**EP 4:** The structure(s) and process(es) of the Care Delivery System involve the patient and/or his or her support system in the planning and delivery of care. Provide at least two (2) examples of a plan of care that included patient and/or family member involvement.

The MGH has long held a history of genuinely caring for its patients and truly listening to the voices of the patients and their families. The foundation for these values are driven by Massachusetts General Hospital’s (MGH) Guiding Principles that states, “We recognize the importance of encouraging patients and families to participate in the decisions affecting their care” and, “We acknowledge that maintaining the highest standards of patient care delivery is a never-ending process that involves the patient, family, and nurse.” (OOD 1) The Credo further upholds the belief system for the MGH community in the affirmation, “As a member of the MGH community and in the service of our mission, I will listen and respond to patients, and patients' families” (OOD 1). The importance of patient-centered care and the role of families in decision-making are central to the culture at MGH and palpable throughout the organization.

The Professional Practice Model (PPM) (OOD 11) is grounded in values and beliefs that embrace the patient and family in that it is patient- and family-centered and interdisciplinary in nature. The PPM's central component is one of “Patient-Centeredness” thus guiding the nurse to embrace a partnership with the patient and the family along with other members of the health care team. At the heart of patient- and family-centered care is the belief that health care providers and the family are partners, working together to best meet the needs of the patient. Patient- and family-centered care is a continual effort to be responsive to the needs and choices of each family. Value is placed on the dynamic and therapeutic interactions that occur between the nurse, the relationships that are strengthened by the nurse’s presence and involvement in the delivery of care.

**Organizational Structures and Processes**

Throughout the Care Delivery System, there are many examples of how units have created the infrastructure and processes to assure that patients and families play a key role in the development of the patient’s plan of care and that they have a voice in the decision-making that affects their outcomes and ultimately, their lives. Some wonderful examples of organizational structures that exist at MGH are the Patient and Family Advisory Councils (PFAC), the Maxwell & Eleanor Blum Patient and Family Learning Center, and the Speak Up Campaign.

**Patient and Family Advisory Councils**

It is implicit in the MGH mission that the work, the care and the decision be guided by the needs of patients. In order to truly be guided by the needs of patients, they must have a voice. One way that MGH has ensured that the patients’ voices are heard is by inviting them to participate in Patient and Family Advisory Councils (PFACs). MGH launched its first Patient and Family Advisory Council more than 12 years ago to bring together patients, family members and hospital staff in an ongoing effort to enhance the patient and family experience. These councils advise hospital leadership on matters relating to the patient’s experience, the relationships between the patient and the clinicians, quality and safety issues, patient education and other issues that help inform decisions as to how care is delivered.
“GUIDED BY THE NEEDS OF OUR PATIENTS AND THEIR FAMILIES, we aim to deliver the very best healthcare in a safe, compassionate environment; to advance that care through innovative research and education; and, to improve the health and well-being of the diverse communities we serve.”

— The Massachusetts General Hospital Mission

With the launch of the hospital’s first Patient and Family Advisory Council (PFAC) in 1999, the MassGeneral Hospital for Children (MGHfC), Massachusetts General Hospital (MGH) began to tap into a vital mechanism for integrating the critical patient and family perspective into our day-to-day operations, various initiatives, and plans for the future. MGH’s PFACs are grounded in the belief that often the most informed voices on the care team are those of the patient and family. Ultimately, they, alone, can confirm whether a plan of care was explained thoroughly; the clinical information provided was fully understood; their questions and fears were appropriately addressed; care was tailored to their specific needs; they felt safe; systems worked efficiently and effectively; and, each was treated as a person — a whole person — and not simply as a chart or a medical record. In contrast to being cared for at a hospital with a distinct specialty (i.e., cancer, pediatrics, diabetes) in which patients are more likely to present with common diagnoses, challenges and courses of treatment, patients and families of MGH are likely to enter with differing sets of needs and to follow varying pathways. The experience of a cardiology patient will be quite distinct from that of a pediatric, cancer, neurology, or general medicine patient, or that of a new mother. In light of the broad spectrum of patient and family experiences within the same institution, MGH, along with participating patients and family members, have found it beneficial to operate multiple PFACs, each bringing voice to a specific patient and family experience, environment of care, and/or priority area for the hospital. To this end, the Minutes of all PFAC meetings and their
accomplishments (attachment EP 4.a) are provided directly to the hospital’s governing body, the Board of Trustees (attachment EP 4.b, attachment EP 4.c, and attachment EP 4.d.). Individually, these PFACs are optimally situated to impact the delivery of care directly. Collectively, they are positioned to influence hospital wide initiatives, with the added benefit of bringing multiple, authentic and highly relevant perspectives to the table. The PFACs launched to-date have developed to cover the hospital’s most widely used clinical services and represent a large proportion of the care provided at MGH. There are currently four PFACs; MassGeneral Hospital for Children Family Advisory Council (FAC), MGH Cancer Center PFAC, the MGH Heart Center PFAC and a newly formed Steering Council (TL E3O). The following will provide a brief description of each of the PFACs.

**Mass General Hospital for Children — established 1999**

The MassGeneral Hospital for Children’s Family Advisory Council is dedicated to fostering the partnership of parents, children, and professionals working together to ensure a climate of responsiveness to the needs of children and their families in all areas of care delivery within MGH. The MGH/C Family Advisory Council has established a visible presence within the MGH/C and the larger hospital community and continues to positively influence patient care by providing a parent’s perspective on how to deliver meaningful patient- and family-centered care, with a special emphasis on family-centered communication. The council’s goals are to align with the broader Mass General/MGH/C goal of enhancing patient-physician communication by fostering family-centered communication and promoting the principles of patient- and family-centered care by ensuring:

- **Dignity and Respect**: Honoring patient and family perspectives, choices, knowledge, values, beliefs and cultural backgrounds.
- **Information Sharing**: Communicating and sharing complete, unbiased, accurate and timely information with patients and families so they can effectively participate in care and decision-making.
- **Participation**: Encouraging and supporting patient and family participation in care and decision-making at the level they choose.
- **Collaboration**: Partnering with patients and families in the delivery of care; policy and program development and evaluation; healthcare facility design; and, professional education.

**The Family Advisory Council exists to:**

- Work together with the administration and staff of MassGeneral Hospital for Children (MGH/C) to promote patient- and family-centered care.
- Collaborate with the MGH/C staff in improving the quality of health care provided to children and their families in both inpatient and outpatient settings.
- Improve patient, family and staff satisfaction.
- Ensure an attractive environment that is responsive to the needs of children and their families.
- Act as an advisory resource to MGH/C leadership on issues of planning, evaluation of programs and services, policies and new facilities.
- Act as an advisory resource to MGH/C giving input to teaching documents generated by the hospital regarding families.
- Promote a positive relationship between MGH/C and the community; and serve as a vital link between the community-at-large.
Some of the accomplishments achieved by the MGH/C members were: participation on the committee designing changes to the Pediatric Admission, Pre-op and Discharge areas; participation in an Ambulatory Care rotation for Residents as a way to share their experiences having their child cared for in primary care; and, presenting at Grand Rounds on “Building an Effective Healthcare Team”.

MGH Cancer Center PFAC
Established in 2001, the mission of the MGH Cancer Center’s PFAC is to ensure that the voices of patients and families are represented in an effort to enhance their entire experience at the MGH Cancer Center. The PFAC provides a valuable opportunity to hear feedback and recommendations from patients and families about the care they received during their healthcare experience in the Cancer Center. As such, members serve in an advisory role regarding aspects of the planning and delivery of care. Their areas of focus include:
- Improving the human experience,
- Supporting patient- and family-centered care,
- Promoting staff education, and sharing with and,
- Learning from others, in an effort to expand the voices of patients and families beyond.

The Cancer Center PFAC has had many accomplishments over the past year: provided substantive consultation to inpatient Nursing regarding patient and family experiences related to inpatient cancer care; provided suggestions to the Lunder Building architects and Nursing staff regarding the design of the two newest cancer inpatient units; and, participated in the Thoracic Care Redesign Initiative and the Colon Cancer Redesign Pathway.
MGH Heart Center PFAC

Established in 2007, the MGH Heart Center PFAC exists to ensure that the voices of patients and families are represented in a multidisciplinary effort to enhance the experience of care at MGH. The MGH Heart Center PFAC consists of 13 members (eight patients, two family members and three MGH representatives) who represent a diverse perspective and experience relative to age, gender, nature of cardiovascular illness, and socio-economic status. Recruitment of patient and family council members is initiated by referrals from all disciplines, including MGH Physicians, Nurses, other healthcare professionals, and staff. Invitation letters and application forms are then sent to potential members.

To this end, the Council focuses on several key goals:

Advise: Work in an advisory role to enhance cardiovascular care at the MGH Heart Center.

Support: Act as a sounding board for implementation of new MGH Heart Center programs, and improvement of existing programs.

Participate: Provide input to improve the physical environment of care; provide representation on committees within the MGH Heart Center to represent the voice of the patient and families.

Identify: Opportunities to promote wellness and prevention of heart disease; patient- and family centered care strategies; new services, programs and/or communication, for consideration, that may benefit the Heart Center patients and/or the MGH Heart Center, itself; and new programs, efforts and/or mechanisms for consideration that would enable the MGH Heart Center patients to be able to give back to the Mass General community through either support, community involvement or recognitions.

Represent: Patient and family perspectives about the overall experience of care at MGH; the MGH Heart Center has a commitment to listening to the voices of patients and families.

Educate: Collaborate with MGH staff to create, review, and revise MGH Heart Center educational materials and processes; influence and participate in the education of MGH staff, including Nurses, Nurse Practitioners, Physicians and support staff. The MGH Heart Center Patient & Family Advisory Council (PFAC) has achieved many accomplishments from July 2010 to 2011 in several areas by enhancing patient and family-centered areas; enhancing patient service communication and development; and, strengthening and enhancing awareness of the MGH Heart Center PFAC.
**Patient and Family Learning Center**

The Maxwell & Eleanor Blum Patient and Family Learning Center (Blum Center) is a patient-education resource providing health information and services to a diverse community of patients, families and staff. Since its inception in 1999, the Blum Center has assisted thousands of patients to understand more about health and illness, make informed treatment choices and health care decisions, and improve communication with healthcare providers. The Blum Center is a valuable resource to patients and families in that its services include: conducting information searches on any healthcare topic; sending education materials to patients at home and on patient care units; providing access to a library that contains more than 500 files; and, providing journals and pamphlets on a variety of health topics. The Blum Center makes use of a Patient and Family Advisory Council (PFAC) to provide feedback on its many services, to field-test educational materials, and to guide decisions around educational programs, information displays, and acquisition of new materials.

**Health Information Services**

In 2011, the Blum Center staff assisted over 17,789 patrons with a myriad of health information requests on a variety of clinical, health system and research-related topics. The Blum Center staff fields these requests from patrons who visited the Blum Center in person, by phone or e-mail. The center’s expert staff assists patrons in locating high quality and accurate health information by using the MGH intranet or other resources such as brochures and other print material.

Educational program offerings from the Blum Center greatly expanded in 2011, from one monthly book offering to four different monthly lecture series. The series are:

- **“Book Talks” Series** – a discussion with an MGH author of a book on a health-related topic.
- **Shared Decision-Making Series** – co-sponsored with the Stoeckle Center, this session promotes active and shared decision making between patients and clinicians.
• National Health Observances Calendar Series – this session is presented by an MGH clinician and content relates to a health-related topic of the month.
• Healthy Living Series – this session focuses on health promotion and prevention.

The Blum Center sponsored 20 regular programs within these four series which were attended by approximately 500 participants, an average of 20 people per session. Participant feedback after the programs is overwhelmingly positive; an important finding is that these programs have the potential to have a positive impact on participants’ health behaviors as:
• 96.5% of participants reported they had a better understanding of the health topic.
• 74.3% of participants reported that they would use the information gained in the program when talking to a doctor, nurse, or therapist.
• 82.3% of participants reported they would make a change to improve their health because of the program.

As part of the Blum Center’s goal of expanding educational programming, the Blum Center sponsored a special Pain Awareness Evening Lecture Series in September developed in collaboration with expert clinicians from the Pain Clinic and the Institute for Patient Care. Over 150 participants attended one of the five sessions on different aspects of pain management including: patient/clinician communication, coping with chronic pain, post-surgical pain control, cancer pain, and symptom control using prescription and non-prescription medication. Again, overall feedback was extremely positive about the offerings. One patient stated, “I will be a more educated consumer of health care. I will be more knowledgeable when I go to MD appointments. When I take medications, I will be aware of what to expect (side effects, alternatives).”

In addition, Blum Center staff updated the MGH Patient Education Television Channel with 21 new educational videos. Two hundred thirty (230) educational videos are now available to patients and families. Patients and/or families accessed a video 2,625 times during 2011 using the televisions on the inpatient units.

Through an ongoing partnership with the Stoeckle Center for Primary Care Innovation, the Blum Center hosts the Shared Decision-Making project. The goal of the program is to enhance patient decision quality and satisfaction with care. The program has two major initiatives: the provision of decision aids to patients facing significant decisions and the training healthcare providers to tailor medical treatments to patients’ individual goals and concerns. Clinicians can easily “prescribe” more than 35 DVD decision aids for patients to watch. These decision aids present balanced, unbiased information on a particular health condition or treatment. Over 2,412 videos were prescribed by MGH primary care clinicians to assist patients with medical treatment decisions and learn health management behaviors, almost double the amount that was prescribed last year.

As part of our commitment to meeting the needs of patients, families and staff with disabilities, the Blum Center underwent an assessment of its equipment designed to support this population. As a result, all equipment and software was updated to maximize usability. The Blum Center also renamed the Disabilities Access Center space devoted to these services, “The Assistive Technology Center” in order to more positively reflect the equipment and software available. As part of this redesign, a built-in counter was replaced with an adjustable height table to be able to accommodate both manual and electric wheelchair users. The assistive technology software was also updated in order to enable users with visual and hearing impairments the tools needed to use the computer independently. Finally, Blum Center staff developed a process that allows staff to request written materials in Braille for patients with sight impairments; Braille services were provided to four patients this past year.
Health Literacy Efforts

As part of an evaluation of currently-offered services, Blum Center staff developed and introduced a new process to enhance support for nurses and other clinicians. While staff of the Blum Center had previously assisted clinicians in writing patient education documents on an informal basis, a plain language consulting and material development review process was officially introduced in 2011. Blum Center staff trained in health literacy and plain language evaluation collaborated with MGH clinicians to evaluate or produce patient education documents that meet plain language guidelines to better facilitate patient understanding. A total of 125 documents were reviewed/revised which ranged from a one-page fact sheet to an eight-page brochure.

Staff Education

An innovative two-hour program for all newly-hired Registered Nurses was incorporated into orientation sessions in 2011. During Registered Nurse Orientation (RNO), newly-hired Registered Nurses participate in an interactive session where they learn to identify and assess patient education needs and then integrate health literacy methods into their teaching. By the end of the session, Registered Nurses demonstrate that they are able to independently search the intranet for appropriate patient education materials. In 2011, 310 nurses attended this orientation session.

