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Addressing a Lack of Palliative Care Resources for Intensive Care Unit Patients and Families

University of Rhode Island

Jeffrey Chiv

Addressing a Lack of Palliative Care Resources for Intensive Care Unit Patients and Families

An alarming trend in hospitals across the United States is the increased prevalence of end-of-life care issues the healthcare team must face. This increase can be attributed to the advent of new medical technology, as the average life expectancy of the population is increased due to new treatment options for acute diseases. As a result, population trends are showing a large increase in the percentage of the population over the age of 65, and this percentage is expected to grow (Department of Health and Human Services Administration on Aging, 2010). The dire tradeoff of more treatment options for acute diseases is that the main cause of death has shifted from acute diseases to chronic diseases such as cancer. These debilitating diseases often result in situations where patients are no longer able to exercise autonomy or communicate, relying on family and healthcare providers to advocate for their wishes. This is especially true for the ICU nurse, a member of the healthcare team who has the opportunity and privilege to assist the acutely ill patient and their family in making end-of-life care decisions (American Nurses Association, 2005; International Council of Nurses, 2006). Palliative care, a movement in the healthcare system that is in the beginning stages of adoption, is a care model that targets this population. Unfortunately, this model of care is often misunderstood and underutilized by staff, patients, and families.

For the past year, the Student Nurse has been conducting nursing research towards creating a resource that can be used by ICU staff, patients, and families faced with end-of-life care issues. This project initially started as a collaborative effort between the Student Nurse and Mohini Yalanis, a URI Graduate Nursing Student in the Family Nurse Practitioner Program working on her capstone research project. The results of the collaborative research showed the potential need for patient education materials which would assist ICU staff in dealing with end-

of-life care issues. After the conduction of a literature review, it became clear that the most feasible intervention by the Student Nurse was to create web and print-based education materials. for patients and families. The premise behind the creation of these materials is that they would assist with initiating early conversations about palliative care, resulting in better staff and patient satisfaction in the critical care environment. It is the hope of the Student Nurse that this intervention will alleviate the anxiety burden for patients, families, and care providers associated with end-of-life care.

The following is a description of the palliative care model used, the rationale and relevance of the project, summary of the literature review used to justify the production of patient education materials, and description of the development of the patient education materials. Limitations of this project and implications for future practice are also discussed.

Defining the Need for Palliative Care Resources in Today's Healthcare System

Palliative care is not new to nursing practice, however the acceptance of palliative care by healthcare providers and patients is still in the beginning stages. This is partially due to what Lynne Ann DeSpelder and Albert Lee Strickland, the authors of "Culture, Socialization, and Death Education," referred to as the "death denying attitudes" of Western Civilization (Balk, 2007). Death is a taboo topic in the culture of both patients and healthcare providers, which makes it more difficult to initiate dialogue about end-of-life care decision-making. These claims are not only evidenced by portrayals of palliative care in the media, (Durkin, 2010) but also by evidence-based research. This lack of dialogue is problematic for nursing, as a recent study, "Nurses' advocacy behaviors in end-of-life nursing care," demonstrated that lack of communication, time, and support are major barriers to end-of-life advocacy (Thacker, 2008). Also, there is much evidence that shows end-of-life care issues are linked to moral distress for

ICU nurses, which contribute to Burnout Syndrome (Beckstrand, Callister, Clark, & Karin, 2006). The study conducted at the Newport Hospital ICU, which will be discussed in more detail later, supports the claim that there are still struggles with palliative and end-of-life care by hospital staff, despite extended years of experience in nursing.

A challenge to adoption of palliative care is the fact that the model of palliative care is constantly changing; what the public perceives palliative care to be last year is different than what palliative care today. The older model for palliative care focuses on end-of-life care, therefore it is a common misunderstanding today that palliative care is "end-of-life care" or "Hospice care." However, as Stephen R. Connor notes in his article, "The Family, Larger Systems, and Dying," "All of hospice care is palliative; however, not all palliative care is provided by hospices" (Balk, 2007, p. 38).

In order to attain a better understanding of how palliative care is defined today, the Student Nurse attended the Rhode Island ICU Collaborative on April 8th, 2010, a conference tasked with addressing goals and protocols for palliative care. The results of the conference showed that today's definition of palliative care is congruent with what the Centers for Medicare & Medicaid Services proposed in 2004: "Palliative Care is defined as "Patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice" (Balk, 2007, p. 38). The newer model of palliative care follows an integrative approach that incorporates both palliative and curative care upon admission to the hospital. In other words, the patient's disease is treated, while concurrently maintaining their comfort levels.

Also, the maintenance of patient autonomy has been identified as valuable to both care providers and patients (Johnston & Smith, 2006).

This integrative model of palliative care is superior for several reasons: one cannot reliably predict who will survive or succumb to critical illness, it is distressing for the patient and family to suddenly switch from one set of care goals to another, and the act of designating a specific group of patients as "palliative care patients" is segregation. All patients can benefit from this new model of palliative care, as it reduces suffering, which is congruent with the nursing value of nonmaleficence (American Nurses Association, 2005; International Council of Nurses, 2006).

There is evidence that the public is starting to see more exposure to palliative care through the media, as the prevalence of end-of-life care ethical dilemmas continues to rise. An example of this is an article recently published in the New York Times, "Helping Patients Face Death, She Fought to Live," which outlined the experience of a woman diagnosed with cancer. The woman, who was also a palliative care doctor, was described to have a painful end-of-life because she did not take advantage of palliative care. The article stated that her outcomes may have been different if palliative care interventions were instituted earlier. While the best outcomes occur when dialogue about palliative care are initiated early, the prevalence of this media exposure capitalizes on the need for appropriate patient education about palliative care. Doing so will insure that needs and expectations of the patient and family are met during their time at the hospital.

Research Study Conducted at Newport Hospital

Mohini Yalanis's study, "How do ICU nurses perceive their ability to care for their patients at end-of-life?" was a descriptive correlational study conducted at the Newport Hospital

ICU. The goal of the study was to identify the special needs of the ICU, by surveying and assessing the comfort levels of the ICU nurses with end-of-life care. The study was conducted in order to assist with the formulation of Newport Hospital's Palliative Care Advisory Team, a team whose role is to "improve the quality of life of patients with advanced illnesses by supporting patient-centered care through a multidisciplinary team." The interventions provided by this team include addressing symptom management, education about advance directives, discerning preferences for withdrawal or withholding of care, and spiritual support. The premise behind the conduction of the study was that the initial data collection would be used as pre-intervention data. After the introduction of the Palliative Care Advisory Team, a second post-implementation survey would be conducted to determine the effectiveness of the Palliative Care Advisory Team.

In addition to discerning the attitudes of the nurses on the unit, Yalanis's study was also aimed at determining whether or not there was a correlation between experience in the ICU and comfort with end-of-life care. The theoretical framework used to assess experience was Patricia Benner's "From novice to expert: Excellence and power in clinical nursing practice." The framework distinguishes between five levels of proficiency: novice, advanced, beginner, competent, proficient, and expert. The main idea behind Benner's framework is that as nurses gain more experience in practice, their actions are dictated less by theory, and more by intuition. Therefore, "expert" nurses are more comfortable with providing care, and act more on instinct rather than a set of rules (Benner, 2001).

The sample for this study included twenty-eight registered nurses, who worked at the Newport Hospital ICU, with no exclusion criteria. Each nurse was asked fifteen questions, ten of the questions relating to palliative care, four of the questions related to withdrawal of care at end-

of-life, and the last question where nurses were asked to identify interventions that they believed would help improve end-of-life care in the ICU. Each of the responses was rated on a 0 to 5 Likert Scale: 0 - No opportunity (I've never performed this activity), 1 - Extremely uncomfortable (Novice), 2 - Uncomfortable (Advanced Beginner), 3 - Comfortable (Competent), 4 - Confident (Proficient), and 5 - Leader (Expert). Demographic information was also collected from the nurses, which included number of years they have been a nurse, number of years they have been in the ICU, and what shift they normally worked. Finally, the nurses were given the opportunity to offer open-feedback related to the survey.

