in a higher per patient per day cost. Financial losses occur as the per-diem costs increase and reimbursement stays steady.” The same report noted that costs for providers often exceed reimbursements by 10-20 percent.<sup>24</sup> Hospices are often dependent on charitable giving and community support to make up for the gap in reimbursement for hospice care for Medicare and Medicaid. A report released on March 10, 2006 from RAND Corp. and the Medicare Payment Advisory Committee confirmed that first and last days of service require higher expenditures, suggesting that the centers for Medicaid and Medicare may move towards increasing reimbursement for those days.”<sup>25</sup></p>
<p>Return on Investment</p>	<p>According to an article published in the <i>Journal of the American Medical Association</i>, hospice care and advance directives can save between 25 percent and 40 percent of health care costs during the last month of life.<sup>26</sup></p> <p>In 1995, Lewin-Value Health, Inc. (VHI), a Washington-based health care consulting firm commissioned by the National Hospice Association, documented that nationally for every dollar Medicare spent on hospice, it saved \$1.42 in Part A and Part B expenditures (looking at Medicare hospice and non-hospice users with cancer.) Greatest savings occurred in the last month of life where costs for non-hospice care averaged \$3,900 more than costs for the comparative hospice group.<sup>27</sup></p> <p>Another study by the Health Care Financing Administration and the Social Security Administration in 1997 demonstrated that for Medicare, hospice had a significantly lower per day reimbursement cost (\$111), compared with a skilled nursing facility (\$426) and a hospital stay (\$2,002).<sup>28</sup></p> <p>The following findings are also important to consider in investment in hospice care:</p> <ul style="list-style-type: none"> <li>• 83 percent of people who die each year are eligible for Medicare.</li> <li>• At least 1/3 of all Medicare expenditures go to care for an eventually fatal illness.<sup>29</sup></li> <li>• Medical care at the end of life consumes 10-12 percent of the total health care budget and 27 percent of the</li> </ul>

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Medicare budget.<sup>30</sup>

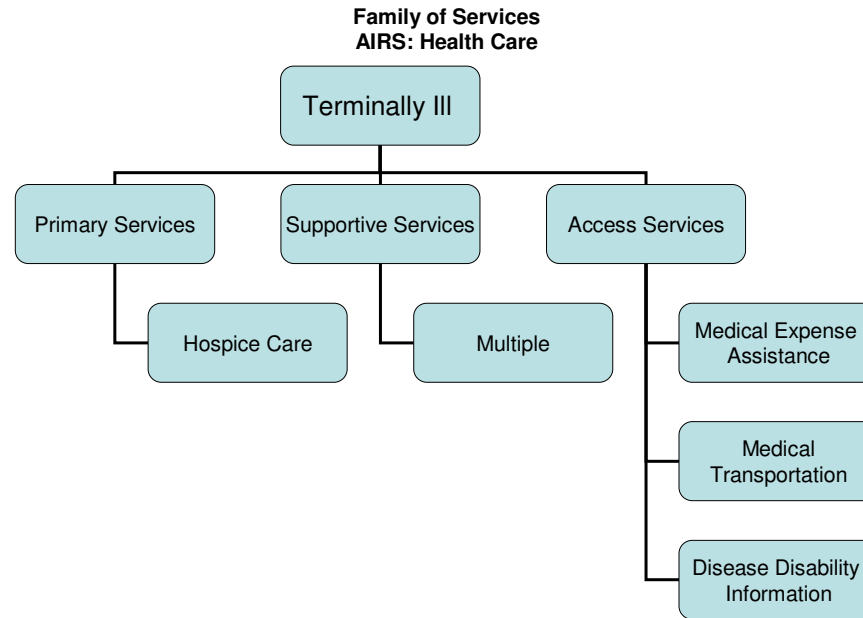
With the largest cohort of individuals aging into Medicare eligibility, and with the severe cost containment measures being considered for Medicare, the cost savings from appropriate use of hospice have potential to offset need for cuts.