The Blum Center has also played a key role in developing an extensive patient education database by collaborating with expert clinicians from clinical departments and patient care units to revise and update over 275 patient discharge documents. A key component of this work is ensuring that these documents are developed using plain language and that they are accessible to clinicians in the Partners Handbook. Finally, the Blum Center was also involved in many educational internships and collaborative initiatives. Several internships provided college and graduate students from UMASS Lowell and Simmons College with direct work experience in health education.

Speak Up Campaign

Prominently and publicly displayed in the first floor lobby are poster displays, SPEAK UP, informing patients that “To improve quality of care, patients are urged to speak up”. MGH believes everyone has a role to make sure they receive high quality care and as a patient, he/she is invited to become a partner in their care. Patients are empowered to make sure that their care is better and safer by being an active, involved and informed member of their health care team. The SPEAK UP campaign is articulated as thus:

- **SPEAK UP** if you have questions or concerns.
- **PAY ATTENTION** to the care you receive.
- **EDUCATE YOURSELF** about your illness.
- **ASK A TRUSTED FAMILY MEMBER** or friend to be your advocate.
- **KNOW WHAT MEDICINES** you take and why you take them.
- **USE** a hospital like the MGH that has been carefully checked out by the Joint Commission.
- **PARTICIPATE** in all decisions about your treatment.

Encouraging the active participation of patients in their own health care is an important component of patient safety. As part of an effort to promote patients’ and their families’ involvement, MGH/C joined the “Speak Up” program, an award-winning initiative developed by the Joint Commission to encourage patients to take a role in preventing health care errors by becoming active, involved and informed participants of their health care team. The MGH/C Speak Up program is led by an interdisciplinary committee of caregivers, quality and safety administrators, and
members of the Family Advisory Council. Their goals include engaging staff, patients and families in quality and safety initiatives and developing practical strategies to address quality and safety concerns. The group conducts weekly inpatient rounds, speaking with the parents of pediatric patients about their child’s care experience. All information is logged, and items requiring follow-up are acted upon immediately.

A Speak Up Rounds pilot was conducted by the interdisciplinary committee from December, 2011 to March, 2012. The committee made rounds on the Pediatric inpatient floors and spoke with 45 patients and families and 42 staff members. Preliminary data demonstrated that overall, patients had positive experiences and most families stated that they did not have much significant feedback to share. Most negative feedback related to environmental issues; noise, food, and sharing rooms, all of which are currently being addressed. The committee is now exploring the development of a structured script to obtain consistent and reliable data, and to explore methods to analyze relationships to other factors, such as, length of stay and diagnosis.

Unit Based Structures and Processes

To assure that patient involvement that provides support for the patient and /or his or her to participate in the planning and delivery of care, there are many structures and processes within MGH. Illustrated in the following discussion will be Patient and Family Meetings, Patient and Family Notebooks, Patient White Boards, Peer Mentoring Program, Rapid Response Teams, and the Asthma Action Plan.

Patient and Family Meetings

One of the foremost Strategic Goals for 2012 (exhibit OOD 5.i) is to “Develop an efficient and effective patient- and family-centered model of care delivery advancing a relationship-based care philosophy.” The philosophy of relationship-based care has added a further dimension to our delivery model which guides the interdisciplinary patient- and family-focused care. The philosophy of relationship-based care emphasizes the importance of cultivating the relationship between the caregiver and the patient
and family, the caregiver’s relationship with colleagues, and the caregiver’s relationship with himself or herself. Patient and family meetings are often held to facilitate communication between health care providers and families of patients. The belief and commitment to these meetings is in knowing that effective communication improves family satisfaction, clinical decision-making, and the psychological well being of family members.

A wonderful illustration of how this philosophy is operationalized is demonstrated in the Medical Intensive Care Unit (Blake 7). A program has been implemented that assures initial family meetings occur within 48-72 hours for all new patients and their loved ones and provides training for all RNs and House Staff. This program begins with a one-hour talk which reviews the family experience and provides an evidenced-based program for how to conduct a family meeting. It is supported by a unit-based documentation form that captures the contents of the family meeting. (Attachment EP 4.e). The unit secretarial staff monitor a daily list of patients whose family has not yet had a meeting, places this information on the white board for all staff to visualize, and includes family meeting completion in the daily checklist during rounds. In addition, families are consistently invited to rounds, and are assured that either the RN or MD or both “translate” any foreign content at some point throughout the day, preferably shortly after rounds have concluded.

To further demonstrate the commitment to patient and family involvement in the plan of care, cards from the family whose member passed away in the Medical Intensive Care Unit (Blake 7) were collected during from January to June, 2008. The contents of the cards were analyzed for themes and five themes emerged: quality of care, open communication, being in a presence, dignity: being treated as a human not a patient, guiding family to say goodbye. Staff have found that family thank-you cards are enormously instructive, rich in qualitative data and contribute to the ongoing development of their professional practice.

This card, written by a family whose loved one died in the Medical Intensive Care Unit (Blake 7) at the start of this year, so clearly illuminates their perceptions of the goals that we attempt to achieve on a daily basis. The following captures a family’s words of appreciation …

January 1, 2012:

“My father, and the rest of my family, has never questioned the excellence of medical care which Mass. General provides. What we found so completely remarkable was the quality of the professional compassion and kindness with which my entire family was treated during our father’s stay in the Medical ICU on Blake 7. At first, I was surprised at the level of openness and transparency with which we were met. We were encouraged to listen in on rounds and ask any questions we had. The level of transparency makes the family feel like part of the treatment team, which allows us to feel confident that we know everything we need to in order to make decisions. I can’t tell you how important this is in the family’s healing process, especially when a patient is terminal.”

Patient & Family Notebooks

As part of the innovations initiatives at MGH, patients on Innovation Units are provided with “The Patient and Family Notebook” intended for sharing information to guide the patient’s care. The notebook opens with a warm and welcoming message from the Chief Nurse, stating that “as always, your comfort and well-being are the focus of all we do.” Next, patients are presented with the “Universal Patient Compact” – an agreement that is comprised of 14 Principles for Partnership which reinforce the importance of the clinician-patient dyad in this journey. Often patients are confused about the roles and relationships of the Nurses and Physicians and this booklet describes the roles of all members of the healthcare team and support staff. Space is allotted for patients to write down questions they may have, for example: their diagnosis, medication, tests, nutrition and procedures; questions about leaving the hospital, date of intended discharge, medications and medical equipment needed and follow-up care; and questions about care
at home such as visiting nurse or other home services, physical activity, nutrition and resources/services. Lastly, patients and families are encouraged to contact the Office of Patient Advocacy should they have compliments or concerns about their healthcare experience. This has been successful initiative to affirm MGH’s commitment that patients and families are encouraged to ask questions, give feedback, and be a partner in their care. Early feedback on this initiative has been such that the Patient & Family Notebooks will be implemented throughout the organization.

In May, 2012, various surveys were launched to evaluate the effectiveness of the Patient and Family Notebook (attachment EP 4.f). Patients and families were interviewed by Patient Advocates about their perceptions intervention to guide future improvements. Staff also had the opportunity to give their feedback through electronic surveys and personal interviews. Overall, patients generally found the notebook helpful, particularly the employee descriptions, the descriptions of the patient-provider relationship and the welcome letter explaining the concept of the Innovation Units and the patient and family welcome packet. Areas for improvement were noted and will be implemented in the coming months.

In Room White Boards

An effective means of facilitating communication with the patient and the family and ensuring that they are involved in the planning and delivery of care, has been the use of white boards in the patients’ rooms. Key information about the goals of the plan of care for the day are documented and maintained in a timely fashion in order to keep the patient family apprised of the patient’s goals and progress. Not only are the Nurse, the Physician and the Care Team identified, but the estimated discharge date and goals for the day are noted. An area is also dedicated for patients and families to leave questions for their Care Team. This allows patients and families to be more engaged in discussions around their healthcare and participate in the decision-making around their plan of care.
Rapid Response Team

A key component to the effective implementation of the Rapid Response Team has been the participation of the patient and family. Patients and families are encouraged and empowered to notify their nurse should they be concerned about an apparent change in the patient’s condition or if something does not look right or seem right with the patient and the family. There are signs/plaques in the room encouraging family members to request additional assistance when they are concerned about a patient's condition. They are also encouraged to ask the staff if there is any part of their care that they do not understand. The enlistment of patient and families in team activation sends a message to our patients and families that MGH is responsive and that their concerns are taken seriously. From April 1, 2011 to March 30, 2012, there were 163 Rapid Response Calls. (attachment EP 4.g)

Peer Mentoring Program

An excellent example of a plan of care that includes the patient is the Peer Mentoring Program that was established in August, 2010, for children who undergo proton therapy. A Pediatric Nurse at the Proton Center has cultivated a program in which children who have undergone treatment without anesthesia show new patients how to do the same. The children actually assist other children through treatment with the goal of avoiding daily anesthesia.

Proton radiation therapy requires that patients must lie extremely still inside the three-story tall proton therapy machine in a room resembling a spaceship. The treatment requires that children lie still; therefore, patients must wear a fitted plastic mask in order to keep them still. The process is not painful, but can be frightening. Many children require anesthesia to assure precise treatment delivery and depending on the diagnosis, most patients receive 30-40 treatments, Monday through Friday, over the course of two or three months. Treatment sessions usually last about 20 minutes.
The program is especially helpful for children ages five to seven who are in between the typical range of those who need anesthesia and those who do not. Without anesthesia, the child and family can leave immediately after treatment and enjoy outside interests. If undergoing treatment with sedation, the child must fast the night before, and will typically spend at least an extra hour in the Center before returning to regular activity.

Since its inception in August, 2010, 19 children, ages six to eight years old, have participated in the mentoring program. The first patient to participate in the program has gone on to mentor five other children; two others have been mentored by staff. Of the seven children mentored, five were able to proceed into treatment without anesthesia. Of all the children mentored, seven have gone on to mentor other children. The quantified benefits include: reduction in treatment cost and in cumulative risks of daily anesthesia. Future study will measure other benefits including: reduced anxiety, increased self-esteem, improved quality of life, fostering of a social emotional bond, and empowerment. This mentoring program has the potential to decrease the need for daily anesthesia, but also empower a child undergoing radiation therapy. Peer mentoring is an effective, low-cost intervention.

Asthma Action Plans for Families upon Hospital Discharge

Nurses, as health educators, play a key role in the discharge teaching of children hospitalized with a diagnosis of asthma and their families. In 2007 the Asthma Expert Panel, commissioned by the National Asthma Education and Prevention Program (NAEPP) Coordination Committee, and coordinated by the National Heart, Lung, and Blood Institute (NHLBI), made recommendations and presented Guidelines for the Diagnosis and Management of Asthma. The panel recommended “that clinicians provide to a patients who have asthma a written asthma action plan that includes instructions for (1) daily management and (2) recognizing and handling worsening asthma, including adjustment of dose of medications.” The recommendations provided guidance for nursing practice with regard to the Asthma Action Plan used to plan for discharge home from Pediatric Units (Ellison 17 and Ellison 18) and the Pediatric Intensive Care Unit (Bigelow 6 (attachment EP 4.h).

The Joint Commission (JC) has been working in collaboration with The Centers for Medicare and Medicaid Services (CMS) since 2003 to evaluate performance measures related to asthma in children. As of April 2007, the JC and the Children’s Asthma Care (CAC) Advisory Panel mandated the following asthma measures: (1) use of relievers for inpatient asthma, (2) use of systemic corticosteroids for inpatient asthma and (3) home management plan of care given to the patient/caregiver. As of April 2010, Massachusetts Medicaid mandated this performance measure for public reporting (the only pediatric inpatient measure).

At MGH, Pediatric Nurses have worked collaboratively with Physicians and Respiratory Therapists to improve MGH’s performance on the Pediatric Asthma CAC #3 measure, “Home
Management Plan of Care Given the Patient/Caregiver.” In order to fulfill the requirements of the measure, the following elements are required:

- A separate Asthma Action Plan must be present in the medical record
- There must be documentation that the plan was given to the child's parent/guardian
- All five required elements must be present (i.e., follow up appointment, triggers, rescue plan, use of controllers, use of relievers).

MGH has been conducting quarterly chart reviews on all patients ages 2 to 18 who were discharged with a primary diagnosis of asthma to determine compliance with the CAC #3 measure. Prior to June 2011, an Asthma Action Plan form was developed, which included all of the required elements. A prompt was developed in the electronic documentation system to remind the discharging nurse to place the Asthma Action Plan in the medical record. Quarterly record reviews indicated that compliance varied between 30% and 60%. This represented an improvement over previous audits, but did not approach the 85% target set by MGH for the measure. Based on the results, the Clinical Nurse Specialist consulted with Staff Nurses to better understand the challenges. Staff Nurses related that in most cases, they believed the families were receiving the Asthma Action Plans, but that the challenge lay in coordinating the photocopying of the action plan and placement of the copy in the chart, especially as the plan itself was reviewed with the family throughout the hospitalization. The extra step of photocopying the plan required reviewing the plan with the family, taking it from the family for photocopying and then returning it.

Based on Staff Nurse feedback, the action plan was revised in June, 2011, as a duplicate form. Staff nurses now complete the form with the family, give one copy to the family and return the duplicate to the chart. As a reminder to staff, there is a watermark on the duplicate copy which states, “Place in patient’s chart when complete.” An additional prompt as the nurse is completing the discharge documentation in the electronic medical record reminds the nurse that the family should have received an Asthma Action Plan and a copy should be placed in the medical record.

Quarterly chart reviews show marked improvement in compliance with the measure since the implementation of the new form. Staff Nurses will continue to be consulted re: the patients’ records which do not pass the measure to determine additional opportunities for improvement on this important component of asthma care. For example, recently staff reported the need to have the action plan translated into Spanish, which was completed by a Staff Nurse this past spring.

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**Plans of Care**

The MGH Patient Care Delivery Model (PCDM) is where mission, vision, values and long-range goals converge to support the delivery of patient care. Our model depicts the dynamic and therapeutic interaction that occurs between the professional care provider and the patient around issues of health and illness. The PCDM reflects an open, evolving interactive system where there is continuous exchange occurring between the clinician and the patient. The nursing process is an integral part of the fabric that comprises patient care at MGH. In all locations, the nurse assesses
the patient, uses diagnostic reasoning to identify problems, creates a plan for nursing care that includes interventions and measurable patient care goals, and continually evaluates progress toward those goals. The narratives illustrated will describe the structures and processes of the Care Delivery System at MGH that involve the patient and/or his support system in the planning and delivery of care affirming one of our guiding principles; “We recognize the importance of encouraging patients and families to participate in the decisions affecting their care.”