The results of the study suggested there was a correlation between years of experience in the ICU and the comfort level associated with end-of-life care. This conclusion was based on the fact that the majority (66.7%) of the nurses who took the survey had greater than ten years of nursing experience; and for all fourteen of the question items, the majority of participants rated themselves 3 (Comfortable/Competent) out of 5 in comfort. This was alarming to the Student Nurse, and interpreted this as an opportunity for an intervention to increase comfort levels in the ICU. As a result, the focus of the Student Nurse's project shifted towards creating a resource that would improve these comfort levels and improve patient/family satisfaction.

Major limitations of this study included the small representation of inexperienced nurses as well as the small sample size. Future studies should consider larger samples in other intensive care units, in order to confirm validity of findings. Since nurses with less than 1 year of experience and those who have 3-5 years of experience made up 0% and 7.4% of the sample size respectively, these population groups should also be the focus of future studies. Despite these limitations, it was clear that there was a lack of comfort with end-of-life care at the Newport

Hospital ICU. As a result, the Newport Hospital ICU was the model institution used for the Student Nurse's project.

Justifying the Need for Patient Education Materials

Overview.

The first step of the project for the Student Nurse was to identify an intervention/product suitable for implementation at the Newport Hospital ICU. The following two studies address potential interventions to improve outcomes in ICU's relating to palliative care. CINAHL (EBSCOhost) was the main database utilized for this literature review, using the following terms: palliative, care, end-of-life, interventions, bundles, ICU, intensive care unit, nurses, and outcomes. A limiting factor in this literature review is the exclusion of the search term, "hospice." This was deliberately done by the Student Nurse since the focus of the Student Nurse's intervention is what is able to be done by the nurses on the ICU unit, not hospice. It is noted that only a few articles were found outlining interventions for palliative care, possibly due to the fact the adoption of palliative care is still in its early stages. Also, when dealing with this type of research, there may be some ethical and legal issues with research conduction, as it may be considered unethical to withhold helpful treatments or institute harmful treatments. Overall, this literature review has steered the Student Nurse towards creation of patient education materials.

Domains in end-of-life care.

The first study, "Quality indicators for end-of-life care in the intensive care unit," was originally conducted in order to respond to the increasing prevalence of inadequate symptom management in the ICU, as well as reports that communication between clinicians and the family were poor (Clarke et al., 2003). As a result, the researchers aimed to identify end-of-life care

domains for ICU care, and define quality indicators within these domains that could be measured. These domains were identified by thirty-six participants from the Robert Wood Johnson Foundation (RWJF) Critical Care End-of-Life Peer Workgroup and fifteen nurse-physician teams from fifteen intensive care units. The process in identifying these domains included a literature review to develop a preliminary draft, an initial consensus process with authors, an initial review by the RWJF Critical Care End-of-Life Peer Workgroup, a review by the fifteen nurse-physician teams, a final review by the RWJF Critical Care End-of-Life Peer Workgroup, an updated final literature review, and a final consensus process with authors.

The results of the study produced seven end-of-life care domains: patient and family centered decision making, communication within the team and with patients and families, continuity of care, emotional and practical support for patients and families, symptom management and comfort care, spiritual support for patients and families, and emotional and organizational support for ICU clinicians. Within these domains, fifty-three quality indicators were identified.

Within the domain of "Emotional and practical support for patients and families," was the quality indicator "Distribute written material (booklet) containing essential logistical information and listing of financial consultation services and bereavement support programs/resources. The study stated that a pamphlet that also "states the hospital's commitment to comprehensive comfort care," will "emphasize the comprehensive comfort care that will be provided to the patient, rather than removal of life-sustaining treatments" (Clarke et al., 2003, p. 2258).

Limitations of this study included the fact that there was little discussion related to pediatric and neonatal care, as these patient populations have special needs that are not identified with the adolescent, adult, or older adult population. For example, the anticipatory grief, grief

and bereavement support that these populations require is different, due to the social taboo of dying young as well as the steep death trajectory associated with neonatal death (Balk, 2007, p. 6). Regardless, this study has laid down a framework for potential interventions that will be of value in the context of palliative care in the ICU. Future research should seek to connect these interventions with improved outcomes in the ICU. The next study, "Improving comfort and communication in the ICU: a practical new tool for palliative care performance measurement and feedback," (Nelson, Mulkerin, Adams, & Provenost, 2006) does exactly this.

Care bundling in the ICU.

The goal of the study "Improving comfort and communication in the ICU: a practical new tool for palliative care performance measurement and feedback," was to develop a practical set of measures for monitoring, feedback, and improvement of palliative care quality in the context of the intensive care unit; effectively closing the gap between best evidence and daily practice. This study in essence was a continuation of the previously discussed study; the researchers aimed to determine if the previous research was still valid, revise the domains and indicators, determined whether the previously defined domains and quality indicators were feasible, and tested these indicators in ICUs. The researchers distinguished between "structure," "process," and "outcome" measures, and noted that they focused on creating "process" measures. For example, a process measure would be whether or not the healthcare staff offered a patient and family grief support, where an outcome measure would be whether or not the grief support was effective. The researchers' rationale behind the adoption of process measures was that they are "actionable" by healthcare providers and still can be associated with improved outcomes (Nelson et al., 2006).

The end result of the study were the development of process "bundles," a group of process measures based on best practice, which when implemented together result in quality care and better outcomes. An example that the study used to describe bundles was a hypothetical ventilator bundle that included semi-recumbent positioning, deep vein thrombosis prophylaxis, and daily assessment for sedation. These palliative care bundles were created with an interdisciplinary team of critical care physicians, critical care nurses, a social worker, a healthcare quality improvement consultant, and data management experts. This team sought to create palliative care bundles that not only resulted in improved outcomes, but also were feasible in the ICU environment.

The palliative care bundle was first reviewed by 30 intensive care unit teams from 37 intensive care units at a national "Transformation of the ICU" (TICU) meeting, and then was revised based on their feedback. The bundle was then reviewed by national experts affiliated with the Steering Committee of the National Consensus Project for Quality Palliative Care, the Center to Advance Palliative Care, the Critical Care Workgroup of the Robert Wood Johnson Foundation's Promoting Excellence in End-of-Life Care Project, the Joint Commission on Accreditation of Health Care Organizations, and the Research and Development Corporation for the Agency for Healthcare Research and Quality. Finally, the palliative care bundle was piloted and implemented in 19 ICUS. The results were then collected and used to revise the palliative care bundle.

The final bundle contains process measures that are organized by domains of care and time triggers. These domains included "Patient/family-centered decision making," "Communication," "Symptom management," "Emotional and practical support for patients/families," and "Spiritual support for patients/families" (Nelson et al., 2006). Unlike the

study discussed previously, the researchers opted to exclude the indicators of "continuity of care," "bereavement support," "communication within the ICU team," "education of ICU staff in palliative knowledge and skills," and "emotional support for staff." The rationale for these exclusions was that the researchers wanted to limit the number of indicators to a feasible number.

The time triggers were the first day after admission (Day One), the third day (Day Three), and then the fifth day (Day Five). The process measures for Day 1 were designating a medical decision maker, identifying an advance directive, determining resuscitation status, distribution of a family information leaflet, and regular pain assessment and management. Day Three included social work support and spiritual support, while Day Five included an interdisciplinary family meeting.

The results of the pilot study showed that out of the nine process measures, pain management (87%), pain assessment (85%), advance directive status (72%), and determining a medical decision maker (71%) were the most completed process measures. The lowest were distribution of the information leaflet (43%) and conduction of the interdisciplinary family meeting (40%) (Nelson et al., 2006).

The results of the study showed that the implementation of the palliative care bundle and process measures was feasible, making it a potential tool in the management of palliative care patients. However, the use of process measures also acted as a limitation of the study. While process measures are controllable by staff, and were reviewed by multiple ICU teams and experts, they are not directly indicative of positive outcomes. Therefore, further research needs to be conducted as to whether or not these process measures lead to possible improved outcomes in the ICU. Ethical and legal issues also need to be considered when conducting this future research.