It is also important to note that although Medicare is the largest payor for hospice care, reimbursement rates (which are exclusively at a per diem rate) often do not cover all services required for a hospice patient who needs not only medical care but other supportive and home-based services such as counseling and chore services. Additionally, some comfort care measures proven to be highly beneficial, such as palliative chemotherapy or radiation, are not made available because they are too expensive.

Finally, investment in a core service that educates and supports death with dignity where patient's choices are discussed and acted upon has the opportunity to positively affect the dying person's quality of life and support productive community dialogue around end of life issues.

# ATTACHMENTS

## Attachment 1: Family of Services



Attachment 2: Consumer Matrix

CORE SERVICES	SUB-CONSUMER GROUPS	ESTIMATED PERSONS IN NEED			ESTIMATED UNIVERSE OF POSSIBLE CONSUMERS		
		Description	Number	% of Total Population Families Households	Description	Number	% of Total Population Families Households
Hospice Care	Terminally ill people who are in the final stages of their illness, and their families.	Seventy percent of annual average deaths based on research: Connor, S. (1999). New initiatives transforming hospice care. The Hospice Journal, 14(3/4): 193-203. Seventy percent of annual deaths are predictable and therefore possible users of hospice.	11,403	0.8% Population	The study by Connor (1999) noted that the potential number of person who could utilize hospice care is far greater than the number that actually does, perhaps as great as 70 percent. Applying this to the estimated number of unknowns results in 5,388 would-be users, or those who have unrealized access. (7,697 x 70% = 5,388) Including both realized (3,706) and unrealized (5,388) access, the estimated universe of possible consumers for hospice is 9,094.	9,094	0.7% Population

**Attachment 3: First Call for Help**

Persons who are terminally ill											
CORE SERVICES	TOTAL REQUESTS					%Change*	MET				
	2000	2001	2002	2003	2004		2000	2001	2002	2003	2004
Hospice Care	26	16	15	17	22	(15%)	26	16	11	17	22
<b>Total</b>	<b>26</b>	<b>16</b>	<b>15</b>	<b>17</b>	<b>22</b>	<b>(15%)</b>	<b>26</b>	<b>16</b>	<b>11</b>	<b>17</b>	<b>22</b>

Persons who are terminally ill										
CORE SERVICES	UNMET					TOTALS 00-04			%	
	2000	2001	2002	2003	2004	Req.	Met	Unm.	Unmet	
Hospice Care	0	0	4	0	0	96	92	4	4%	
<b>Total</b>	<b>0</b>	<b>0</b>	<b>4</b>	<b>0</b>	<b>0</b>	<b>96</b>	<b>92</b>	<b>4</b>	<b>4%</b>	

Attachment 4: Revenue Tables

Hospice Care					
Revenues as of May 11, 2006					
Funder	Period	A		B	
		Identifiable Total Dollars Countywide		Total Dollars UW-Funded Agencies (Actual FY2004)	
		Amount	% of Total (A)	Amount	% of Total (B)
<b>Total - Contributions and dues (less UW designations)</b>			<b>0.00%</b>	<b>1,895,839</b>	<b>3.78%</b>
Cleveland Foundation, The	2004	11,042		14,050	
McGregor Foundation, The	2004	28,000			
Murphy Foundation, The John P	2004	5,000			
Other Private Foundations - Not Elsewhere Classified				25,000	
Eaton Charitable Fund	2003	16,000			
Key Foundation	2003	340			
Other Corporate Foundations - Not Elsewhere Classified				25,000	
<b>Total - Foundations &amp; Trusts</b>		<b>60,382</b>	<b>0.33%</b>	<b>64,050</b>	<b>0.13%</b>
<b>Total - Special Events - Growth</b>			<b>0.00%</b>	<b>183,865</b>	<b>0.37%</b>
Combined Federal Campaign				10,540	
Jewish Community Federation	2004	400,000			
<b>Total - Federated Fundraising Organizations</b>		<b>400,000</b>	<b>2.18%</b>	<b>10,540</b>	<b>0.02%</b>
United Way of Lake County				65,000	
<b>Total - Other United Ways</b>		<b>0</b>	<b>0.00%</b>	<b>65,000</b>	<b>0.13%</b>
HIV Services Planning Council Ryan White Title I	2004	17,582		12,200	
<b>Subtotal Cuyahoga County Funding Sources</b>		<b>17,582</b>	<b>0.10%</b>	<b>12,200</b>	<b>0.02%</b>
Medicaid	2004	17,677,216		2,347,195	
Medicare				39,902,323	
Other Private Insurer				3,755,513	
<b>Subtotal Third Party Payee/Direct Bill</b>		<b>17,677,216</b>	<b>96.48%</b>	<b>46,005,031</b>	<b>91.76%</b>
<b>Total - Contracts/grants from government organizations</b>		<b>17,694,798</b>	<b>96.58%</b>	<b>46,017,231</b>	<b>91.78%</b>