#1 Plan of Care - Patient and Family Meeting, re: the Care of Stage IV Pressure Ulcer

The following example will discuss a 56 year old patient, Mr., W, with Stage 4 mantle cell lymphoma diagnosed in February, 2011, with an extensive and complicated hospital course since admission on June 2, 2011. Mr. W. had been transferred from another facility for emergency surgery for bowel perforation and for consideration of chemotherapy. Prior to the initiation of chemotherapy, the patient was transferred to the Medical Intensive Care Unit (Blake 7) with a massive pulmonary embolus (PE) requiring extracorporeal membrane oxygenation (ECMO). On June 23, the patient underwent a sternotomy, thrombectomy and patent foramen ovale (PFO) closure for cardiogenic shock and right heart failure secondary to the massive PE. Despite a stormy course throughout his stay in the Medical Intensive Care Unit (Blake 7), Mr. W was eventually transferred to the General Medical Unit and began a cycle of chemotherapy. Unfortunately, the patient was discharged from the Medical Intensive Care Unit (Blake 7) with a Stage 4 ulcer.

The CNS for Wound Care consulted on Mr. W and verified that he had all of the HCUP factors (Healthcare Cost and Utilization Project, available on the Agency for Healthcare Research and Quality (AHRQ) website: http://www.ahrq.gov) which are associated with the highest rates of hospital-acquired pressure ulcers, including infection/septicemia from gastric perforation; impaired oxygenation/perfusion from two massive PEs; cardiogenic shock and pressor therapy; and impaired mobility due to being unable to turn for a duration of four-day course of ECMO and prolonged episodes of hypotension. He had also been transferred from a community hospital having not eaten for five days and then an additional nine days; therefore, nutrition was not in place to help repair the damage begun or to prevent further damage. All of these contributing factors were part of Mr. W’s medical condition that created terrible conditions allowing the pressure ulcer to develop. This information was shared with the patient’s wife (attachment EP4.i).

Email correspondence between family members and the Patient Advocate began on July 17 allowing the family to voice their concerns about this unfortunate outcome. Daily reports were sent by the Patient Advocate to a spokesperson in the family so that they were fully apprised of the situation with the pressure ulcer. An interdisciplinary team met with the family and Mr. W; the Associate Chief Nurse, Patient Advocate, Nursing Director, Clinical Nurse Specialist (CNS) for Wound Care, and the CNS for Oncology. Meeting Minutes were recorded by both the family (attachment EP 4.j) and Nursing Director (attachment EP 4.k). The meeting began by agreeing that the goals were assurance for patient and family that all appropriate measures had been taken in treating the patient’s pressure ulcer and to honor the patient and family’s request to partner with the clinicians in looking at ways to improve prevention and care of patients with pressure ulcers (attachment EP 4.l) The CNS for Wound Care provided a detailed explanation of the pathophysiology of a Stage IV pressure ulcer and explained, why, in her estimation, this pressure ulcer was unavoidable. The family clearly found this information helpful.

In preparation for discharge to rehabilitation, family and patient were concerned about adequate pain control during discharge. The Nursing Director assured the family that daily team rounds occurred where readiness for discharge/transfer is reviewed as well as the pain management plan for pain control. She also assured the family about the efficiency and effectiveness of the handoff process between MGH and rehabilitation hospital. The wife requested a
meeting with the team prior to the transfer. (attachment EP 4.m). The meeting was held (attachment EP 4.n) and a plan of care was communicated with the wife (attachment EP 4.o). Communication with the family continued upon discharge to the rehabilitative setting assuring both the patient and family that this situation would provide opportunities for looking at ways to improve prevention and care of patients with pressure ulcers (attachment EP 4.p).

This is a fine example of the dignity and respect given to the patient and family at MGH in the development of partnerships to assure that the core of our patient care delivery system, patient- and family-centered care, is upheld and preserved.

#2 – Plan of Care: Patient and Family Involvement in the Decision for Palliative Sedation

The following describes a very unfortunate 51-year-old male patient, TG, who was diagnosed with metastatic malignant melanoma in November 2010. TG took advantage of cutting-edge chemotherapy trials and radiation therapy at Memorial Sloan Kettering and MGH and even traveled to NIH for treatment. TG received many therapies including Phase I clinical trials and XRT for his cancer. He also received several surgical interventions which included a C4-6 laminectomy, a C3-6 instrumentation and fusion, and T11-L1 fusion and decompressions for spinal metastases.

However, despite his willingness to fight this dreaded disease, in December, 2010, TG’s disease was classified as Stage IV malignant melanoma with metastases to liver, bone, spine chest wall and soft tissue.

Through the course of his hospital stay, the patient experienced uncontrolled back pain in spite of many different pain management strategies, very well described in the Nursing Progress Notes of July 24, 2012, (attachment EP 4.q). The nursing staff continued to assess patient’s pain very carefully with a goal of 4/10 and would intervene appropriately. The Palliative Care team worked tirelessly and collaboratively with all team members in partnership with TG to find effective strategies for his pain control. In August, 2012, TG reported that his pain at that time was unbearable. He expressed his suffering through statements such as, “I can’t take it, the pain has gone on too long, if I move I’m in such much pain. I have tried everything including the epidural and cordotomy. I honestly cannot stand it any longer. I am at the end of my rope with this pain.” As noted in the Nursing Progress Note of July 30, 2012, (attachment EP 4.r), Patient able to speak about his illness and states that he has made peace with his life and is ready to pass. States that he ready to die. The care team continued to provide emotional support.

At that time, a request for an Optimum Care Consult (attachment EP 4.s) was made for ethical consideration of the possible option of palliative sedation. Given his terminal prognosis, the acceleration of metastases and associated intractable pain, TG requested that palliative sedation be implemented. An interdisciplinary team meeting was held that included his Attending Physician, the Palliative Care Physician, his Primary Nurse, and many other team embers, including Nurse Practitioners, Social Workers and the Oncology Chaplain. TG’s persistent suffering despite implementation of aggressive treatment options including epidural catheter delivered medications and cordotomy and the fact that he was unable to move without severe pain was discussed. It was agreed that palliative sedation was the only remaining therapy to protect him from the continued harms of pain and symptoms that are unrelieved by advanced combination of medications and technologies.

TG was well informed about his decision, as was his brother (attachment EP4.t) and it was believed that this was an autonomous decision for him which was honored, as it is both ethically and legally permissible. Palliative sedation was implemented on August 8, 2012, and the patient succumbed shortly thereafter.

This plan of care demonstrated the nurses’ willingness to engage in the difficult discussions about death and dying. The decision for “palliative sedation” is a weighted decision and
not one that many professionals experienced. It was through the support of the palliative care professionals working with the oncology interdisciplinary team that allowed for review of the case and the justification and procedure for palliative sedation that allowed the team to support Mr. G in his journey to the end of his life.

#3 Plan of Care: Patient and Family Involvement in Discharge to Home

An 86-year-old male was admitted to the vascular surgical floor, with a medical diagnosis of early onset Alzheimer's Disease/Dementia. He went to his local bank, with his home health aide, to withdraw $7,000.00 so “he could pay some bills.” The bank teller was concerned his escort was trying to take financial advantage of him, so he called the police and his Health Care Proxy (HCP). He was brought to MGH and admitted with a diagnosis of early onset Alzheimer’s. An Elder Abuse report was also filed with South Shore Elder Services (attachment EP4.u).

The Admitting Nurse’s assessment found the patient to be forgetful at times, but re-oriented well. She was aware of the Health Care Proxy who also has Power of Attorney. When she met with the Health Care Proxy to discuss the plan of care, the Health Care Proxy made a request to keep the patient admitted for at least 3 days to qualify for respite care. The nurse communicated this request to the Admitting Physician, the Social Worker and Case Management. The Case Manager planed to discuss the plan of care and discharge disposition with the Medical Team, Social Work, the patient and the Health Care Proxy. Concerns have been expressed by the team that the patient should not be discharged to home (The patient expressed his desire to go home (attachment EP 4.v).

The Health Care Proxy and the patient did not want a skilled nursing facility placement plan; they both felt that creating a supervised home setting was in the patient’s best interest. The Nurse, Social Worker and Health Care Proxy set up a journal for the man to keep daily notes regarding medications, food, activities of daily living and general concerns (attachment EP 4.w). This method worked well while he was in the hospital and the process would be continued when he went home. A Family Meeting was held on July 10 with a plan to discharge to home rather than a skilled nursing facility. The Health Care Proxy and the team coordinated a 24/7-supervised plan of care with a Visiting Nurse Association (attachment EP 4.x).

This is a great example of how the Health Care Proxy and the patient’s preferences were the cornerstone to the development and delivery of the plan of care.

Clinical Exemplars

The following clinical narratives describe beautifully the nurses’ involvement with patients and families in the planning and delivery of care. In each story, the nurse’s voice is clearly heard as he/she advocates relentlessly for the rights of the patients, whether it be the right to have a death with dignity, to participate in the choice of treatment, or remaining present for the patient and family throughout the most difficult and challenging of times.

Plan of Care Exemplar #1

Mr. C was a very loved man, husband, and father who unfortunately had been suffering from advanced Alzheimer’s Disease for over 15 years. His devoted wife was his complete caregiver since Mr. C was unable to feed himself, take his medications, and in most recent years even make slight body movements. Despite her small build, she was capable of lifting him from his bed to his chair. She then would cook and puree his daily meals so she could spoon-feed his breakfast, which would often take several hours to complete. As she was finishing up feeding her husband breakfast, it would be time for his lunch and the cycle would start all over again. In the evenings, the couple would often be visited by one of their sons, who would assist their mother to get Mr. C back into bed. She would then set her alarm in 45-minute increments so she could awake during the night to change his position.
This loving routine was carried on while I was his nurse at MGH. Instead of Mrs. C being the sole caregiver, I could provide her respite by tailoring my care to best suit his needs, while still respecting his home schedule. This nurse-family support was mutual, as I often made sure to include Mrs. C on the plan of care each day so she could offer me insight on what techniques or methods were effective when caring for Mr. C. For instance, when the Physician ordered a CT scan with contrast, I feared that Mr. C would be unable to drink all three bottles of gastrografin preparation. I teamed with Mrs. C who recommended I mix the medication in berry juice, which I then thickened so he would not aspirate. Over the course of an hour we took turns spoon-feeding him the preparation and he began opening his mouth without cueing. I knew he would be able to finish the preparation and he was actually quite thirsty for our tasty drink.

Unfortunately, his current condition was not entirely a success story. He was admitted with a urinary tract infection complicated by blood and fungal infections that made him somnolent for most of the day. He was anuric (no longer making urine) and in acute renal failure as a result of kidney stones, as the CT scan that day confirmed. The Urologist explained that he would need an operation to place stents in the urethra in an attempt to allow the kidney stones to pass. The doctor explained this portion of the surgery as fairly routine. However, given his advanced Alzheimer’s and the several blood infections he was fighting, he was at risk of dying from the anesthesia alone. Unfortunately, the family hung on to the fact that the procedure was explained “as routine” and all other relevant risks seemed overshadowed.

When I left that day, the family was still undecided about whether they would consent to surgery. The Urology physician was hoping he explained the dire risks, but I knew he had started with the wrong details. The family ultimately clung to that piece of information, and when I returned the following morning, Mr. C was on intravenous hydration and not eating in preparation for a two o’clock operation. The family had consented to surgery. Mrs. C, especially, was reluctant to understand her husband’s mortality. Despite being under hospice care outside of the hospital, she wanted everything done at MGH to save her husband. Although I could respect Mrs. C’s expertise in caring for his daily needs, I had to draw the line. As his nurse, I had to advocate for his needs and his wishes. This presented quite a dilemma, since he could not communicate his preference for surgery or not, as he was incapable of communicating except when withdrawing to painful stimuli. After discussing my concerns with the Primary Medical Team, I urged that we call a family meeting including the sons, the wife, and family priest. The Team agreed that the news that Mr. C’s blood was now infected with fungus needed to be explained as a further risk to the ones the Urologist explained the previous evening. Given the circumstances, the meeting occurred only two hours prior to Mr. C’s scheduled operation.

The meeting was very lengthy. The Physician and I discussed several different scenarios of what could happen if Mr. C underwent surgery. Even if he survived the surgery, the prognosis did not look good and even the physician clearly stated that if this situation was occurring to her family member she would not proceed with the operation given his extensive illness and co-morbidities. Unfortunately, the family still shifted the conversation’s focus on whether the surgery would cause pain. I could tell that family was still leaning towards surgery. An hour had passed and it seemed as if the conversation was going in circles. It was at this point that the doctor had to leave to attend another scheduled family meeting. Instead of fearing the lack of her presence, I embraced this turning point as an opportunity to discuss Mr. C’s wishes for his own life.

I had answered the family’s questions for over an hour, and now I had one question I needed answered, "What ultimately is the goal for your father?” In asking this poignant question, the son described this ideal situation of taking his father home, having him stand from his wheelchair, and sit down at the kitchen table and eat with their family. I asked, "Given his current state, could we achieve this goal today, without surgery?” The son sadly confirmed this was not possible given how sick he was. Knowing Mr. C from previous admissions, I emphasized that his condition declined each time he came to the hospital. His baseline had further deteriorated this admission and surgery may even worsen things further. The family was still not ready to make a decision and asked what other sources of pain his father would suffer as a result of the surgery. I spoke sincerely and from my nursing knowledge about how sometimes patients never come off ventilators when intubated for surgery. Immediately, the son stated he absolutely did not want his father to be intubated. Seemingly amidst all the discussions with physicians and the Urology Team, the
fact that Mr. C would need to be intubated was never clearly explained. In discussing the basics of anesthesia and intubation, the family had made their decision. The wife, who had not spoken during the entire meeting, placed her hand on my shoulder and asked me, “Can I go feed my husband now?” I smiled and knew that they were making the right decision, a decision that Mr. C would have made had he been able to communicate his needs and wishes.

When I left work that day, I was proud of how I handled the family meeting. I had grown a lot from when I first became a nurse and relied on veteran nurses’ advice on how to say the right thing during challenging discussions with my patients. Would my words express compassion? Would I be able to understand their grief and struggle? Could I eventually deal effectively with discussions regarding life and death? Four years later, I can honestly say I can speak with compassion during these challenging discussions as I did so on that day. The family meeting that day portrayed the importance of my nursing care in explaining procedures correctly to my patients and families. I knew that the family was torn with their decision but felt compelled to do everything medically indicated to save their loved one. I avoided giving my personal opinion and instead truthfully answered their questions while presenting the medical facts in terms they could understand. I helped them avoid the hardship of having him undergo surgery, only to realize that surgery would entail certain procedures (like intubation) that they did not want their father and husband to endure. Instead, Mr. C was eating homemade tomato soup and surrounded by at least 10 nieces, nephews, and grandchildren within hours of our family meeting. Although his days were numbered, his family knew of his impending death and could be there lovingly at his bedside.

This exemplar expresses the nurse’s passion and commitment about her role as an advocate to assure that the patient’s needs and wishes were honored and respected. She knew the family had made the decision initially to forego further treatment at home and understood that the hospital setting presented them with confusion and doubt about whether or not to pursue aggressive treatment. Her compassion towards their desires to return their father to his former lifestyle and her understanding of the moral dilemma they felt, allowed the family to move through this difficult process. In the end, the nurse helped them to accept the futility of trying to change the outcome and accept with grace and dignity the time they had to love and treasure their father.