Despite these limitations, the results of this study had several implications for the Student Nurse's project. The process measures that were a part of the final palliative care bundle were subject to rigorous review, and excluded indicators that were considered "not feasible," lending value to these interventions. Also, the results of the pilot study showed that the two most under-implemented interventions are the interdisciplinary family meeting and the distribution of patient education materials. Out of the nine process measures, the one that appeared most feasible and practical for the Student Nurse was the "distribution of patient education materials." Since materials that fit the description in the study do not exist at Newport Hospital; the Student Nurse has chosen to focus his intervention on creation of these materials.

Conclusion.

The Student Nurse conducted a literature review in order to identify a product/intervention that would be effective in assisting with end-of-life care, cost-effective, and able to be developed within the timeframe of this project (one year). Unfortunately, very little literature was found relating to the perceptions of quality care from the viewpoint of patients and families, as well as interventions in palliative care that are directly associated with positive outcomes. This can be attributed to the fact that there are ethical dilemmas relating to this type of research, as well as the fact that palliative care is a new field. As a result, more research is needed in the fields of determining what interventions lead to positive outcomes, possibly through the development of outcome measures. Despite this shortcoming, the Student Nurse has elected to focus on creating a product identified in both of these studies: education materials for patients and families.

Development of Educational Materials

Overview.

The main concerns of the Student Nurse during the formulation of the education materials included the format, the delivery, and the content of the materials. In order to address this concern, the Student Nurse conducted a literature review relating to end-of-life care recommendations and creation of education materials. The Student Nurse also used other existing education materials as models for implementation. It is noted that due to their similar nature, the design guidelines for the print and web materials are the same. The following is an overview of the design decisions regarding the educational materials, as well as supporting literature if available.

Target audience.

The first concern of the Student Nurse was the audience of the education materials. The goal of the Student Nurse was to reach the largest audience possible, while still delivering the information correctly and accurately. The reason the end product of this project is described as "education materials" and not "patient education materials," is that there is a large amount of literature that focuses on the inclusion of the family in the care in the ICU. Improved patient care and outcomes are associated with improved communication with the family (Mitchell, Chaboyer, Burmiester, & Foster, 2009; National Consensus Project for Quality Palliative Care, 2009; Truog, 2008). Ideally, the education materials should be utilizable by both patients admitted to the ICU, as well as their families.

Due to the fact that hospitals such as Newport Hospital work with such a diverse patient and family population, the Student Nurse had to narrow the target population. For the purposes of this project, the Student Nurse assumed the person utilizing these education materials would be over the age of 18, and have completed a minimum of a Junior High School education. The rationale for this decision was the fact that in the state of Rhode Island, one must be over the age

of 18 in order to independently make legal decisions, including end-of-life care decisions. The other reason, is discussed in the "Writing and Design" portion of this paper.

Accessibility.

The second concern of the Student Nurse was accessibility; there are several formats available for delivery of the education materials. While the literature specifies written patient materials (Clarke et al., 2003; Nelson et al., 2006), the Student Nurse also considered the utilization of web-based education materials. These materials cut costs for the hospital and decrease the environmental impact of this intervention, as it reduces the amount of paper and ink purchased to distribute materials.

A major implication of web-based materials is the fact that the website is accessible from any computer with internet connection. Due to the unexpected nature of most hospitalizations, this will make it easier to disseminate information to families that reside far from the hospital, or are unable to visit. This is especially useful in the scenario where the health care proxy or durable power of attorney is unable to come to the hospital, but requests information about where their loved one is residing.

Also, this web-based resource can be made available on the computers that already exist at hospitals. Newport Hospital for example, houses a library where computers and internet access are made freely available for families to use.

Web-based materials are extremely versatile, easy to update, and do not implicate wasted funds on printed materials that become out-of-date. The ability to integrate multimedia is also a strong point for web-based materials, as a study in 2007 shows that video performs exceptionally well in patient education. In a trial of 120 patients, interest in comfort care increased from 50% to 89.2% after showing the group a video on the potential outcomes of advanced dementia. More

importantly, the number of those unsure of their preference decreased from 10.8% to 2.5% (Volandes, 2007). Due to video production being outside the scope of experience, resources, and time for the Student Nurse, video was not implemented on the web-based materials. However, future implementations of this web-based resource should consider inclusion of video if resources are available.

It is noted that print based education materials were still produced, [Figure 9 & Figure 10] for several reasons. The role of the print-based materials is more supplementary, as it acts as a gateway to the web-based patient education materials. The amount of information included was also less, as to avoid information overload for the patient, as well as promote "white space" in the document. Another rationale of creation of print-based materials is that being able to take home something tangible related to the hospitalization is reassuring to the family, especially if they are not comfortable with technology. Finally, the materials offer an alternative in the event web-servers are unavailable, or if technology is temporarily unavailable.

Writing and design.

Several pieces of literature were reviewed to validate the writing and design of the educational materials. As mentioned previously, an assumption of the Student Nurse was that the individual is a person over the age of 18 who has completed a minimum of Junior High School. The rationale for this was found in Michael Aldridge's "Writing and Designing Readable Patient Education Materials" (Aldridge, 2004). He noted that the majority of adults are unable to read above an 8th grade reading level, and if patient education materials cannot be read, there is little hope of the information being consumed. As a result, the content of the educational materials was written at an 8th grade reading level in order to accommodate for this phenomenon. Aldridge also made points about writing education materials, which were utilized in this project.

These included using an accepted method of determining readability, simplifying complex words, being consistent with word choice, turning the passive voice into the active voice, defining words the patient might not understand with a glossary, using numerals instead of numbers spelled out, and using the second person instead of the first-person, because it is more personal.

Aldridge (2004) also contributed to how the education materials were designed. Guidelines proposed by this article included: important elements and key points highlighted with visual cues such as bold text, a limited number of fonts, all type in at least 14 point font, bulleted lists so they are easy to follow, graphics and pictures to augment the text and help to explain difficult concepts, and a lot of white space on the page. Aldridge also advised that a portion of the materials allow the patient to personalize the material with their medications, lab values, blood pressure, etc (Aldridge, 2004). All of these components were integrated into the final product: bold text was used to highlight important concepts, only one font was used, with all text being larger than 14 point, the FLESCH reading scale was used to determine reading level, bulleted lists were used to explain palliative care, and emphasis was placed on empty space on the page.

Finally, recommendations were used from their article, “Easy to Write? Creating Easy-to-Read Patient Education Materials” (Karten, 2007). The study pre-tested a publication for the Leukemia and Lymphoma Society in the field, by distributing their work to patients. For two months, telephone interviews were conducted to elicit information about the patients’ impressions and comprehension of the materials. Several of the findings were utilized in the Student Nurse’s project, including: have one main objective to easily identify needed information, organize the information like a conversation, and avoid using words with more than

one meaning. Every page of the website and pamphlet lists at the top the objective of the page. Also, the Student Nurse followed Aldridge's suggestion and used "you" vs "I" language, to keep the website like a conversation (Aldridge, 2004).

Components of the Website

Overview.

In addition to considering writing and design of the website, the Student Nurse also used literature to determine what was excluded and included in the education materials.

Addressing quality care indicators.

The components of the website were heavily influenced by the study, "Improving comfort and communication in the ICU: a practical new tool for palliative care performance measurement and feedback" (Nelson et al., 2006). As mentioned earlier, the distribution of an "information leaflet" to the family, was among the process measures proposed to improve outcomes in the ICU. Included with the process measure were quality indicators that made specific recommendations for the intervention. The quality indicator for the "Family Information Leaflet" included a description of the information leaflet: "general information about the ICU and hospital including visitation guidelines, services provided such as financial consultation services and bereavement programs, and logistical information (nearby hotels, banks, restaurants, directions, etc), names of ICU caregivers, diagram of a typical ICU room with the names of all devices, glossary of terms commonly used in the ICU (Nelson et al., 2006). In response to these recommendations, the Student Nurse has dedicated a portion of the website to each of these components.

Homepage.

The landing of the website shows a picture of the inside of Newport Hospital. [Figure 1] Below this is a description of the hospital with a welcome message. To the right of the picture is the address of the hospital, location of the unit, phone number of the hospital, and visiting hours. Across the top of the page in large print are navigation buttons that the user may click to navigate the website.

Community resources.

Using Google Maps, the Student Nurse has been able to create a "community resources" page, [Figure 7] where there is a listing of local banks, restaurants, hotels, and locations of emergency services such as the Fire Department. Under each of the listings is the address and phone number of each location, and driving directions to the hospital. [Figure 6]

Commonly used terms.