Attachment 4: Revenue Tables (continued)

<b>Hospice Care</b>					
<b>Revenues as of May 11, 2006</b>					
<b>Funder</b>	<b>Period</b>	<b>A</b>		<b>B</b>	
		<b>Identifiable Total Dollars Countywide</b>		<b>Total Dollars UW-Funded Agencies (Actual FY2004)</b>	
		<b>Amount</b>	<b>% of Total (A)</b>	<b>Amount</b>	<b>% of Total (B)</b>
Private Pay/Fee for Service				938,878	
<b>Total - Program Service Fees</b>		<b>0</b>	<b>0.00%</b>	<b>938,878</b>	<b>1.87%</b>
<b>Total - Investment Income</b>			<b>0.00%</b>	<b>585,253</b>	<b>1.17%</b>
<b>Total - All Other Revenue</b>			<b>0.00%</b>	<b>211,057</b>	<b>0.42%</b>
<b>Subtotal Non - UWGrCle Support</b>		<b>18,155,180</b>	<b>99.09%</b>	<b>49,971,713</b>	<b>99.67%</b>
<b>Total - UWGrCle designations applied to program</b>		<b>140,220</b>	<b>0.77%</b>	<b>140,220</b>	<b>0.28%</b>
<b>Total - UWGrCle investment committee allocation</b>		<b>25,923</b>	<b>0.14%</b>	<b>25,923</b>	<b>0.05%</b>
<b>Subtotal UWGrCle Support - 4001, 4701 &amp; 4703</b>		<b>166,143</b>	<b>0.91%</b>	<b>166,143</b>	<b>0.33%</b>
<b>Total Support/Revenue</b>		<b>18,321,323</b>	<b>100%</b>	<b>50,137,856</b>	<b>100%</b>

Attachment 5: Revenue Checklist

Persons who are terminally ill					
Category	Administrator of Funding	Hospice Care			
Private Foundation	Cleveland Foundation, The	✓			
Private Foundation	McGregor Foundation, The	✓			
Private Foundation	Murphy Foundation, The John P	✓			
Corporate Foundation	Eaton Charitable Fund	✓			
Corporate Foundation	Key Foundation	✓			
Federated Organization	Jewish Community Federation	✓			
Cuyahoga County	HIV Services Planning Council Ryan White Title I	✓			
3rd Party Payee/Direct Bill	Medicaid	✓			
3rd Party Payee/Direct Bill	Medicare	x			
United Way Greater Cleve	United Way of Greater Cleveland designations applied to program	✓			
United Way Greater Cleve	United Way of Greater Cleveland investment committee allocation	✓			
<p>✓ = Revenue was identified specifically for this core service and the amount allocated in Cuyahoga County appears in the revenue table of the core service report.</p>					
<p>x = Revenue was identified from these sources, but no dollar amount is available because either it was not possible to obtain data for Cuyahoga County alone, or it was not possible to obtain data specifically for this core service because funding covers multiple core services.</p>					