Plan of Care Exemplar #2

As an oncology nurse on Lunder 9, I was recently dealing in the care of a young man; Mr. Z. Mr. Z had a very tough life. He had an abusive father and an absent mother and had been diagnosed with pancreatic cancer at the age of 30. The cancer was complicated by a surgical scar that split open, not once, but twice. In this wound, he developed a fistula that leaked bile fluid into his stomach, which caused severe pain and left him with six tubes placed throughout his abdomen and chest. Reasonably so, Mr. Z was angry with life. He developed a reputation of yelling, swearing, and threatening the nurses and staff. On my first day with Mr. Z, he lived up to that reputation by calling me names even my older brother could not think of. But there was something about him that I really liked. He had a very distinct sense of dry humor that I loved and I wanted to get to know him better. However, I needed a way to establish a mutual trust that would allow him to feel comfortable enough to open up to me.

Mr. Z’s obvious concern was pain and at this point in time he was in need of pain medication every two hours. His biggest fear was the nurse was going to forget about him and he would be left without medication and in escalating pain. I knew the best way to establish trust with Mr. Z was to bring in his pain medication every two hours right on the hour without him having to ask. This was my goal and I accomplished it every time I cared for him. This worked extremely well and allowed Mr. Z to feel more at ease. Mr. Z even openly expressed to me that he felt very comfortable knowing that I “cared about his pain as much as [he] did.” Over the next days, weeks and months, Mr. Z opened up to me. He told me about his favorite places to eat, how to fish and his most favorite things in the world, his two dogs. And his dogs, other than his sister, were seemingly the only two living things he trusted. Mr. Z was an overall sensitive, kind, caring person, but it was being masked by severe physical and emotional pain, a loss of independence and overall a loss of hope. Mr. Z did not need a psychiatrist or anti-depression medication that some suggested, he needed a trust worthy nurse, friend and coach. This is exactly what I set out to be.
Over his months in the hospital, I pushed him to take walks, shower and even to be a little less harsh on us nurses. I gained his trust by walking with him even after the shift was over, always being present when a doctor had to deliver news or information, and simply listening to him when he had input or just when he wanted to talk about a movie. We would schedule his two-hour dressing change for the days when I was on shift. During those dressing changes, I rarely did any physical tasks. I was in the room simply for support and to help ease the burden during a time he truly felt alone with his disease. After a month and a half on our floor, Mr. Z finally made it home to be with his sister and two dogs. Unfortunately, Mr. Z came back to our floor after a few weeks. This time he had a systemic infection that was ravaging his entire body. Mr. Z was in severe pain, could not eat and had absolutely no quality of life left. He confided in me by telling me he was ready to die. Mr. Z expressed that all he wanted was to be comfortable and no longer pursue treatment. However, Mr. Z was not technically dying of cancer, but this new infection. How it does sometimes happen in the medical world, his doctors did not want to give up. I felt as if no one was listening to Mr. Z’s wishes. Each day for six days straight I advocated for his wishes. I reiterated that he no longer wanted to pursue treatment over and over again. I called family and team meetings so the doctors could hear from him directly. I came in early in order to talk to his sister before the shift started to assure her I would keep fighting. But still, the infection continued to be treated. After only making small strides from my own fight, I organized a meeting for Mr. Z and Patient Advocacy Services. Mr. Z, his family, me and Patient Advocacy Services participated in thorough communication sessions which helped Mr. Z articulate what he truly wanted in a firm, but also respectful manner. This in turn brought us to a final team meeting where Mr. Z, with my support, explained in detail why he no longer wanted to live this life. After this meeting was when the team finally understood. The treatments were stopped and Mr. Z had a comfortable final two days with his sister and his dogs.

I write about Mr. Z because this experience was a changing point in my career. He made me realize that true nursing care is not elaborate or complicated, but is simply about understanding the needs of a fellow human being. True nursing care is about connecting with another person and trying to share in their suffering. As human beings, we all have our time of anguish and our time of need. We all need that someone to share in our pain, to trust and rely upon, to instill hope and to connect with on that basic human level. I learned from Mr. Z, and all the people I care for, that true nursing care does not occur between nurse and patient, but between person and person. Mr. Z will forever remain in my heart and mind as one of the true reasons I wanted to become an oncology nurse.

This narrative exemplifies the essence of what an oncology nurse is and should be. In this situation, the nurse took on the role of a leader, an advocate and a teacher. He took the time to get to develop strong interpersonal relationships with the patient as well as the family in order to provide the best and the most collaborative care possible. This story is emotionally laden but heartwarming to know that this nurse was truly present for this patient and was there to advocate for him at the end of his life.

Plan of Care Exemplar #3

When I first met Charlie 20 years ago I never could have imagined this tumultuous journey we would take together. But let me start at the beginning…

Charlie was just 42 when I met him; he was doing what he loved, coaching a little league game when he had symptoms of lightheadedness and palpitations, the cause was Ventricular Tachycardia. He was diagnosed with a life changing diagnosis of viral cardiomyopathy; this is what led him to MGH and Ellison 10.

Charlie was charming and engaging but when it came to his illness very stoic. Charlie quickly became our “friend.” From the very beginning, he had a devoted care team that over the years, he trusted could take care of him and his compromised heart. Charlie needed and took control, never letting his diagnosis run his life; he did everything he wanted to do. He defied the odds, and although his EF remained low, he complied 100% with his medical regimen. He remained active, continuing to work and pursue his passions, which included breeding dogs and raising and showing horses, always spending time outdoors as much as possible. Charlie was also very proud of his family, which
included a son and daughter and twin grand-daughters. He frequently told me he was married to “his best friend” Betty Ann.

Charlie had many admissions, from 1992 to the summer of 2010, for all the usual things that go along with a diagnosis of CM; ICD generator changes, ICD infections, device upgrades, CHF exacerbations, and medication adjustments. He quickly got to know his team on Ellison 10, and I had the pleasure of getting to know Charlie and his family. Charlie was always very social and went out of his way to engage in conversation, displaying his gift to gab. Everyone knew that when you went into Charlie's room, you were in there for awhile but Charlie didn't want to stay awhile; the first thing he would always ask was, “When can I go home?”

It wasn’t until the summer of 2010, when Charlie was admitted with ICD firings, that things really started the downward spiral. The options were getting slimmer. He had already been tried on all meds available, but he was still coming in with frequent ICD shocks. EP services felt strongly that they wanted to give Mexilitene another try, even though it was listed as an allergy. After a lot of discussion and with Charlie’s reluctant approval, he was taken to the CCU for desensitization. He soon returned to Ellison 10 very miserable because the desensitization didn’t work; he was now covered with itchy hives. Charlie began to doubt our ability to care for him; he was upset thinking that we “didn’t believe that he had the allergy to Mexilitene in the first place.” Charlie finally went home but returned several times with ICD firings. Charlie spent a month here at MGH following one of these ICD shock admissions and had two complex high risk procedures. Charlie was very optimistic following the first VT ablation but in reality only two of the three VT foci were ablated; the VT was still inducible but at a much slower rate. As we watched Charlie over the next few days we began to see more runs of VT and ICD shocks. Clearly this option was not going to work.

Charlie's anxiety grew each day, as he continued to question the ability of his medical team to “fix his heart.” This was not the Charlie I knew. He was now desperate and losing control. Realizing something else needed to be tried, the EP Service suggested an epicardial ablation, burning the surface of the heart that is causing the VT. After much discussion, Charlie agreed. He was still weak from the first ablation, but, anxious to do anything that would make his ICD stop firing, and give him more time with his family. As he waited for an OR date, his anxiety heightened. He repeated conversations over and over; he became easily agitated at my suggesting that he wasn’t coping so well and for very good reasons. I tried desperately to persuade him to talk to a Psychiatrist or a Psych Nurse; he refused saying, “I can handle this, I’m not crazy if I see those people, that means I’m weak and besides, that isn’t a very macho thing to do.” The days leading to the ablation were tough for Charlie emotionally, but finally, the epicardial ablation was done. It was as expected, a very involved procedure taking a huge toll on him. He was very weak, the weakest I’ve seen him, and he needed time to recover. The day finally came for discharge; everyone was so excited thinking the miracle procedure cured him, or at least, toned down the VT. Were we wrong! That night at home, Charlie’s ICD fired three times. He and his wife were so anxious; they felt an overwhelming urgency to get to MGH. Despite being quite a distance away, they decided to attempt to drive to MGH. As Betty Ann drove the car, Charlie’s ICD proceeded to fire again. Betty Ann drove faster. Ultimately she was stopped by the police, which resulted in an escort straight to MGH. When I saw Charlie, my first thought was he looked beat. I was sad because I felt like we might be losing the battle. There was something different about Charlie—he was as usual, happy to see us, but, he was clearly frightened. He grabbed my hand and wouldn’t let it go; he must have told me at least 20 times how the ICD had fired and how worried he was about Betty Ann. Over and over he kept saying “Donna, I can’t keep doing this to her; it’s going to kill her.” I tried to reassure Charlie the best I could, mostly, by sitting with him and listening.

Before Charlie left the previous admission he was told about a “cryoablation procedure” which would be saved for a last attempt at ablating the VT. One of the possible adverse effects of this type of ablation was that it could possibly make Charlie’s EF worse, a risk Charlie obsessed about, but was willing to take. Given this risk, Charlie was quickly worked up for a heart transplant before the procedure was done. Charlie spent the next several days getting ready for the surgery; he had to wait a bit for a date because he needed the expertise of a specific cardiac surgeon. This wait proved to be one of his most difficult times on Ellison 10. Charlie knew his options were few; he verbalized about his feeling about the hardships his family suffered commuting to Boston, and how much they worried about what would happen. He finally admitted he was afraid he was going to die. We talked for a long time, but no matter how I
phrased it, he would NOT agree to talk to anyone. I so wanted to get the Psych CNS and Palliative Care Team involved.

Unfortunately, during this timeframe, Charlie converted to VRE+. I found him walking down the hallway one day with a yellow gown on, with a sign taped to his back. It read “Contaminated…This is B.S.” I immediately reacted, and redirected him back to his room, telling him to take the gown off. I knew he needed an intervention; I had to play my last card. I sat down in Charlie’s room and said, “This is serious, Charlie; we need to talk”. I told Charlie how concerned I was and that he needed to find other ways to cope. I began with, “Charlie, how many times over the last 18 years have I done things for you; how many times have you been admitted to other floors in MGH and you call me, even though it’s not the typical protocol. I got you transferred to Ellison 10. You’ve trusted me over the years to do the right thing for you, this is not the time to stop trusting me…please talk to my friends and colleagues in Palliative Care and the Psychiatric Nurse Specialist; I am asking you to do this for me.” Charlie’s eyes filled with tears as he spoke about his family, and how much they meant to him, and how badly he felt about what they were going through. Betty Ann was left with all the responsibility of taking care of the animals, the house, and works full time, as well. He finally said, “Ok, I’ll do it but for you, not for me.” The consults went in immediately, and as expected, Charlie enjoyed having two more people to share his story with. Palliative Care and the Psychiatric Nurse Specialist proved to not only be supportive to Charlie, but, to the nursing staff as well. Charlie was becoming very needy, requiring a lot of emotional support; consuming the vast amount of my day. I needed help developing strategies that would make the best use out of the time I spent in Charlie’s room.

The ablation was finally done. During the recovery, Charlie struggled with symptoms of heart failure, and by the time he was discharged it was clear that his ejection fraction (a number we use to indicate how well the heart was pumping) had been adversely affected. It dropped form the high 20’s to 16%; normal is 60-80%. Charlie was aggressively diuresed, his appetite remained poor, his weight was down but Charlie reported feeling well. Charlie was so anxious to go home, nothing would have stopped him. I spent a while reviewing with Charlie the signs and symptoms of heart failure, the importance of daily weights, and dietary restrictions. I stressed to Charlie that although he was back to what we considered his dry weight to be, he still had edema, which was clearly evident when I discontinued his peripheral IV, and my fingers were still imprinted on his arm after I held pressure to stop the bleeding. Charlie and I agreed that it was very likely that his dry weight was much less than we thought, since, his appetite was adversely affected by all the recent admissions and procedures. Charlie agreed he needed to be vigilant about his weight, and symptoms, and agreed to call the heart failure team if needed. Despite Charlie’s meticulous attention, he was readmitted several times for heart failure; each time he was admitted, Palliative Care and the Psych CNS were involved, Charlie grew to appreciate each of these services, and looked forward to their visits. After five months of frequent heart failure admissions, Charlie was admitted to Ellison 10. He was not diuresing well, and was transferred to the CICU for more invasive therapy. It was during this admission that Charlie received his heart transplant. I was away during this admission and unfortunately not able to share what I knew about him with the CICU and the SICU, but, as you can probably expect Charlie’s transplant did not go very smoothly…. While I will not go into his post-op course, it was very traumatic. I remained supportive to both he, and his wife, visiting when I could. After taking care of Charlie for 20 years, he now has his new heart. I’ve heard through the transplant team that he is doing well; I recently sent him a note. We have not heard from him, nor has he stopped by when he has appointments…perhaps the trauma of this ordeal was too much for him to bring himself back here.