In order to determine the most commonly used terms on the unit, the Student Nurse visited the Newport Hospital ICU and interviewed several nurses and staff about commonly used terms on that unit. [Figure 4] A limitation of this portion of the project was that due to the long time the nurses have been working on the unit, it was difficult to elicit responses because they were unable to distinguish between medical terms and layman's terms secondary to long experience in the healthcare field. Additional help was provided by the other Student Nurses on the unit. When transposing this list to the website, adherence to the reading level guidelines was observed.

Helpful tools.

The "Helpful Tools" portion of the website gives patients and families a resource they can print, where they can keep information essential to their stay nearby. [Figure 5] This includes a place to write down goals related to their stay at the hospital, the telephone number of the

hospital, the name and number of a family member staying nearby, the contact information for the care provider, as well as a place to write down medications prescribed for the patient (Aldridge, 2004).

Unit tour.

The next portion of the website is the unit tour, designed to alleviate anxiety related to admission to an unfamiliar location. [Figure 2] The Student Nurse, with permission of the hospital, photographed the normal admission path at Newport Hospital. The page on the website plays a slideshow of the journey with captions; it starts at the entrance of the hospital, moves to the hallway of the ICU, into the waiting room, to the nurse's desk, and into the patient room. [Figure 3] The slideshow also has many photos of medical technology with their respective labels.

Palliative care.

"Recommendations for end-of-life care in the intensive care unit: The Ethics Committee of the Society of Critical Care Medicine," (Truog et al., 2001) outlined recommendations in seven areas of concern including: "Preparation of the Patient, the Family, and the Clinical Team," "Ensuring Comfort of the Patient," "Withdrawal of Life-Sustaining Treatments," "Terminal Extubation vs. Terminal Wean Withdrawal Prototypes," "Special Issues in Communicating with Families Near the Time of Death," and "Special Ethical Issues." For the purpose of this project, the section "Preparation of the Patient, the Family, and the Clinical Team," was the main focus. The article placed emphasis on how "Clear and explicit explanations on the part of the clinician may alleviate anxiety and refocus familial expectations" (Truog et al., 2001, p. 2333) . Therefore, it was important that the content of the education materials was congruent with what was being performed by the nurses on that unit, and explain what was being

done on the unit. A measure taken to achieve this was the dedication of a portion of the website to explaining what palliative care is, and what the Palliative Care Advisory Team can offer patients and families. This also helps achieve the other major goal of the education materials, which was to help initiate dialogue early about resources such as palliative care.

Adaptability of the Product

As mentioned previously, hospitals do not have control of the populations that go there for care. Instead, the patient demographic is affected by several different variables including the geographic location of the hospital, the socioeconomic status of the population in the immediate area, the resources available at the hospital, the culture of the community the hospital is in, the ethnic makeup of the population, as well as the economic climate of the community.

In response to the recognition of these variables, it became a goal of the Student Nurse to make two versions of the website to demonstrate two points, that the website resource is versatile and adaptable, and that correct implementation of this resource needs to take into account the aforementioned variables. As a result, the Student Nurse has collaborated with the Providence Veteran's Affairs Medical Center (PVAMC) Intensive Care Unit as well. [Figure 8] The reasons behind this choice include the fact that PVAMC serves a completely different patient population, the PVAMC is in a different geographic location, the VA does not operate within the private sector, and the socioeconomic client of the community the PVAMC is in is different.

The Student Nurse also conducted interviews with the staff regarding commonly used terms on the unit, and also made a different "Community Resources" portion of the website. Due to limitations made by the hospital, the Student Nurse was unable to produce another unit tour.

Conclusion

Implications for future research.

In conclusion, the Student Nurse has been able to create evidence-based resources that will hopefully decrease caregiver burden, and increase patient and family satisfaction in the ICU. Unfortunately due to time constraints, the Student Nurse was not able to implement this intervention by the writing of this document. However, if the Student Nurse were to implement this intervention at Newport Hospital, the Providence Veteran's Affiliation Medical Center, or any other healthcare system, the Student Nurse would make it a point to do a pre and post-intervention assessment, much like Yalanis's study. Much research supports allowing the consumers of the educational materials to offer feedback, so this would be implemented as well (Karten, 2007; Seligman et al., 2007). There are also many recommendations in the field of creating patient education materials, which support having the materials in multiple languages such as Spanish (Aldridge, 2004). Implementators of this project should consider translation into a foreign language that is used by the community the hospital it in. This harkens back to the concept of properly implementing this intervention; the content of the website should be personalized and reflect that of the community the hospital is contained.

Lessons learned.

In this experience, the Student Nurse has had the privilege of working with a Graduate Level Student Nurse and challenged himself in participation in the conduction of nursing research that will contribute to future practice. The current cohort of nurses have the most potential for revolutionizing practice, as they have the marriage of many years of clinical practice with the exponential growth of information technology. This has manifested itself in this project, as the Student Nurse has been able to marry his experience with technology with a passion for nursing practice.

It is the hope of the Student Nurse that while healthcare providers in the field of palliative care are creating these palliative care "bundles," one does not lose sight of the individuality of the patient or family. The Student Nurse has learned that implementing interventions such as providing patients and families education materials, can help empower them to exercise autonomy. This is integral to positive care outcomes, as every patient and family has a unique set of needs that should be addressed.

Palliative care is a relatively new field that has many research opportunities in the future. Researchers are still in the beginning stages of discerning appropriate goals, attitudes, and interventions for best practice. It is the combination of best practice, the acknowledgement of the goals and needs of the patient, and the acknowledgement of the individuality of hospital system, that will bring nursing practice to the next level in the provision of palliative care.