**NOTES**

- 1 Retrieved on April 30, 2006 from [www.aarpsegundajuventud.org/english/health/2003-nov/glossary.htm](http://www.aarpsegundajuventud.org/english/health/2003-nov/glossary.htm)
- 2 Centers for Disease Control and Prevention. (2005). Chronic disease: The leading causes of death – Ohio. Retrieved April 3, 2006 from <http://www.cdc.gov/nccdphp/publications/factsheets/ChronicDisease/ohio.htm>
- 3 42 Code of Federal Regulations, Part 418, Section 418.22 (b), Medicare Hospice Regulations, 1993 as quoted in Kinzbrunner, Barry M., M.D. (2001). The Medicare Hospice Benefit. *American Academy of Hospice and Palliative Medicine Bulletin*. Retrieved April 4, 2006 from <http://www.aahpm.org/sites/MHB.pdf>
- 4 Ohio Department of Health Vital Statistics. (2004). Cuyahoga County resident deaths for 2002. Retrieved April 10, 2006 from <http://dwarehouse.odh.ohio.gov/datawarehousev2.htm>
- 5 Ohio Department of Health Vital Statistics. (2004). Cuyahoga County leading causes of mortality for 2000-2002. Retrieved April 10, 2006 from <http://dwarehouse.odh.ohio.gov/datawarehousev2.htm>
- 6 Ohio Department of Health Vital Statistics. (2004). Cuyahoga County 1999-2001 behavioral risk factor survey. Retrieved April 10, 2006 from <http://dwarehouse.odh.ohio.gov/datawarehousev2.htm>
- 7 Johnson, C.B. and Slaninka, S.C. (1999). Barriers to accessing hospice services before a late terminal stage. *Death Studies*.
- 8 Ibid.
- 9 Jennings, Bruce; Ryndes, True; D’Onofrio, Carol; Baily, Mary Ann. (2003) Access to hospice care: Expanding boundaries, overcoming barriers. The Hastings Center. Available from <http://www.thehastingscenter.org/news/features/hospicecare.asp>
- 10 National Hospice and Palliative Care Organization. (2004). NHPCO research agenda for 2004. Retrieved April 3, 2006 from [www.nhpco.org/files/public/2004\\_Research\\_Agenda\\_May04.doc](http://www.nhpco.org/files/public/2004_Research_Agenda_May04.doc)
- 11 National Center for Health Statistics and the Center for Disease Control. (2005, February 28). Life expectancy hits record high. News Release. Retrieved on December 14, 2005 from <http://www.cdc.gov/nchs/pressroom/05facts/lifeexpectancy.htm>
- 12 National Hospice and Palliative Care Organization. (n.d.). NHPCO’s 2004 facts and figures. Retrieved April 3, 2006 from [http://www.nhpco.org/files/public/Facts\\_Figures\\_for2004data.pdf](http://www.nhpco.org/files/public/Facts_Figures_for2004data.pdf)
- 13 United States HIV & AIDS Statistics by Year. Retrieved on April 17, 2006 from <http://www.avert.org/usastaty.htm>
- 14 CDC Foundation. (2003). Tackling chronic diseases: A conversation with Dr. James Marks. Retrieved April 10, 2006 from [http://www.cdcfoundation.org/frontline/2003/tackling\\_chronic\\_diseases.aspx](http://www.cdcfoundation.org/frontline/2003/tackling_chronic_diseases.aspx)
- 15 Hospice and Palliative Care Association of New York. (n.d.). Hospice: A historical perspective. Retrieved April 3, 2006 from [http://www.hpcanys.org/about\\_hp\\_historical.asp](http://www.hpcanys.org/about_hp_historical.asp)
- 16 National Hospice and Palliative Care Organization. (n.d.). Keys to quality. Retrieved on April 3, 2006 from <http://www.nhpco.org/i4a/pages/index.cfm?pageid=3303>
- 17 WebMD. (2005). Transcript of interview with Marcia Lattanzi-Licht conducted October 19, 2005. Retrieved April 3, 2006 from [http://www.webmd.com/content/chat\\_transcripts/2/111206.htm](http://www.webmd.com/content/chat_transcripts/2/111206.htm)
- 18 Last Acts. (2002) Means to a better end: A report on dying in America today. November 2002. Retrieved on December 21, 2005 from [http://www.endoflifecommission.org/end\\_pages/national\\_report.htm](http://www.endoflifecommission.org/end_pages/national_report.htm)
- 19 Robert Wood Johnson Foundation. (2003). Living and dying well with cancer: Successfully integrating palliative care and cancer treatment. Retrieved April 3, 2006 from [http://www.promotingexcellence.org/downloads/dying\\_well\\_cancer.pdf](http://www.promotingexcellence.org/downloads/dying_well_cancer.pdf)
- 20 Doorenbos, A. Z., & Schim, S. M. (2004). Cultural competence in hospice. *American Journal of Hospice & Palliative Care*, 21:28-32.
- 21 Medicare Payment Advisory Committee. (2004). Hospice care in Medicare: Recent trends and a review of the issues. Retrieved April 2, 2006 from [http://www.medpac.gov/publications%5Ccongressional\\_reports%5CJune04\\_ch6.pdf](http://www.medpac.gov/publications%5Ccongressional_reports%5CJune04_ch6.pdf).