This exemplar speaks to the strength of the nurse, the patient and family relationship, and the bonds, that often stand the test of time. The nurse possessed tenacity, and fortitude, in committing to an 18-year relationship, with a patient that truly challenged the nurse’s plan of care, in refusing to let the resources of Palliative Care and Psychiatry support him. It is this strong commitment to the development of interpersonal relationships that allow nurses at MGH to play such a valuable role in the planning and delivery of patient care.
PATIENT FAMILY ADVISORY COUNCIL
ANNUAL REPORT 2010-2011

Full report available for review on-site and at: http://www.massgeneral.org/patientadvisorycouncils/
Welcome and Introductions

- Passed around attendance sheet

Project Updates

FAC Projects

Dave Ekrem FAC Web[age Review

<table>
<thead>
<tr>
<th>TOPIC</th>
<th>DISCUSSION</th>
<th>ACTION/FOLLOW UP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcome and Introductions</td>
<td></td>
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<tr>
<td></td>
<td>• Passed around attendance sheet</td>
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<tr>
<td>Project Updates</td>
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<tr>
<td>FAC Projects</td>
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<tr>
<td>Dave Ekrem FAC Web[age Review</td>
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<tr>
<td>Goals:</td>
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<tr>
<td>• Increase awareness of the Family Advisory Council and increase applications for membership.</td>
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<tr>
<td>• Placement on <a href="http://www.massgeneralforchildren.org">www.massgeneralforchildren.org</a>:</td>
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<tr>
<td>• Home page placement:</td>
<td></td>
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</tr>
<tr>
<td>• Home page &gt;&gt; For Patients and Families tab &gt;&gt; Family Advisory Council</td>
<td></td>
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</tr>
<tr>
<td>About Us (<a href="http://www.massgeneral.org/children/about/">http://www.massgeneral.org/children/about/</a>)</td>
<td></td>
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</tr>
<tr>
<td>• We have the &quot;Family-centered care&quot; spotlight on this page.</td>
<td></td>
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<tr>
<td>• Dave could add the Family Advisory Council to the &quot;About This Hospital&quot; navigation (upper right corner)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&quot;Learning from families&quot; spotlight is on:</td>
<td></td>
<td></td>
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<tr>
<td>• Visitor Information (<a href="http://www.massgeneral.org/children/visit/default.aspx">http://www.massgeneral.org/children/visit/default.aspx</a>)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• MassGeneral Hospital for Children Overview (<a href="http://www.massgeneral.org/children/about/overview.aspx">http://www.massgeneral.org/children/about/overview.aspx</a>)</td>
<td></td>
<td></td>
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<tr>
<td>• Are there other pages we should consider adding it to?</td>
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<tr>
<td>• Note: spotlights are fine, but they don't drive a lot of clicks. It's actually better to get placement right in the copy on the page as we have on the Family Centered Care page (<a href="http://www.massgeneral.org/children/about/family_centered_care.aspx">http://www.massgeneral.org/children/about/family_centered_care.aspx</a>)</td>
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### MGHfC Family Advisory Council Meeting Minutes – Tuesday, June 19th, 2012

<table>
<thead>
<tr>
<th>TOPIC</th>
<th>DISCUSSION</th>
<th>ACTION/FOLLOW UP</th>
</tr>
</thead>
</table>
|      | • Dave recommends changing the title of the spotlight from "Learning from families" to "Family Advisory Council"; that might help get the message to people that we have a Family Advisory Council even when they fail to click on the spotlight. Also, he’d love to see a photo of a conversation on that spotlight—could we have MGH Photo to one of your meetings? (There is some cost for that: $42.50 for a 30 minute shoot, $85 for an hour; $35 per contact sheet produced).  
• We also talked about adding the Family Advisory Council to the Patient Experience [http://www.massgeneral.org/children/experience/](http://www.massgeneral.org/children/experience/). Dave will investigate that for us.  
• We’ll work on creating a new page with list of members and projects they are working on. | |
|      | Placement on [www.massgeneral.org](http://www.massgeneral.org):  
• The Family Advisory Council is listed on [http://www.massgeneral.org/patientadvisorycouncils/](http://www.massgeneral.org/patientadvisorycouncils/)  
• And we talked about asking for placement on the Heart Center page [http://www.massgeneral.org/heartcenter/pfac.aspx](http://www.massgeneral.org/heartcenter/pfac.aspx). You and I should talk about the best way to make that happen.  
• Is there any place else we should request placement? I didn't find other hospital councils, but I thought there was at least a Cancer Center council. | |
|      | Social Media:  
• Facebook in particular actually drives a lot of traffic to the site, so when we have a new article, we should be sure to post it to Facebook. | |
|      | Other:  
• We agreed that we need more articles and more photos.  
• Are there initiatives we should write about? The communications pilot, family centered patient ED materials, family centered rounds, Speak Up?  
• Do we want people to drop in on meetings? Perhaps FAC meetings could be announced in Hotline? | |
|      | **Debrief Family Centered Rounds**  
• It was agreed by all who attended that Erin did a wonderful job facilitation and Sarah Santos and panel did wonderful  
• We discussed that the change to 8:00 am Grand Rounds was a difficult time for outside attendees, like parents, but more physicians are able to attend at this time.  
• It was suggested that staff show the taped Family Centered Rounds at meetings for those |  
• We will invite Dr. Scott-Vernaglia and one of the chief residents to attend a family advisory council meeting  
• We will work directly with Dr. |
MGHfC Family Advisory Council Meeting Minutes – Tuesday, June 19th, 2012

<table>
<thead>
<tr>
<th>TOPIC</th>
<th>DISCUSSION</th>
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</table>
| who were not able to attend.  | - Discussed that the next Grand Rounds should involve positive stories of relations between patients, residents, and attendings  
                                  - We will try and work with Dr. Shannon Scott-Vernaglia to develop these rounds                                                       | Scott-Vernaglia to coordinate the next Family Centered Grand Rounds.            |
| Debrief Intern Meet and Greet | - Lisa C and Sandy C both attended the meet and greet and described the new interns as delightful                                                                                                          |                                                                                 |
| Update of Family Centered Rounds – Patient Education Material | - Document is being distributed to patients and families when admitted  
                                  - Surgery does not follow the same policies and procedures, so they will develop their own handout                                                                                           | We will invite Erica Masini to attend a family advisory council meeting in August to discuss how parents can comment on documents |
| Committee Updates             | - Membership – No updates  
                                  - Ethics – Erin updated the group on discussions at the last ethics meeting  
                                  - Quality and Safety – Dr. Israel will present on the Q&S project at an upcoming meeting  
                                  - Speak Up – No updates  
                                  - Patient Experience – No updates – next meeting is in August  
                                  - Volunteer Office – Lisa Cimino discussed her experience with the volunteer office orientation                                                                                   | Sandy C will work with Dr. Israel to get a meeting date in place for Q&S presentation  
                                  - Sandy C and Jen will see if we can have the volunteer office orient our parents during a regular meeting since we now have several                                                                 |
| Wrap-Up                       | - No July Meeting  
                                  - Next meeting on August 21st, 2012.  
                                  - Same night as ice cream social  
                                  - We will go right from the ice cream social to the meeting                                                                                  |                                                                                 |
<table>
<thead>
<tr>
<th>Topic</th>
<th>Discussion Leader</th>
<th>Comments</th>
<th>Next Steps</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attendance at the July Meeting</td>
<td>Paula Gilman Bayles, Maggie Carvan, Julia Gaynor, Charlie Gillis, Av Green, Ted Groves, Deb Kanady, Michael McCarthy, Selma Mirsky, Sally Hooper, Barbara Cashavelly, Jill Allen, Renee Johnson</td>
<td></td>
<td>Renee will send the June minutes to Patient Care Services for their records</td>
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<td></td>
<td>Guests: Taylan Bozkurt, Mira Spaulding</td>
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<td>Renee will email July minutes to the group for review, and we will approve at the July meeting</td>
</tr>
<tr>
<td>Review of Minutes from June</td>
<td>All</td>
<td>Minutes unanimously approved</td>
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<tr>
<td>Termeer Center Survey</td>
<td>Mira Spaulding &amp; Taylan Bozkurt</td>
<td>Pilot will have 2 parts: ethnographic focus groups, and a Redcap survey</td>
<td>Mira and Taylan have started the ethnographic surveys with RNs, SWs, MDs, and Administrators and are requesting their feedback on the content/format of the written survey</td>
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<td>Targeted Participants:</td>
<td>Mira and Taylan will edit the survey based on RN, SW, MD feedback and email to PFAC for feedback</td>
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<tr>
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<td>• RNs and social workers—What they can do to better provide care for their patients (focused towards nurses/clinical research)</td>
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<td></td>
<td></td>
<td>• Staff who will specifically “touch” Termeer infusion pts/nurses/staff.</td>
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<td></td>
<td></td>
<td>• Patients and caregivers</td>
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<td></td>
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<td>• All patients should be asked in infusion unit, not just people on trials.</td>
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<td>• Expand to cover all nursing staff, not just infusion?</td>
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<td>This survey project will help to determine:</td>
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<td></td>
<td>• Things easily implemented that will have the biggest impact</td>
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<td>• Things to think about down the line</td>
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<td>• Maybe roll out these ideas into other areas, but Termeer is the first priority</td>
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<td>“Ethnography” meeting one-on-one or small groups in the practice setting</td>
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<td></td>
<td></td>
<td>• PFAC role play/training</td>
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<td></td>
<td>• What in current center is going well, what needs improvement?</td>
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<td></td>
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<td>• Ask about social support being given, human support, psych/social support</td>
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</table>
Survey:
- Administered by bringing iPads into the Yawkey 8 infusion center
- Engaging patients will be tricky
- Going through the nursing staff to educate surveyors on how to approach it—For instance, asking, “Are you up to it?”
- Could PFAC do the surveying or Network members?
- Introduction of the surveyor from the nurse
- Do not call it “research,” or use the word, “ethnography”
- Make sure that participants are aware that it’s not a marketing ploy
- Couch it that “Termeer Center is so special and groundbreaking, we need your help to make it the best center, possible”
- Give surveys at the start and end of treatments
- Do both with the same patient (ethnography questions and survey)
- Leave the iPad as a second part after the interview
- No typing, just click buttons, more detail in the personal interviews

Specific thoughts about the survey questions:
- 1st question might be too leading towards positive responses.
- 2nd question open-ended enough, launch with that instead.
- Language should be simplified for lower health literacy levels

What happens when Termeer patients have special amenities, then go to other areas that don’t?
- Special education for the transition
- Same staff as Yawkey 8, with a shared Nurse Director, so both areas will not be markedly different

There are key differences between standard chemotherapy and Phase I trial chemo
- Patients may be overwhelmed by our staff excitement about Phase I
- Side effects unknown
- Multiple biopsies
- Intensive
- Can get taken off easily, which would then send the patient back to standard chemotherapy
- Phase I docs identified on each unit, who are not necessarily your doc; patients should be made aware of that up front
- There can be a lot of psychological/social support needed
- Some phase I patients may be brand new, but most will have tried the
### Cancer Center Patient and Family Advisory Committee Meeting Minutes

**July 2012**

<table>
<thead>
<tr>
<th>Brief Updates</th>
<th>All</th>
<th><strong>Follow-up from Quality Rounds – Julia Gaynor</strong></th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>• Didn’t know what to expect. Thought they were “rounds.”</td>
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<td></td>
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<td>• 7-8 people at her session</td>
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<td></td>
<td></td>
<td>• Powerful video about medical error</td>
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<td></td>
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<td>• Illustrated that errors are most often systematic, not personal error</td>
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<tr>
<td></td>
<td></td>
<td>• Having a PFAC member in the room is so valuable; MDs needed to hear personally that patients and caregivers are their own best advocates.</td>
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**DeVito Verdi – Julia Gaynor**

• Julia spoke to the brand consultants over the phone (from vacation!)
• Perception of hospital before having a cancer experience here?
• Changed perceptions now that you’ve gone through this?
• Why is it better to be at a large institution rather than a stand alone?
• Who are the rockstars here in the Cancer Center?
• Additional DeVito Volunteers = Ted Groves

<table>
<thead>
<tr>
<th>Planning a 10+ Year Celebration/Reunion for PFAC</th>
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<tbody>
<tr>
<td>• September/early October</td>
<td></td>
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<tr>
<td>• Location TBD, very close to the hospital (Scampo?)</td>
<td></td>
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<tr>
<td>• Katie Binda, Mike Anderegg, Jackie Somerville, Dr. Chabner and Ellen Fitzgerald are confirmed to return</td>
<td></td>
</tr>
<tr>
<td>• Sally suggested forming a committee to plan—Selma, Paula and Julia are interested</td>
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<tr>
<td>• Will be reaching out to current and Emeritus members soon to help locate previous members</td>
<td></td>
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| PFAC Member Recruitment | Sally Hooper | |
|--------------------------|--------------|
| • We are especially seeking diversity of all kinds! | |
| • Diversity is here at MGH: How do we get them on PFAC? | |
| • What’s our ideal number of members? | |
| • Perhaps we need a larger number to include representation from all areas and satellites | |
| • Have potential members attend a meeting prior to joining? (The group was divided on this idea, and the final seemed to be that the majority was against this idea) | |
| • Network has a brochure in all waiting rooms—people see it, and it reminds staff that their program is available here at the Cancer Center | |
| • This may cause an overflow of self nominations. Perhaps we could | |

Renee will resend the Quality Rounds dates to enlist volunteers

Renee will reach out to PFAC members, again, to determine interest in phone calls/meetings on July 27th

A date has been chosen: September 6th

Renee will send PFAC membership info and standard language documents to the brochure committee via email

Sally will mail other publications from Patient Ed and her own materials to the brochure committee
<table>
<thead>
<tr>
<th>require that need a “reference” to be considered?</th>
</tr>
</thead>
<tbody>
<tr>
<td>• How do we get the word out about wanting members from Danvers, Emerson, Rad Onc, NWH?</td>
</tr>
<tr>
<td>• Get them a brochure? Have a current PFAC member or staffer make a short presentation at one of their site staff meetings?</td>
</tr>
<tr>
<td>• We could submit grant requests for video conferencing equipment in order to effectively loop members from other sites into the monthly meetings</td>
</tr>
<tr>
<td>• Current PFAC members could reach out to their providers to remind them about the council and ask for nominations? YES!</td>
</tr>
<tr>
<td>• Redefine goals? Defining the work will identify the number we take on</td>
</tr>
<tr>
<td>• Need more satellite involvement. Perhaps that’s our goal for new members?</td>
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<tr>
<td>• Satellite locations could potentially start their own PFAC? Once a year/quarter all PFACs come together?</td>
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</table>

Brochure to be developed
• 2-sided, 3x6
• Subcommittee: Julia, Debbie, Ted
• Conference Call
• Template, Word Count guidance, Other materials, Pictures

Shorten nomination email
• Jill Allen has taken on this project
• Tagline? We want you! To nominate a PFAC Member
• Needed: Cancer heroes!

Renee will schedule the brochure committee for a conference call, and they will circulate a draft of the text to PFAC

Jill Allen will send PFAC her proposed edits for the nomination email
Patient and Family Advisory Council (PFAC)
August 7, 2012
5:30 PM – 7:00 PM
Yawkey 2-220

AGENDA

5:30 – 6:00

1. Welcome new members:
   - Mary Therese Daniels
   - Bob Brunelle
   - Pat Hollenbeck
   - Tom Quirk

6:00-7:00 PM

2. Lee Schwamm, MD, FAHA, Vice Chairman, Department of Neurology
   Director of TeleStroke and Stroke Services

   Dr. Schwamm will present different kinds of stroke, treatments for stroke and services available at MGH. How can the Institute PFAC support the efforts of the Institute for Heart Vascular and Stroke Care and the stroke service in particular?