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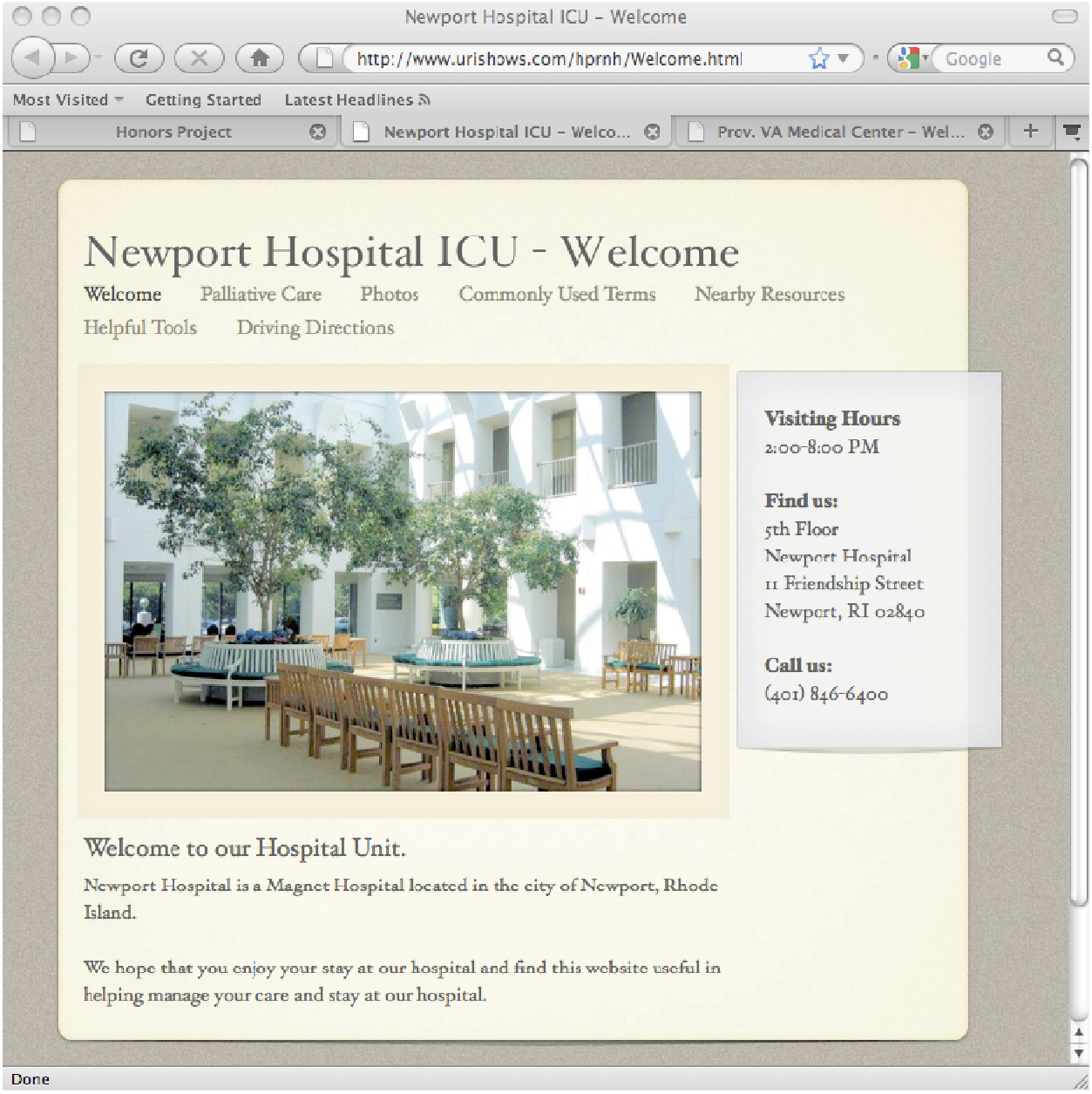
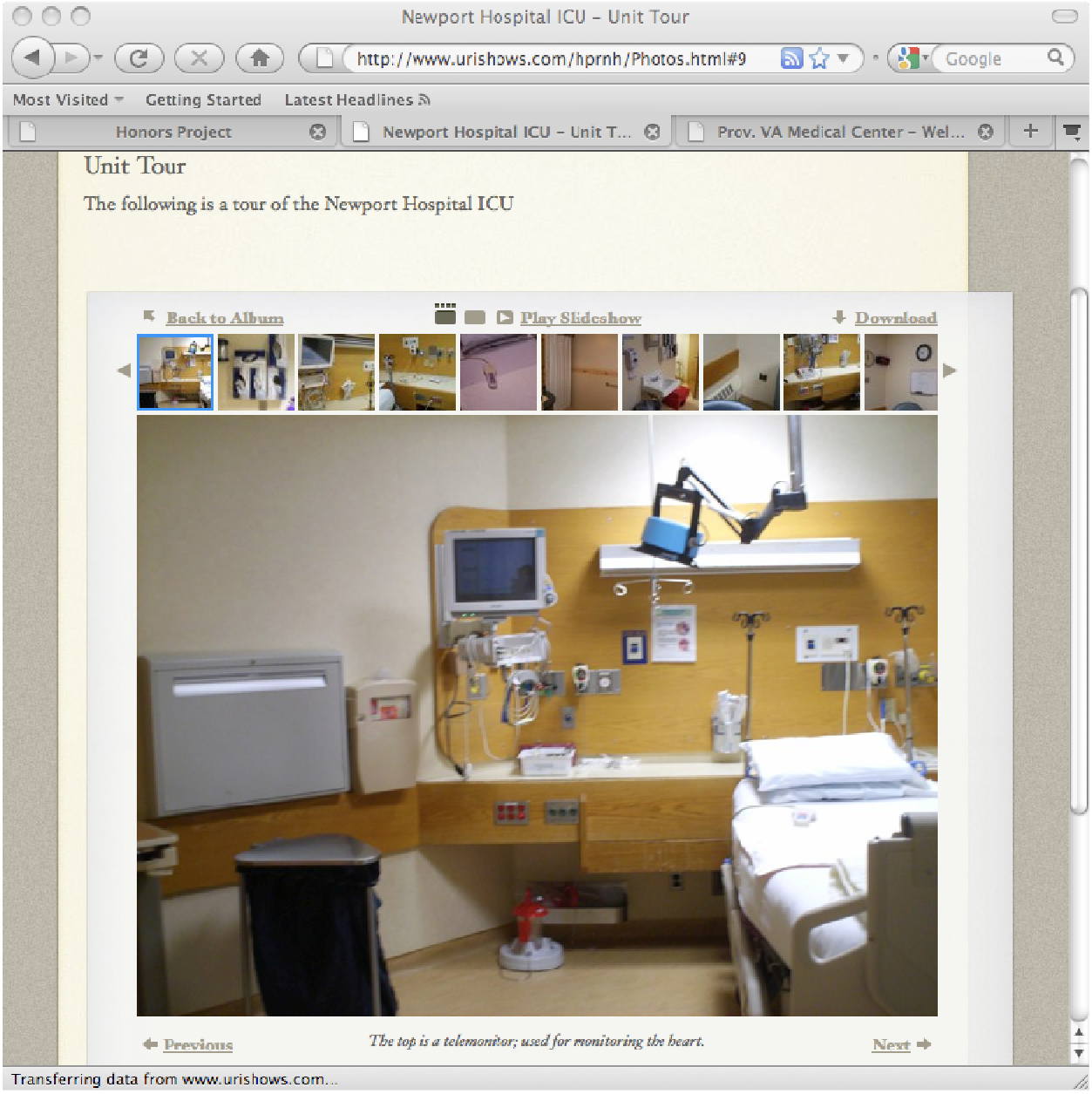
Newport Hospital Landing [Figure 1]

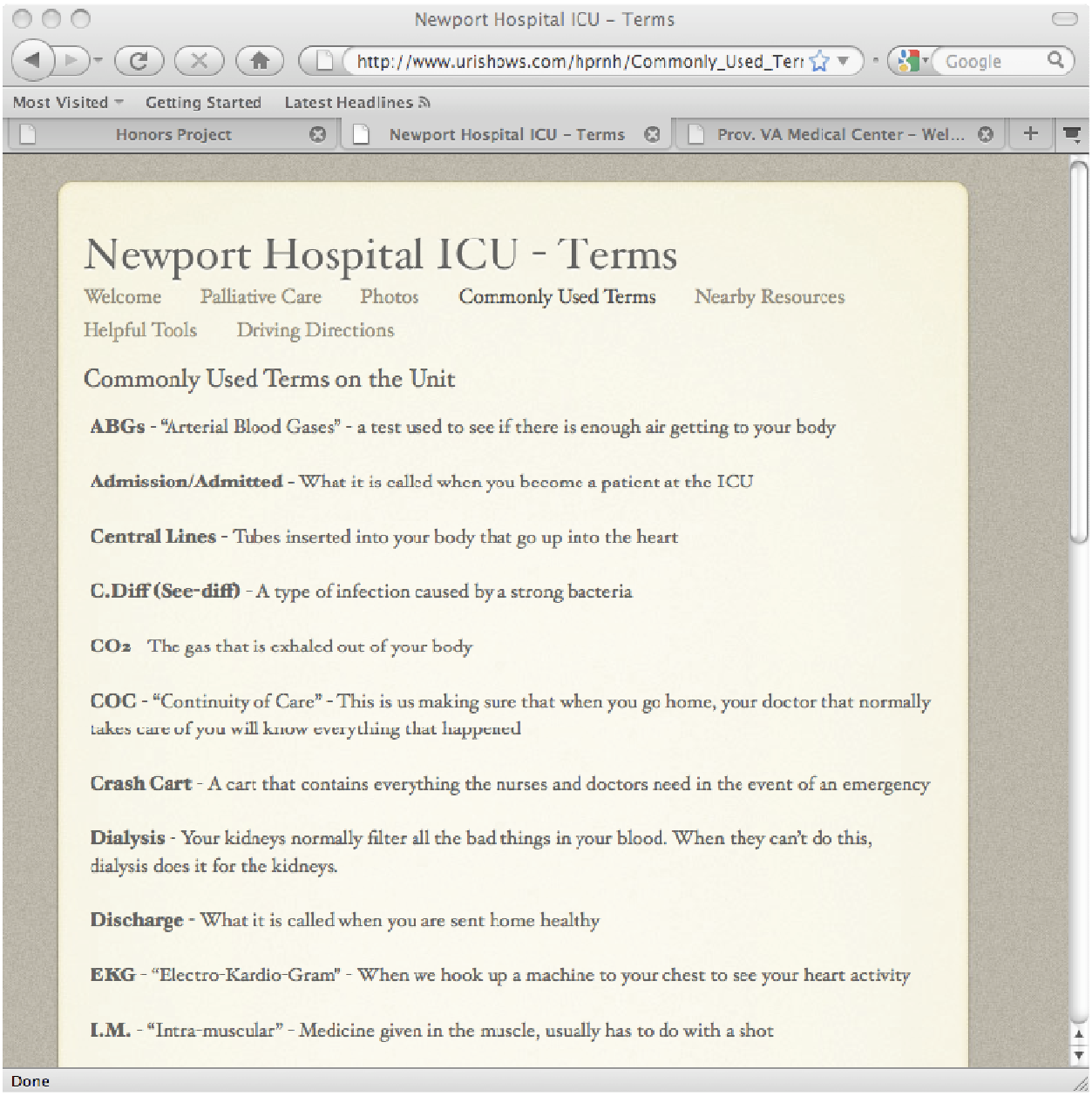


Unit Tour Page [Figure 2]