- 
- 22 Centers for Medicare and Medicaid Office of the Actuary. (n.d.). Last year of life study. Retrieved April 2, 2006 from [http://www.cms.hhs.gov/ActuarialStudies/downloads/Last\\_Year\\_of\\_Life.pdf](http://www.cms.hhs.gov/ActuarialStudies/downloads/Last_Year_of_Life.pdf)
  - 23 Radulovic, Jon and Person, Judith Lund. (2004). Trends in hospice care and palliative care in the United States and Kansas. *Kansas Nurse*. Retrieved April 2, 2006 from [http://www.findarticles.com/p/articles/mi\\_qa3940/is\\_200410/ai\\_n9463425](http://www.findarticles.com/p/articles/mi_qa3940/is_200410/ai_n9463425)
  - 24 Milliman, USA. (2001). The costs of hospice care: An actuarial evaluation of the Medicare hospice benefit. Retrieved April 2, 2006 from <http://www.nhpco.org/files/members/TheCostsofHospiceCare-Millman.pdf>
  - 25 National Hospice and Palliative Care Organization. (2006). NHPCO public policy update: Policy update on Med Pac meeting. Retrieved April 2, 2006 from <http://www.nhpco.org/i4a/pages/Index.cfm?pageID=4817>
  - 26 Emanuel, E.J. (1996). Cost savings at the end of life: what do the data show? *Journal of the American Medical Association*.
  - 27 Center to Advance Palliative Care. (2002). CAPC manual: Expenditures for end of life care. Retrieved April 3, 2006 from <http://64.85.16.230/educate/content/elements/expendituresforeolcare.html>
  - 28 Lycan, Jeff. (2004). Testimony on the Hospice Medicaid Benefit to the Ohio Commission to Reform Medicaid. Retrieved April 3, 2006 from [http://www.ohiomedicaidreform.com/pdf/Jeff\\_Lycan.pdf](http://www.ohiomedicaidreform.com/pdf/Jeff_Lycan.pdf)
  - 29 Center to Advance Palliative Care. (2002). CAPC manual: Expenditures for end of life care. Retrieved April 3, 2006 from <http://64.85.16.230/educate/content/elements/expendituresforeolcare.html>
  - 30 Emanuel, E.J. (1996). Cost savings at the end of life: what do the data show? *Journal of the American Medical Association*.



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