3. Miscellaneous:
   - Heart Walk 9/15/12. T-shirts with a new Institute theme- pick your size
   - Thank you card for Claudia Chae- final meeting 9/4. Please sign.
   - Contact information new members
   - Save the Date: September 12 Bulfinch Tent
     Institute for heart Vascular and Stroke Care Kick off (more to follow)

Next Meeting:
Date: Tuesday, September 4
Time: 5:30 PM – 7:00 PM
Location: MGH Museum
Dinner will be served.
Initial MICU Family Meeting Summary

Meeting Date:
Meeting Start Time: ____________       Meeting End Time: ____________

MICU Admission Date: ________________

Form completed by: ___________________________________________________, RN MD

Clinicians present: Attending MD_______________ Fellow________________ Senior resident_______________
RN________________________ Other________________________________

Has patient’s PCP been notified?  Yes  No

Family present: HCP_______________________ Spokesperson_______________ Other_________________

Meeting Outcomes:

__________________________________________________________________________________________________

__________________________________________________________________________________________________

__________________________________________________________________________________________________

__________________________________________________________________________________________________

Was code status discussed?  Yes  No. If no, why not? ____________________________________________________

Specific milestones, goals, and timeframe:

__________________________________________________________________________________________________

__________________________________________________________________________________________________

If family meeting not completed within 72 hours, please check all that apply, and remove patient from the daily family
meeting list:

Family not available Patient unable to communicate Patient died shortly after admission
Short length of stay Other __________________________
Quick Guide to Holding a MICU Family Meeting:

**Pre-Meeting:**

- Schedule meeting time with nurse and family
- Invite other important participants
- Pre-meet to discuss meeting goals, clinical status, psychosocial issues

**During the Meeting:**

- Try to have some members of clinical team sit next to family
- Introduce yourself and have all other introduce themselves
- Clarify the primary spokesperson and/or health care proxy
- Ask family: “What is your understanding of what has been happening?”
- Verify and clarify the situation
- Ask family: “What was life like prior to this hospitalization?”
- Ask family: “Did your loved one talk about what he’d want in this situation?”
- Set goals, e.g. “Let’s see if by Tuesday we’ve seen improvement”
- Address code status if appropriate, e.g. “Based on what I’ve heard……”
- Summarize the meeting
- Make plans for future meetings

**After the meeting:**

- Ensure documentation gets to chart
- Review meeting document at rounds

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Massachusetts General Hospital
Patient Care Services

Evaluation of Patient and Family Notebook Pilot Report
May 2012

Linda Akuamoah- Boateng PT, MHA
Senior Project Specialist
PCS Quality and Safety

Linda Lacke MPH
Senior Project Manager
PCS Administration
Evaluation of Patient and Family Notebook and Discharge Envelope

Summary

As part of the Innovations Unit effort currently underway at the Massachusetts General Hospital, the Patient and Family Welcome Packet was implemented as one of the 12 interventions geared at improving care and reducing costs. This Patient and Family Welcome Packet comprises of a patient and family notebook designed to facilitate communication between care givers and patients. The Welcome Packet also includes a discharge envelope to help prepare patients for a seamless discharge.

In May 2012, various surveys were launched to evaluate the effectiveness of the Patient and Family Welcome Packet. Patients and family were interviewed Patient Advocates to get their perceptions on this intervention to guide future improvements. Staff also had the opportunity to give their feedback through electronic surveys and in person interviews.

General Themes

Patients

- Patients generally found the welcome packet helpful
- Patients found the following elements of the patient and family notebook particularly helpful: employee descriptions, patient compact describing the patient-provider relationship and the welcome letter explaining the concept of innovation units and the patient and family welcome packet
- Patients were highly satisfied with the discharge envelope; it gave a place to store all information related to discharge
- **Areas for improvement:**
  - *Patient and Family Notebook:* Bigger font, clipboard, waterproofing/plastic folder, more note pages, some redundancy with Unit handbook.
  - *Discharge Envelope:* Stronger and water-proof envelope

Staff Surveys

- Most surveyed staff believe the patient and family notebook has improved communication between providers, patients and their families. It has somewhat improved communication among the care team. However it may be too early to quantify.
- Members of the nursing care team (attending RN or staff RN) usually give and review the welcome packet with patients and families

- **Areas for improvement:**
  - Staff noted they did not receive adequate training on the welcome packet prior to implementation and would appreciate a more interactive training process.
  - Need for a more proactive outreach to members of the therapies and disciplines

Evaluation Team

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Department</th>
</tr>
</thead>
<tbody>
<tr>
<td>Linda Akuamoah-Boateng</td>
<td>Senior Project Specialist</td>
<td>PCS Quality and Safety</td>
</tr>
<tr>
<td>Bryan Jones</td>
<td>Intern</td>
<td>PCS Administration</td>
</tr>
<tr>
<td>Melissa Marinace</td>
<td>Intern</td>
<td>PCS Administration</td>
</tr>
<tr>
<td>Rick Evans</td>
<td>Senior Director</td>
<td>Service Improvement</td>
</tr>
<tr>
<td>Linda Lacke</td>
<td>Senior Project Manager</td>
<td>PCS Administration</td>
</tr>
<tr>
<td>Cindy Sprogis</td>
<td>Senior Project Manager</td>
<td>Service Improvement</td>
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</table>
Evaluation of Data

Staff Surveys

Staff interviews were designed to measure the “usual practice” of clinicians.

**Therapies and Disciplines Electronic Survey**
- Electronic survey launched May 15
- Data collection May 15 – May 20, 2012
- Number of respondents: 30
- Therapies and disciplines surveyed:
  - Case Management (3)
  - Chaplaincy (2)
  - IV Therapy (0)
  - Medical Interpreters (3)
  - Nutrition (3)
  - Occupational Therapy (7)
  - Pharmacy (1)
  - Physical Therapy (3)
  - Respiratory Therapy (0)
  - Social Services (4)
  - Speech and Language Therapy (4)

**Patient and Family Notebook (PFN)**
- Most do not use in their practice (47%) or another member of the care team usually gives out
  - Patient and Family Notebook (37%)
    - The attending RN often gives out the PFN
- 56% of members from therapies and disciplines review PFN with patients, their families or other involved care givers
  - The PFN review occurs on an “as needed” basis
- Members of the therapies and disciplines report that the PFN has improved communication with patients and families as well as colleagues on the care team however most feel it is still too early to quantify the effect the PFN has had on communication

**Discharge Envelope (DE)**
- Most members of the therapies and disciplines do not give out the DE. Other members of the care team usually give it out (mainly nursing staff –ARN, staff RN etc)
- 64% do not review the DE with patients or families
  - Members of the therapies and disciplines who review the DE often review with other involved care givers
  - The DE is often reviewed on an “as needed” basis or once during admission
- Most do not find the discharge envelope helpful in preparing their patients for discharge

**Training**
- 63% of respondents feel they did not receive adequate training on the PFN and DE
In-person Unit-based Staff Interviews

- Unit staff interviewed by project management staff
- Data collection: May 3 – May 16, 2012
- Number of respondents: 39
- Units surveyed:
  - Bigelow 14 (4)
  - Blake 10 (1)
  - Blake 11 (4)
  - Blake 12 ICU (2)
  - Blake 13 (4)
  - Ellison 9 (4)
  - Ellison 16 (5)
  - Ellison 17 (3)
  - Ellison 18 (3)
  - Lunder 9 (4)
  - White 6 (2)
  - White 7 (0)

- **Role Groups**:
  - Direct care RN (18)
  - ARN (10)
  - Other (10) – mostly nursing directors and CNSs

**Patient and Family Notebook (PFN)**

- 90% of respondents use the PFN in their practice
- 69% of respondents give the PFN to the patients, families, other involved care givers or combination of the three
- The PFN is often given out on admission (83%)
- The PFN is often reviewed with patients or their families (71%) most often on an "as needed" basis or at least once a day
  - Most respondents report the PFN has improved communication with patients and their families (77%)
  - 30% of respondents agree the PFN has improved communication among members of the care team

**Discharge Envelope (DE)**

- 69% of respondents use the DE in their practice
- 66% of respondents give the DE to their patients and families often on admission and review it on an "as needed" basis
- 74% of respondents review the DE with patients, their families, other care givers or combination of the three
- 53% of respondents find the DE helpful in preparing patients for discharge

**Training**

- 60% of respondents feel they did not receive adequate training on the PFN and DE.
Weekend Staff Electronic Survey

- Electronic survey launched May 7
- Data collection May 7 – May 20, 2012
- Number of respondents: 71
- Units surveyed:
  - Bigelow 14 (0)
  - Blake 10 (0)
  - Blake 11 (9)
  - Blake 12 ICU (1)
  - Blake 13 (6)
  - Ellison 9 (10)
  - Ellison 16 (0)
  - Ellison 17 (5)
  - Ellison 18 (7)
  - Lunder 9 (18)
  - White 6 (2)
  - White 7 (13)
- Role Groups:
  - Direct care RN (69)
  - Other (2) – CNS, NP

Patient and Family Notebook (PFN)

- 87% of respondents use the PFN in their practice
- 77% of respondents give the PFN to patients and families
- The PFN is often given out on admission (83%)
- The PFN is often reviewed with patients and their families (83%) most often on an “as needed” basis or at least once a day
  - Most respondents report the PFN has improved communication with patients and their families (79%)
  - 21% of respondents agree the PFN has improved communication among members of the care team

Discharge Envelope (DE)

- 73% of respondents use the DE in their practice
- 82% of respondents give the DE to their patients and families often on admission and review it on an “as needed” basis
- 97% of respondents review the DE with patients and their families
- 43% of respondents find the DE helpful in preparing patients for discharge

Training

- 58% of respondents feel they did not receive adequate training on the PFN and DE
## Patient Interviews

- In person patient interviews conducted by patient advocates and staff from the Office of Patient Advocacy
- Data collection: May 7 – May 11, 2012
- Number of respondents: 47
- Units surveyed:
  - Bigelow 14 (5)
  - Blake 10 (0)
  - Blake 11 (5)
  - Blake 12 ICU (4)
  - Blake 13 (5)
  - Ellison 9 (2)
  - Ellison 16 (5)
  - Ellison 17 (4)
  - Ellison 18 (4)
  - Lunder 9 (3)
  - White 6 (6)
  - White 7 (4)

- **Respondents:**
  - Patients (36)
  - Families (14)

*The analysis below is based on patient and family perceptions and may not necessarily reflect practice in care areas.*

### Patient and Family Notebook (PFN)

- 81% of respondents received the PFN on admission or within 24hrs of admission
- Initial review of the PFN with a member of the care team occurred within 24hrs of admission
  - Follow up review was often done once during admission
  - Review of PFN was most often conducted by nurses
- 81% of respondents read the welcome letter; all found it helpful and informative
- All respondents who read the patient compact (70%) report it helped to clarify the patient-provider relationship
- 74% of respondents read employee descriptions provided in the PFN and all found it helpful

### Discharge Envelope (DE)

- 64% of respondents received the DE on admission or within 24hrs of admission
- Initial review of the DE with a member of the care team occurred within 24hrs of admission
  - Follow up review was often conducted once during admission or on an “as needed” basis
  - Review of PFN was done by nurses
  - Respondents found the DE helpful in preparing for discharge
Thematic Analyses of Comments

Staff Surveys

Therapies and Disciplines Electronic Survey

*Patient and Family Notebook (PFN)*
- More room for therapist/other health professional recommendations
- Place for patient to chart progress after d/c.

*Discharge Envelope (DE)*
- Many like the idea of the envelope
- **Things to improve**: PT/OT scripts checkbox

Training
- Need for more training

In-person Unit-based Staff Interviews

*Patient and Family Notebook (PFN)*
- Reviewing the notebook: depends on what’s happening on the unit/workload, and the patient
- Good for rounds and family meetings, especially on new patients;
- “I don’t review because it’s private”
- Good way for ARN to introduce herself
- Patients take notes for themselves; helps to organize patients/families. Reassuring.
- Many comments state that staff have not really noticed that Notebook “improves communication.” However, staff say that the Care Team role descriptions are helpful – patients direct questions more appropriately, and the Notebook is good for discharge planning and teaching.
- **Things to improve**: font, more languages, more pages, less pages, better staff training (including MDs, residents, etc), provide a pen, add pocket to hold papers *(isn’t that what the D/C envelope is for = more training!)*, d/c checklist on notebook instead of envelope, add unit-specific insert, place to put business card *(some units tape onto cover)*. Phone # for Financial Services, like that it’s simple = don’t add too much.

*Discharge Envelope (DE)*
- Many like the idea of the envelope
- **Things to improve**: Remove title – “Discharge” = feel like I’m being pushed out, not appropriate for all patients (e.g. long-term, transfers); use pre-admission to help them prepare.

Training
- More hands-on; not aware of training; reviewed it myself, more staff than just RNs, reminders to USE these tools/reinforcement needed.
Weekend Staff Electronic Survey

Patient and Family Notebook (PFN)
• Opportunities to present to patients/families limited due to shift (late hour)
• Was giving out at admission but realized it’s too much at one time – give out later.
• Comments that staff do not see the Notebooks (in use).
• “We have no innovation support on weekends” and “involve night staff more in innovation initiatives.”
• Favorable comments about patient/family understanding of role groups, processes
• Patients have place to write questions down as they come up; families use while in waiting room.
• **Thing to improve:** add photos to role groups, more pictures for lower [health] literacy patients, info about Care Pages and Quiet Hours, map of the hospital, and give out prior to admission.

Discharge Envelope (DE)
(No comments)

Training
• More hands-on; not aware of training; reviewed it myself.

Patient Interviews

Patient and Family Notebook (PFN)
• Not a lot of use so limited comments
• Welcome Letter: only 1 comment = “Don’t remember letter”
• Patient/Provider Compact: 1 comment = liked the wording of “…treating your team with respect.”
• Care Team Roles – like these
• **Things to improve:** bigger font, clipboard, waterproofing/plastic folder, more note pages, some redundancy with Unit handbook.

Discharge Envelope (DE)
• Overall like having a place to store things
• **Things to improve:** stronger/waterproofing
Rapid Response System Activation
Volume of Calls
April 1, 2011 - March 30, 2012

Rapid Response System Activation
Location of Event
April 1, 2011 - March 30, 2012
# Asthma Home Management Plan

## When to take action and what steps to take

### Asthma is in Good Control

All of the following demonstrate you are in good control:

<table>
<thead>
<tr>
<th>Medicine</th>
<th>How much to take</th>
<th>Time</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Breathing is good</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No cough or wheeze</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can work/play/go to school</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep at night</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Asthma is Partially Controlled

**Reliever Medications: add to everyday**

**Signs and Symptoms** – when you need to slow down and take action:

<table>
<thead>
<tr>
<th>Medicine</th>
<th>How much to take</th>
<th>Time</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cough</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wheeze</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tight Chest</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wakes up at night</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Asthma Uncontrolled

**Intensive Reliever Medications**

**STOP:** Take these Medications and Call Doctor

<table>
<thead>
<tr>
<th>Medicine</th>
<th>How much to take</th>
<th>Time</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicine not helping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breathing hard / fast</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nose opens wide</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ribs show with breaths</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can’t walk or talk well</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Call 911 if...

- Lips are bluish
- Breathing is getting worse fast
- Can’t talk / cry because of hard breathing
- Struggling to breathe
- Passed out

---

I have reviewed Asthma Home Management Plan with the patient/family and it has been faxed to the primary Pediatrician

<table>
<thead>
<tr>
<th>Signature (MD)</th>
<th>Date</th>
</tr>
</thead>
</table>

I understand this Asthma Home Management Plan and when to get help for my child.