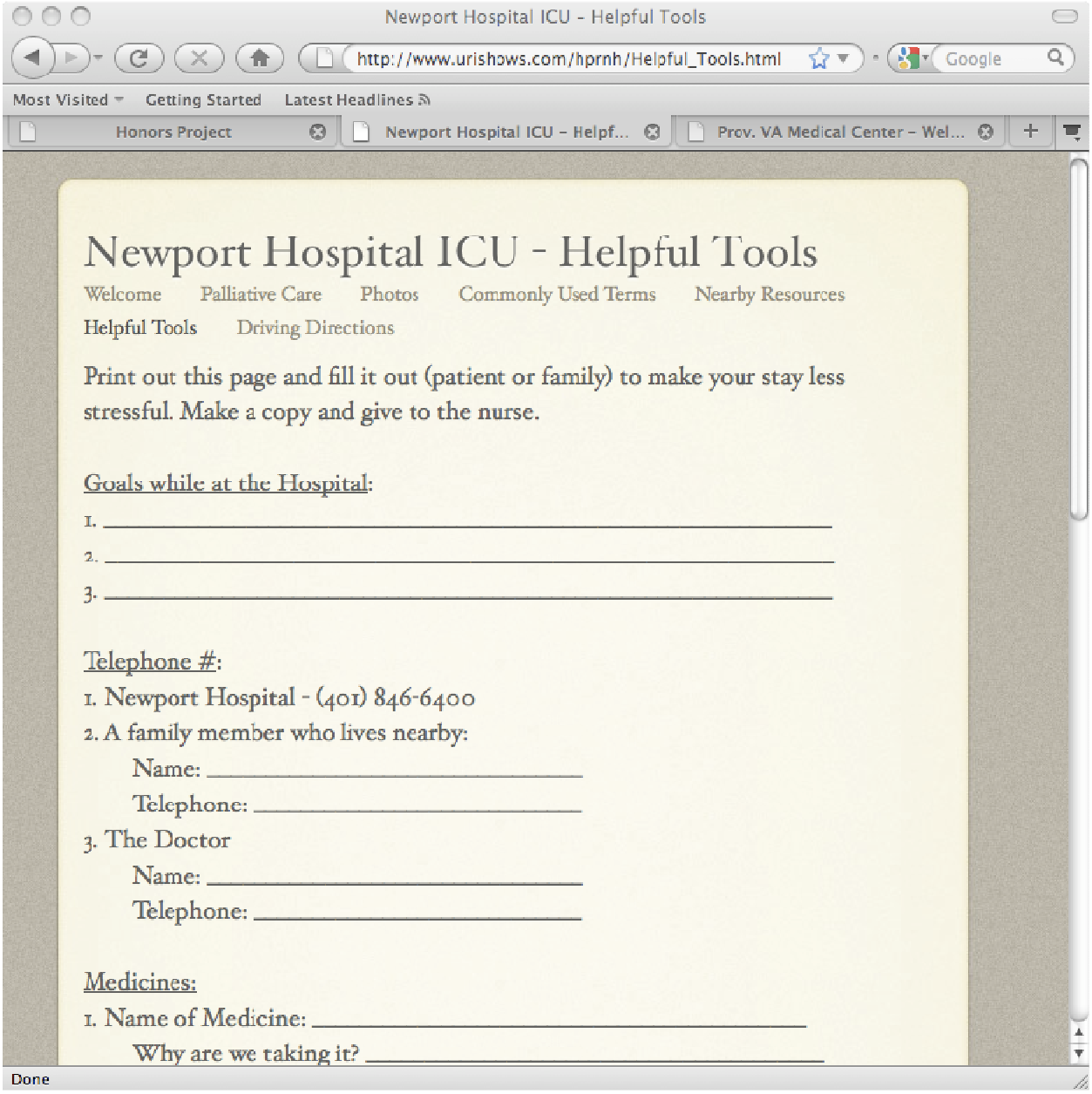
Unit Tour Slideshow [Figure 3]



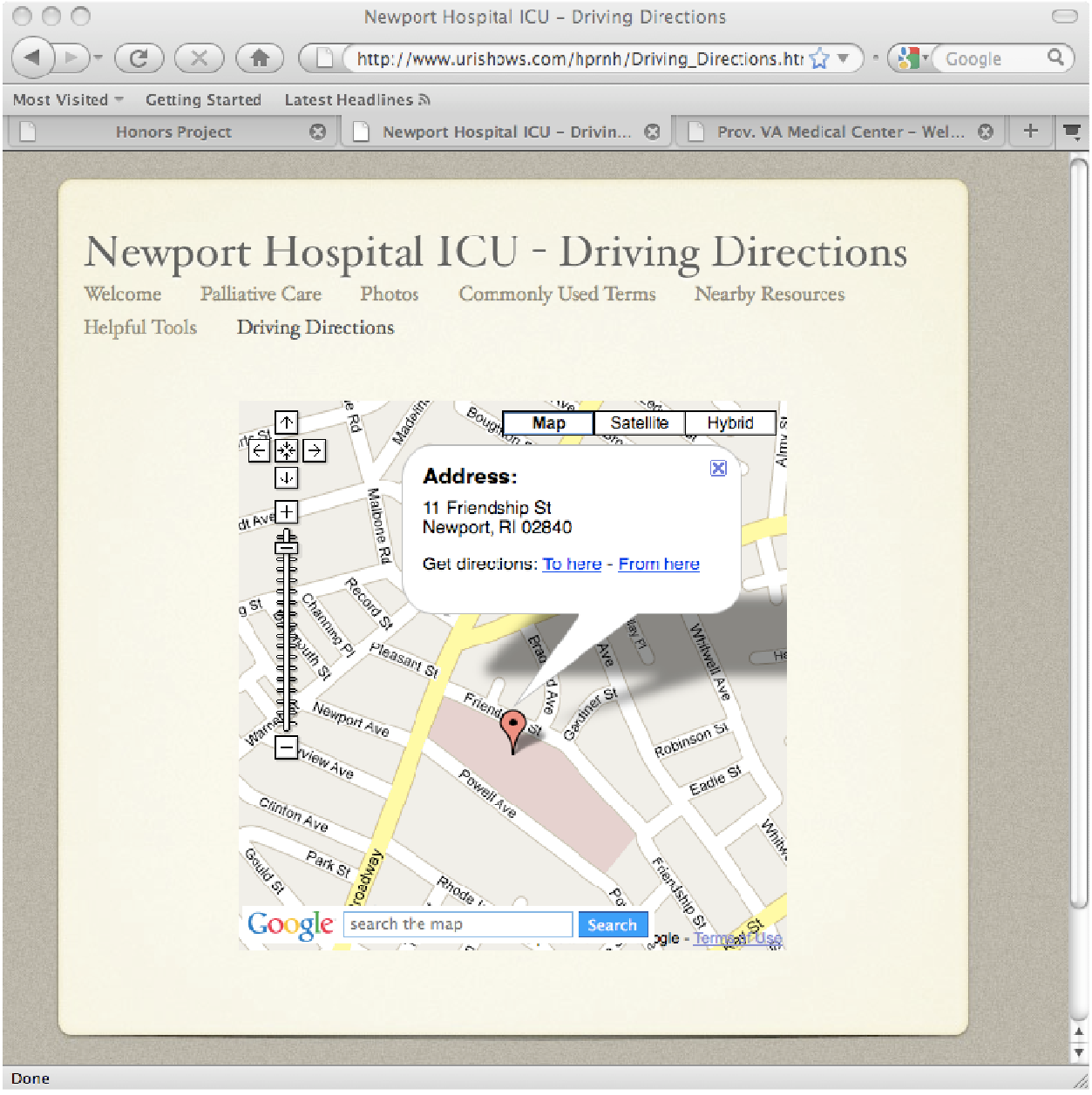
Commonly Used Terms Page [Figure 4]