Parent/Guardian/Patient Signature:

<table>
<thead>
<tr>
<th>Signature</th>
<th>Date</th>
</tr>
</thead>
</table>
ASTHMA HOME MANAGEMENT PLAN

Follow up appointment: Physician: __________________________
Date: __/__/___  Location: __________________________ Phone #: __________

Circled items are triggers your child should avoid:

- Tobacco Smoke
- Foods
- Contagious conditions
- Dust
- Cockroaches
- Aerosol sprays
- Perfume
- Strong smells
- Cleaning Products
- Animals
- Pollen
- Mold

Weather Conditions

Stress

Other: __________________________

I have been educated about my / my child’s asthma: ☐ Written materials  ☐ Inhale  ☐ Nebulizer
☐ Spacer  ☐ Peak flow

I have been educated about my / my child’s medications:  ☐ Controllers  ☐ Relievers

I and/or my child have been educated about the need to stop smoking and the dangers that
smoking and second-hand smoke cause people with Asthma.

☐ Yes  ☐ No
☐ NA  Initials ____

I and/or my child have been offered Smoking Cessation Classes.

☐ Yes  ☐ No
☐ NA  Initials ____

I understand the education provided to me regarding my / my child’s asthma; I am able to state my
/ my child’s individual signs, symptoms and triggers to an asthma attack.

☐ Yes  ☐ No
☐ NA  Initials ____

PATIENT COPY
Communication between the Clinical Nurse Specialist for Wound Care and Mr. W's wife
Monday, August 8, 2011

H. and I just did Mr. W's dressing. During that time, I talked with the patient and his wife, LG. I reiterated with her the pathophysiological background of top-down and bottom-up pressure ulcers and the Healthcare Cost and Utilization Project [HCUP] factors (1 - infection / septicemia [his gastric perforation], 2 - oxygenation / perfusion [his two massive pulmonary emboli], and 3- impaired mobility [d/t ECMO], all of which Mr. W has had. I reiterated that while immobilized on ECMO we cannot turn him, so we could not see the injury. In addition, the technology (3D U/S) that would allow visualization of injury near the bone is too bulky to leave in place; it would worsen the pressure injury. I told her that I tell my clinic patients to stay off the wound 23 hours per day. We agreed to his sitting in the chair one hour for each meal and one additional hour during the day or evening. While in the chair, he needs to reposition every 15-20 minutes to avoid ischial pressure ulcers. He can sit on the side of the bed, up to one hour at a time, avoiding pressure on the sacrum. Otherwise, he will be in the Rite Hite bed, turning side to side, off his back.
Notes to Meeting regarding MW /pressure ulcer development and care  

Aug 5, 2011

Present: MW (patient initials used), Keith Perleberg, Director of Nursing Quality, Theresa Gallivan, Chief Nurse, Robin Lipkis-Orlando from Patient Advocacy, Barbara Cashavelly, Nursing Director, Virginia Capasso, Co-director of wound care, Hannah Lyons, Clinical Nurse Specialist, NW, EW (sibling initials used).

Keith Perleberg opened meeting with introductions and then asked Hannah Lyons to describe current state of MW's pressure ulcer and the current care.

Hannah Lyons described placement, size, depth of wound as well as amount of slough currently on wound and the amount of granulating tissue. She said that although one could see bone, that the transparent tissue through which one can see bone is not cartilage as she had thought the other day, when she explained it to EW, but protective healthy tissue. The bone itself and the cartilage are not exposed to air although visible.

She said they were currently using a wet-to-dry dressing. First applying Santyl to debride the slough and then packing the wound with saline solution soaked gauze that promotes the growth of granulating tissue. This dressing is currently being changed daily.

She said the approaches to healing that they are using are: the Clinitron bed, the seat cushion, the dressings, a new prescription for Nuepogen, which will promote the growth of white blood cells to restore healthy tissue, and good nutrition.

Then Virginia Capasso, the Co-director of Wound Care for MGH described what she knew about the development of the wound from reading MW's case file. She said that when he came from Emerson Hospital there was present some visible dark areas around his sacrum that are the precursors of pressure ulcers. In other words it is clear that he came into MGH with a Stage I pressure ulcer.

She said that her current research using ultra-sound imaging shows that these dark areas are not indicative of break down of surface skin, but rather indicate that the tissue close to the bone is beginning to break down. She stated that recent clinical work has shown that in many instances break down of tissue near the bones occurs before there is significant evidence on the surface. In other words, the pressure ulcer is developing from the bottom up. So current research is beginning to show that Stage I is not always apparent to most observers.

Ms. Capasso then began to describe the campaign against Pressure Ulcers that is launching next week: 4 components: skin and risk assessment, moving patients frequently, incontinence, nutrition,
NW and EW asked what stage they thought the pressure ulcer had been in when MW came out of SICU. They felt that it probably was at Stage 2 or 3 but may not yet have even broken the surface skin at that point. The treatment at that stage is to do what is called micro-shifting—gentle massage of the tissue to stimulate growth and also to use either santyl or duoderm, two chemical debridement agents on the wound that are then put on the wound and kept under a sterile dressing for 4-5 days. These agents under the dressing break down the dead tissue.

We were told that the medical record indicates that this 4-5 day treatment was being done while MW was in Cardio Step Down and also on Ellison 16. This was why we were not able to see the wound at this time or get a handle on how severe it was. We were told he was being treated with the best protocols.

NW and EW asked about cushioning and beds: Why was it left to the family to try to devise cushioning to alleviate MW's pain in sacral area of lower back when sitting? Why did it take so long for a special bed to be prescribed? Virginia Capaasso said that the Spo2rt bed was what he was in both in SICU and MICU and that these beds are used in intensive care precisely to prevent and not exacerbate pressure ulcers, because these are two situations where they find that pressure ulcers are most likely to occur. We do not know why it took until last Friday for the Clinitron fluidized bed to be obtained. This question was not answered.

Virginia Capaasso said that the type of cushioning with air holes cut out to relieve pressure on the ulcerated location have been abandoned by nursing because they find that new pressure ulcers develop where the cushioning is: it just shifts the problem instead of helping it. But she did say that Roho custom makes a cushion for wheelchair users that hinges in the center to be both support of bottom of pelvis and the lower back or sacral area. Currently in MW’s chair is a Roho cushion on the seat, brought in on 8-04-11 by inpatient physical therapy, and the homemade cut out cushioning placed with the cutout at MW’s lower back.

Virginia Capaasso then explained that Medicaid and Medicare now refuse to pay for care of pressure ulcers because they claim that they are all preventable. As a researcher and clinician however she feels that this is not the case, as certain situations, such as being placed on ECMO as MW was and then being immobile in SICU for so long, it is almost totally unavoidable to develop a pressure ulcer.

The nutrition piece was explained: MW hadn’t eaten for 5 days when he came to MGH from Emerson. So nutrition wasn’t in place to help repair damage begun. He was not eating for a further 9 days, so again, nutrition wasn’t in place to help repair damage begun or prevent further damage. This was a part of his medical condition that created terrible conditions allowing the pressure ulcer to develop.

NW and EW asked about why MW wasn’t helped to move more often in Cardio Step down, and Ellison 16. Why wasn’t it until MICU that he had people really helping
him to lie on his side? (MW said that staff tried to put him on his side but he always fell back soon afterwards. It was not until he was on MICU floor that staff was using enough pillows as wedges to support him lying on his side.) This was something they had no explanation for, and Theresa Gallivan and Virginia Capasso said they would investigate this.

We talked about the upcoming move to Spaulding. NW and EW told the group that we had visited Spaulding Cambridge this morning and that our key concerns were for continuity in care for MW overall, care for the pressure ulcer, and that the PTs at Spaulding were trained to work with patients who had pressure ulcers. We said that our concerns had been expressed and that we felt that attention would be paid to MW’s complete care.

We discussed that a major concern of MW’s is the transportation to and from Spaulding. He described the pain he had on being transported to and enduring a CT scan a week or two ago as being the 2nd worst of his experience, the worst being the stomach perforation. He said that during the CT scan he was in such pain that his legs were “hopping up and down” even though he was supposed to remain immobile. He said it took him 12 hours to recover from this pain. We asked that he not get moved to Spaulding until everyone was sure he was ready to be moved, so that it could be “a one way trip.”

NW and EW were told that return visits to MGH are likely to be needed for consultation with some doctors such as the plastic surgeon. NW and EW reiterated MWs concern that severe pain during transport was very debilitating and could compromise recovery.

Theresa Gallivan said that it sounded like this is a pain management concern and that they would turn focus on making sure that MW’s pain associated with the pressure ulcer is addressed, particularly during transport.

NW and EW expressed gratitude for overall excellent care in other areas from staff at MGH. We expressed gratitude for speed with which our recent emails were responded to, and for this meeting.

NW and EW talked about early email correspondence (begun 7-17) between our brother Andre (who was a documented advocate/spokesperson for MW at the time) and Steve Reardon of Patient Advocacy. In those emails Steve had asked the family to appoint one spokesperson for the family so that emails were not coming from numerous people. NW and EW explained that this week, MW’s wife LG is out of town, and she had asked them to act on her behalf. So this week NW and EW are the spokespersons. LG will return on 8-7-11 and will be the main spokesperson. However, since she lives at a distance from the hospital and the 5 siblings of MW feel that she should not exhaust herself with his care, we have arranged for one of the siblings to be available in rotation, (all live in other states than MA) nearly continuously to assist in advocating for and visiting MW. We all are in close contact
through daily reports via email. So all siblings (and our parents) are fully apprised of situation with the pressure ulcer. Thus it is likely that at some point in the future other siblings will be in contact with nurses and patient advocacy office, regarding MW's care.

NW and EW would like to know if earlier correspondence with Steve Reardon created a greater attention to care for Michael’s pressure ulcer. It is not clear to the family that it had.

The MGH staff group expressed appreciation for the extent of the family support for MW.

**Areas for follow up and further action:**

Inquiry into why MW was not effectively repositioned more often when lying, or was left sitting or lying down for long stretches of time.

How long was it between initial requests for the Clinitron fluidized bed, and it’s arrival? Emails between family members document that every conversation with MDs in MICU discussed the pressure ulcer and need for a special bed. An Oncologist (Dr Mahindra?) expressed concern for the pressure ulcer when being transferred out of MICU. When MW was transferred from MICU to White 8 on 7-23 he was given the same regular hospital bed. The new Clinitron bed was not requested until July 29 and did not arrive until July 30. **This means 7 days on an unsuitable bed surface. Did this delay further or compromise healing?**

Family of MW would like to see a time-line excerpted out of the charts that would show the development and treatments at various stages of the pressure ulcer. What was evidence of pressure ulcer on admitting to MGH on Phillips 21 on 20 June? What was stage of ulcer observed while in SICU? What was stage of ulcer on transfer to Cardiac-Step down? What was stage of ulcer while on Ellison 16 and so forth?

With respect to the timeline, it should be documented whether MGH followed its own guidelines for:

- Assessing the risk of forming pressure ulcers, starting with when MW was admitted
- Tracking the progress of the pressure ulcer once it was detected
- Care and treatment of the pressure ulcer
- Prevention of additional pressure ulcers

We would like to request the type of Roho seat cushion that can be custom made described by Virginia Capasso that hinges to support not just the bottom of pelvis but the lower back also, as MW describes greatest area of pain on sitting being
pressure on the low back. We would like this right away, and that it should be available at Spaulding Cambridge. All surfaces that MW is either sitting or lying on at all times should be *STATE OF THE ART now*.

Why did MGH staff allow family members to make cushioning for MW that according to Pressure Ulcer guidelines, are not only not effective, but deleterious? Why did they not immediately supply him with state of the art beds and seating?

Inquiry into whether Steve Reardon contacted nursing staff re the pressure ulcer after the initial email contact of 17 July.

Robin Lipkis-Orlando and Virginia Capasso said they would like to meet with LG on Monday August 8. NW and EW will ensure that LG has contact information for Robin and Virginia.
Email Summarizing Meeting Regarding MW; Pressure Ulcer Development and Care

From: Perleberg, Keith, R.N.
Sent: Friday, August 05, 2011 4:49 PM
To: Cashavelly, Barbara J., R.N.; Lyons, Hannah Felton, R.N.; Capasso, Virginia, Ph.D., N.P., R.N.; Lipkis-Orlando, Robin, R.N.; Gallivan, Theresa, M., R.N.
Subject: FW: Meeting Today with [Masked] Family

Dear Colleagues,

Following is a summary of our meeting with the [Masked] family this afternoon:

- Began meeting by agreeing that goals were assurance for patient and family that all appropriate measures have been taken in treating patient's pressure ulcer and that we wanted to honor patient and family's request to partner with us in looking at ways to improve prevention and care of patients with pressure ulcers.
- Hannah Lyons provided current status report on appearance and treatment of the pressure ulcer.
- Ginger provided a detailed explanation of the pathophysiology of a Stage IV pressure ulcer and explained why, in her opinion, this pressure ulcer was unavoidable - the family clearly found this information helpful.
- Family visited Spaulding in Cambridge this AM, liked the facility. Patient and family aware that discharge to Spaulding will likely happen early next week. Concerned about adequate pain control for patient during actual transfer. Barbara Cashavelly assured family about daily team rounds where readiness for discharge/transfer is reviewed as well as pain control. Also assured family about handoff process between MGH and Spaulding.
- Wife will be back on Monday an Robin will meet with her to reinforce support available from OPA.
- Meeting ended well.
- After meeting with patient and family, we spoke about Ginger and Deb Frost doing another record review with eye on what we can learn from this case and share with colleagues (e.g., multiple transfers with multiple handoffs, communication with the patient and family throughout the hospital trajectory).

What an honor and pleasure to work with all of you. Many thanks. Have a wonderful weekend.

Keith
Progress Note

Enter name and unit number on both sides of EVERY sheet. Addressograph plate to be used when available. Name and unit number to be written distinctly when plate is not available.

Signature should be legible and include name, licensure & pager #

8/8/1730 CNS Skin & Wound follow up note:
Pt completed cycle 2 of Rituximab/bendamustine on 8/3. He is now day 6 with nadir anticipated day 14-21. Pt is receiving Neupogen daily which is elevating WBC falsely to 42K. Hct stable at 30.1. No recent albumin or pre-albumin. Creatinine 0.8, BUN 18, Glucose 86.

Current Precautions: Fall

Nutrition: Pt being followed by Jen Lerman, RD. Taking protein supplements (BeneProtein) 2 x day, appetite has been decreased due to nausea and some vomiting (last emesis 8/5) since chemotherapy which has improved with RTC compazine. Pt reports having some dizziness and being started on a scopolamine patch. Compazine being tapered to PRN. Pt reports appetite is improving

Elimination: Continent; fluid balance even but less than 2L in/out over past 24hrs and prior to that pt negative x 48hrs. PleurX catheters draining 500-600 ml straw colored fluid daily.

Activity: Pt is OOB to chair, ambulating in halls.

Skin: No evidence of pressure injury noted in area of head, elbows or heels. Skin generally pale, moist, intact.