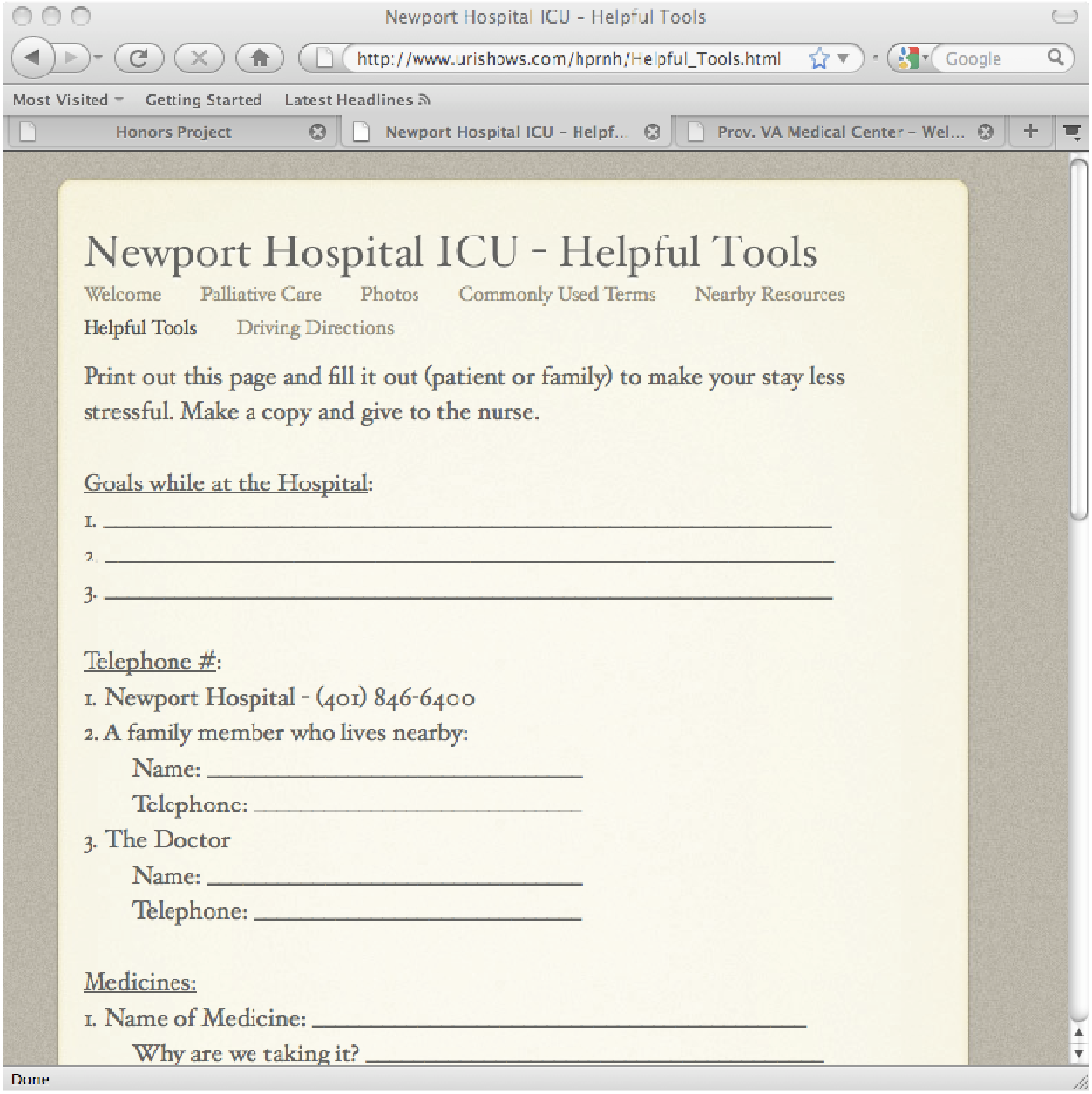
Helpful Tools Page [Figure 5]



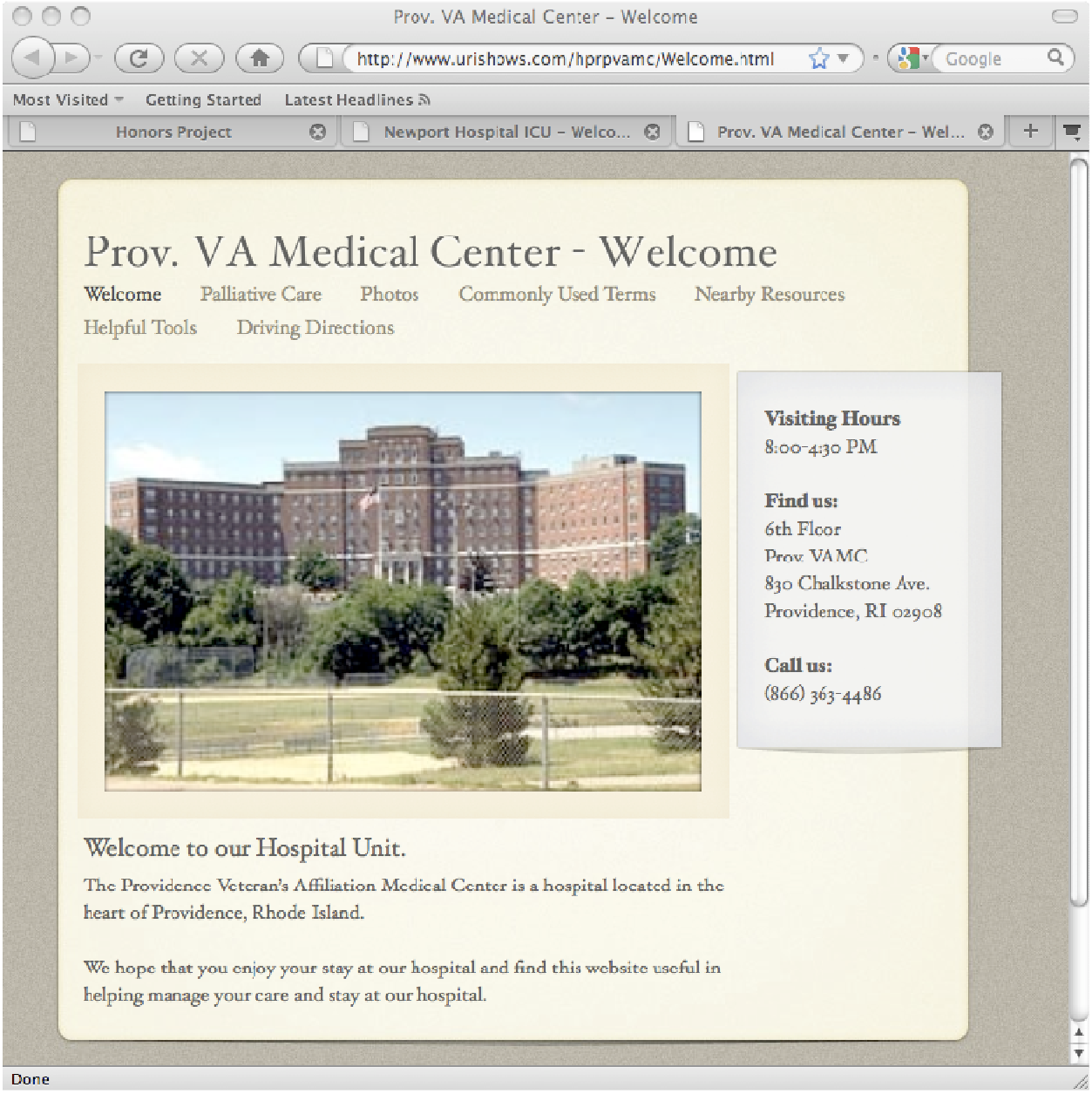
Driving Directions Page [Figure 6]



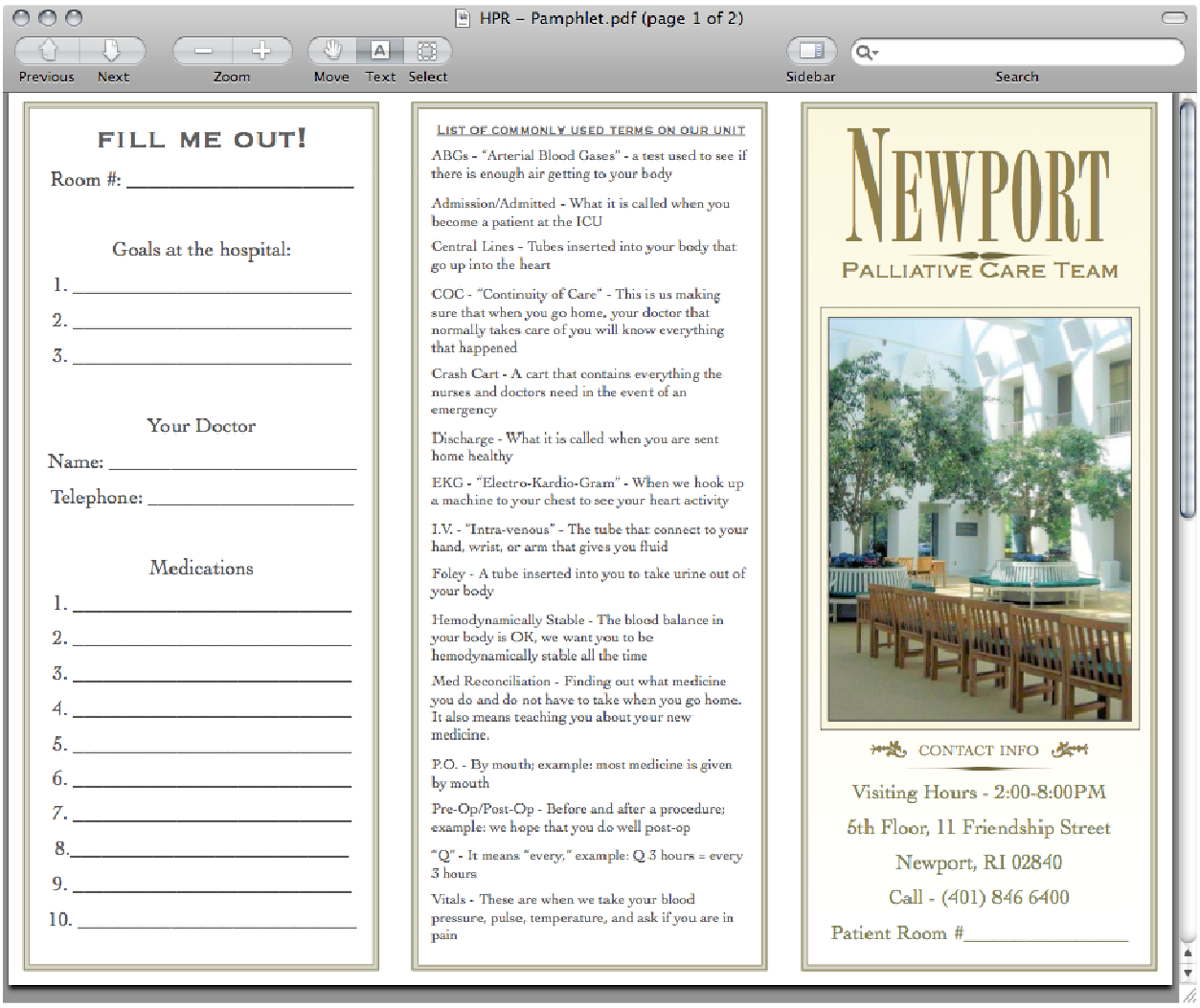
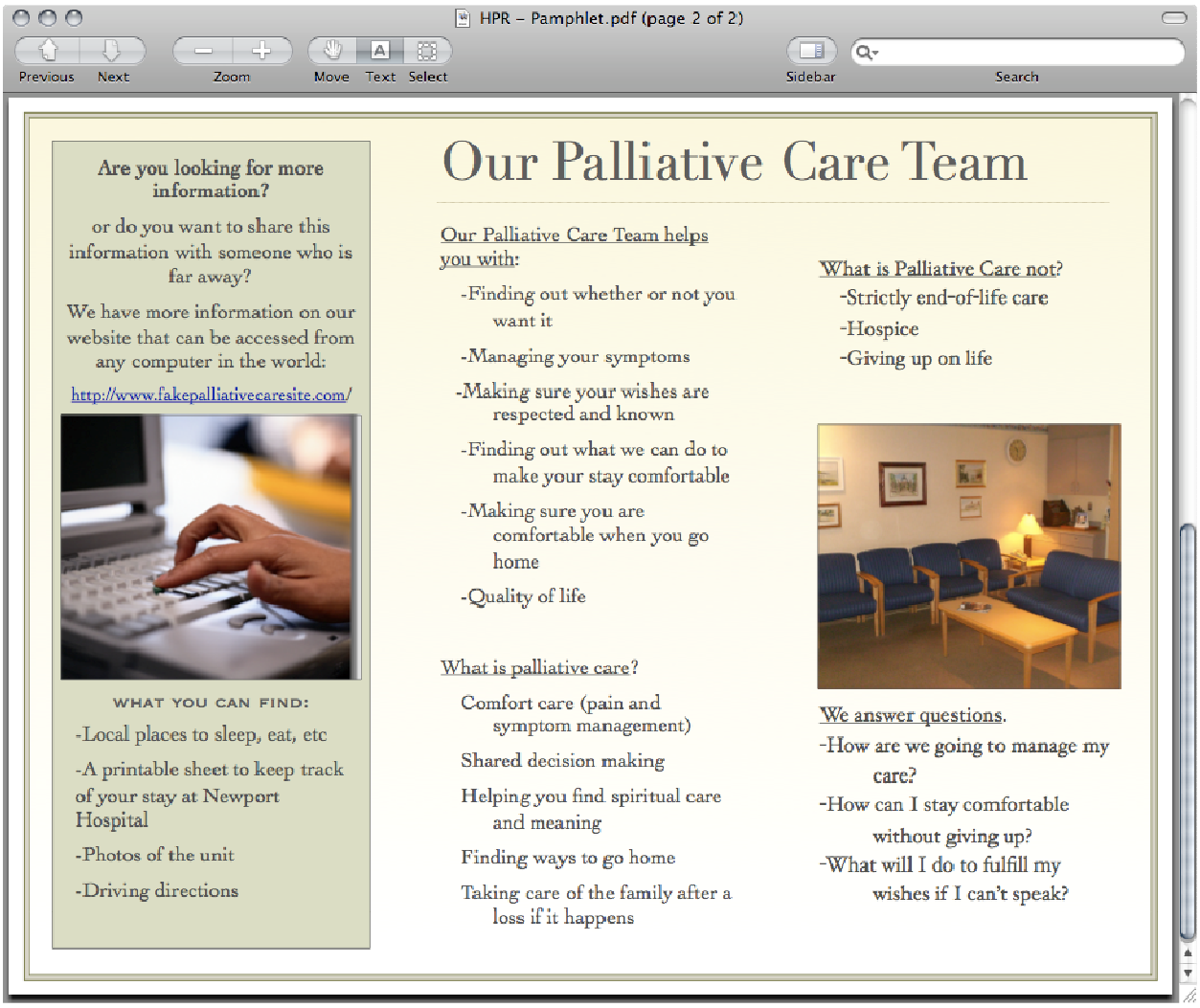
Nearby Resources Page [Figure 7]



Providence V.A. Medical Center Page [Figure 8]



Pamphlet Side A [Figure 9]



Pamphlet Side B [Figure 10]