Wound Measurements:

<table>
<thead>
<tr>
<th>Location</th>
<th>Wound #1</th>
<th>Wound #2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Location</td>
<td>Sacrum</td>
<td>L buttock</td>
</tr>
<tr>
<td>Stage</td>
<td>IV</td>
<td>II</td>
</tr>
<tr>
<td>(Pressure Ulcer Only)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Size: LxWxD (cm)</td>
<td>3.5 x 4 x 0.7 cm</td>
<td>1.4 x 0.7 cm</td>
</tr>
<tr>
<td></td>
<td>Deeper portion of wound measures 2.5cm across</td>
<td></td>
</tr>
<tr>
<td>Undermining (cm)</td>
<td>1.2 cm @ 12 o’clock</td>
<td>None</td>
</tr>
<tr>
<td></td>
<td>1.5 cm @ 3 o’clock</td>
<td></td>
</tr>
<tr>
<td></td>
<td>0.7cm @ 6 o’clock</td>
<td></td>
</tr>
<tr>
<td></td>
<td>No undermining from 7o’clock to 11o’clock</td>
<td></td>
</tr>
</tbody>
</table>

Hannah Lyons, RN, MSN, AOCN
Clinical Nurse Specialist PH21

UNACCEPTABLE ABBREVIATIONS: Applies to all handwritten and electronic ‘free text’ entries

<table>
<thead>
<tr>
<th>QD</th>
<th>QOD</th>
<th>MS</th>
<th>MSO4</th>
<th>MgSO4</th>
<th>hs</th>
<th>ss</th>
<th>µg</th>
<th>U</th>
<th>IU</th>
<th>os</th>
<th>qn</th>
<th>dt</th>
</tr>
</thead>
<tbody>
<tr>
<td>.5</td>
<td>(i.e., use 0.5mg)</td>
<td></td>
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<tr>
<td>1.0</td>
<td>(i.e., use 1mg)</td>
<td></td>
<td></td>
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<td></td>
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<td></td>
</tr>
<tr>
<td>Apothecary Symbols (e.g., amp, grain)</td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>
**Progress Note**

Enter name and unit number on both sides of EVERY sheet. Addressograph plate to be used when available. Name and unit number to be written distinctly when plate is not available.

*Signature should be legible and include name, licensure & pager #*

<table>
<thead>
<tr>
<th>Tunneling (o’clock/cm) - If present</th>
<th>None present</th>
<th>None</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wound Bed Description (estimate using %)</td>
<td>Moist, 30% wound bed yellow tissue; 70% red granulating tissue surrounding intact osteum over two areas of bone– center of wound and LUQ of wound</td>
<td>85% pink granulating tissue, 15% yellow tissue</td>
</tr>
<tr>
<td>Exudate (amount &amp; description)</td>
<td>No odor, small amount of serous drainage with tinge of yellow/green on one corner</td>
<td>None</td>
</tr>
<tr>
<td>Peri-wound area (4cm around wound)</td>
<td>Pink, intact, new epithelial tissue on immediate border. Blanchable, intact skin surrounding border.</td>
<td>Pink, intact, new epithelial tissue on immediate border. Blanchable, intact skin surrounding border.</td>
</tr>
</tbody>
</table>

**PLAN:**

I. Wound Care: Wet to dry dressing change daily per plastic surgery
   a. Cleanse wound with NS 30cc syringe/#18 Blunt tip
   b. Pack Stage IV wound with NS moistened gauze (3/4 of 4x4 gauze) being careful not to pack too tightly or leave extra packing above surface of skin because of risk of causing pressure damage
   c. Cover wounds with Mepitel Border Sacrum to the coccyx
   d. Apply 3M Moisture Barrier to intact skin around the dressing

II. Relieve Pressure:
   a. Continue with Clinitron Rite Hite bed for comfort and prevention of further skin breakdown.
   b. Repositioning q2, shift weight q2.
   c. Pt may sit in the chair one hour for each meal and one additional hour during the day or evening. While in the chair, he needs to reposition every 15-20 minutes to avoid ischial pressure ulcers.
   d. He can sit on the side of the bed, up to one hour at a time, avoiding pressure on the sacrum. Otherwise, he will be in the Rite Hite bed, turning side to side, off his back or ambulating.

_Hannah Lyons, RN, MSN, AOCN  
Clinical Nurse Specialist PH21_
III. HOB ≤ 30 degrees, position patient off of wound/skin breakdown, Roho cushion for chair (requested PT to supply), use foot rest when sitting.

IV. Manage nutrition: Pre-albumin ordered with next lab draw; Monitor I and O; follow Dietary consult POC, check weight bi-weekly

V. Protect areas of pressure with 3M Barrier, extra-thin duoderm as needed

Wound care plan discussed with Dr. Virginia Capasso who was present during dressing change and later by phone with Dr. I. Sinha, Plastic Surgery and with Nicole Tariot, Wound Care Nurse at Spaulding Rehabilitation in Cambridge who will be following patient once he is transferred. Dr. Sinha was amenable to changing to a VAC dressing if a bridge was used to minimize the risk of pressure damage from the VAC apparatus. He also supported using Iodasorb to wound bed x 1 day as an antimicrobial tomorrow.

Above reviewed with patient and wife, Lisa. Patient instructed on activity restrictions.

Hannah Lyons, RN, MSN, AOCN
Clinical Nurse Specialist PH21
Email Regarding Team Meeting Request from the Wife

-----Original Message-----
From: Perleberg, Keith , R.N.
Sent: Monday, August 08, 2011 5:59 AM
To: 'LG Lyons, Hannah Felton,R.N.; Lipkis-Orlando, Robin,R.N.
Cc: Gallivan, Theresa M., R.N.; Hochberg, Ephraim Paul,M.D.; Suit, Herman D.,M.D.
Subject: RE: Request for immediate meeting re: MW

Dear Ms. G

Thanks for your message. Robin Lipkis-Orlando, the Director for our Office of Patient Advocacy, will be contacting you this morning to set a time for meeting today.

Keith Perleberg, RN, M.Div
Director, Patient Care Services Office of Quality and Safety

-----Original Message-----
From: LG
Sent: Sunday, August 07, 2011 10:58 PM
To: Lyons, Hannah Felton,R.N.; Lipkis-Orlando, Robin,R.N.
Cc: Perleberg, Keith , R.N.; Gallivan, Theresa M., R.N.; Hochberg, Ephraim Paul,M.D.; Suit, Herman D.,M.D.
Subject: Request for immediate meeting re: MW

To (MGH): Hannah Lyons, RN; Virginia Capasso, RN*; Robin Lipkis-Orlando, RN
Cc: (MGH): Keith Perleberg, RN; Theresa Gallivan, RN; Peter Dowling, RN*; Ephraim Hochberg, MD; Herman Suit, MD
Cc (family): EW, NW, AW, ACW, PW, R&AW,
[*Please forward to Virginia Capasso and Peter Dowling]
Re: Detailed care plan for MW

I would like to schedule a meeting with you on Monday, August 8, to discuss the care of my husband MW, well in advance of any move planned for him to Spaulding Hospital, Cambridge. I can be at MGH as early as 9 am. My cell phone number is [redacted]

At this meeting I would like to cover the wound care plan for M, the transition to Spaulding Hospital, and communication. M and his family will not be comfortable with a transfer until we have a plan in place for addressing the following issues:

Wound care for pressure ulcer
I would like a detailed written plan for wound care and repositioning from this point forward. This includes management by a wound care specialist, daily regimen, types of dressings and why they are recommended, mobility plan, nutrition, and specialized equipment (including the Clinitron Hite-Rite bed, and a Hinged Roho Cushion to provide
cushioning to his low back and bottom while sitting). The plan should include dates and specific medical-care events (e.g., tests, moves, drainage) that will trigger automatic reassessments of the plan. I would also like a prognosis.

PleurX plan
It is my understanding that there is now a different kind of catheter on each side of MW’s thorax, necessitating two different kinds of caps to seal each catheter. The left side cannot be capped with a PleurX cap. One of the nurses on White 8 made-do with blue IV caps because the correct caps were not included with the kit. The right side has a standard PleurX cap. This inconsistency is problematic for a transition both to Spaulding and subsequently to home.

Transfer of information and protocols to Spaulding
I would like the name of the wound care specialist who would assume the care of M’s pressure ulcer at Spaulding. Before M is moved I would like agreement from both MGH and Spaulding that M’s wound care plan will not be interrupted in any way because of the transfer to a different wound care team.

Transportation to Spaulding and pain management
I understand that MW would be transferred by ambulance. He anticipates that this would be extremely painful. The standard pain meds he is receiving are not alleviating the pressure ulcer pain. I would like arrangements for specialized cushioning for the ambulance gurney to be devised to provide as much relief as possible, as well as a discussion of all possible methods of pain relief including local or topical anesthesia. I need to be reassured that steps will be taken before I can allow a transfer. Given that transfers are difficult to schedule, who will be in place to ensure that the pain management plan is put in place and monitored?

Follow-up appointments with Vascular and Cardiac surgery at MGH
Because MW has been in the hospital for over 7 weeks, he is due to see certain specialists for post-operative appointments. Dr. Robert Schainfeld’s office called to inform us that M's IVC filter will need to come out. M is also due for a post cardiac surgery appointment with Dr. Jennifer Walker. These appointments are not yet scheduled. We prefer that he sees these specialists before he goes to Spaulding to minimize the transport pain issue, and because he will have to be returning to MGH for CT scans and other tests. We want an agreement that transports within MGH will be made via the special bed that he is already in, not via gurney.

Summary
There is much to be resolved, and as I stated earlier, the family cannot approve a transfer to Spaulding until these important issues are discussed, agreed upon and put into place.

I look forward to meeting you on Monday.
Sincerely,
LG
8/8/11 MW Wound Care/Transfer Meeting Notes
1:40 - 2:00PM in Philips 21 Family Lounge
Notes taken by LG

Present: Family: LG, MW, NW (via phone)
MGH: Mary Campbell, NP (Hematology), Barbara Cashavelly, RN (Nursing Director), Peter Dowling RN (Case Manager), Robin Lipkis-Orlando, RN (Patient Advocacy), Hannah Lyons, RN (CNS), Keith Perleberg, RN (Director of Nursing Quality), Mark Scheel (Regional Admitting Director, Spaulding Cambridge)

After introductions, Robin Lipkis-Orlando opened the discussion by stating that they had read LG's 8/7/11 memo and wanted to address the family’s concerns about wound care and the transfer to Spaulding. Hannah Lyons said that she had been in touch with the wound care specialist from Spaulding, whose name is Nicole Theriault. LG asked if Nicole would have hands-on care of M, and Hannah replied yes, that Nicole would be the hands-on coordinator, working along with floor nurses to implement the wound care plan. There would also be a plastic surgery PA, someone who is connected with Brigham and Women's and MGH. Hannah reassured us that M would have a Clinitron Rite-Hite bed (so-called sand bed) and a RoHo cushion for sitting in the chair. In a previous discussion, recommendations were made for a hinged RoHo cushion with back support, and Hannah clarified that they are custom fit. M and family will follow up with the Spaulding rehab team. Lisa asked Mark Scheel to make a note of that. Hannah also mentioned that the Spaulding team would be actively re-evaluating wound care throughout M's stay and that the Spaulding team would able to provide a vacuum type dressing if it was determined to be necessary.

Hannah said she had detailed the current wound care plan with Nicole. LG had been given this plan orally by Hannah and Dr. Virginia Capasso (wound care specialist) this morning when they came to evaluate the pressure ulcer. A copy of LG's understanding of the current plan is attached. Both Robin and Hannah said that this care would continue uninterrupted once M is transferred to Spaulding. LG stressed that in the past, the family had had to start all over with wound care requests every time M was moved between floors. Hannah clarified that she had received emails from 2 CNS nurses about M's wound issues before he arrived at Philips 21. LG responded that she wanted that kind of communication to continue.

LG wanted to know what the prognosis of the wound is, and Hannah replied that if the wound continues to heal as well it has this past week, that it should take a few months to heal fully, notwithstanding bumps in the road due to chemo. LG wondered if we would need a plastic surgery consult before transfer; Hannah said that the plastics team had already come on Saturday at her request.

Mary Campbell talked about wrapping up M's medical issues in preparation for the transfer. Dr. Schainfeld's office told her that the IVC catheter doesn't need to come out for another 2 months from now, placing the removal some time in October. Mary said she would mark that in the chart. She has yet to hear back from Interventional Radiology about replacing the one non-standard PleurX tube fitting so that both catheters have the same cap fitting. Most likely this will take place on Tuesday, August 9. M will have to come back to MGH to meet with Mary and Dr. Hochberg to talk about the next course of treatment, which should start 28 days after this last course. She said she would try and coordinate all of his appointments around that time so that he would have only one trip to make.
LG asked who will ensure that Pleurex drainage would continue at Spaulding. She was told that the requirements for daily drainage were sent to Spaulding in Mi’s treatment charts. She was assured that Spaulding nursing staff are trained and scheduled to do this. LG asked about the Spaulding nutrition plan, as part of wound care. Mark and Hannah stated that a Spaulding nutritionist would develop a plan. LG emphasized maintaining the recommended high protein diet. M mentioned he has difficulty eating standard proteins such as meat due to problems with thrush. Mary replied that she is addressing the thrush problem with drugs.

Barbara Cashavelly described the discharge plan, outlining that the MGH physicians and nurses will contribute to the notes. All of the specialists will do a discharge plan. MGH will call the Spaulding oncology unit, where it is anticipated M will go, and will talk with the nurse director there. Robin stated that the family would be given written discharge info so that they could disseminate it amongst themselves. MGH will give a list of Spaulding contact names and information to M, L and the family. Once M is at Spaulding, the team there will be in charge.

LG asked what the transfer timeframe was, and Keith Perleberg said that after the MGH medical issues were addressed, they would do the transfer. He thinks it will be Wednesday morning and said that they are looking for a morning transfer so M can get settled during the day. LG expressed a very strong preference not to have the transfer on a Friday or weekend, and the MGH staff agreed with that.

Mark Scheel described the Spaulding oncology floor treatment team as having a hospitalist (floor doctor), a nurse manager whose name is Elaine Kelly, a chemo manager specialist, nurses, aides, a dietician, a case manager, and a physical rehabilitation group (PTs and OTs). He said Dr. Carolyn Krasner would lead the oncology team rounds. M would be assessed for physical rehab during the first few days.

Mark said that private rooms were usually given to patients who are immuno-compromised and asked M what his preference was. M expressed a concern about lowering blood counts because of his chemotherapy, mentioning his thrush again, and asked for a single. L stated that if the room was a double, a bed by a window would be preferred to help with morale since he has now been hospitalized more than 7 weeks.

LG brought up MW’s past painful experiences with his wound during transfers, and Peter Dowling offered to have a member of the ambulance crew come up today to talk with M about appropriate cushioning for his wound. LG asked if Hannah would be on morning duty this week to help oversee a comfortable transfer, and she said yes.

LG expressed her gratitude for the meeting.

Action Items and Follow-Up
- Family and Mark Scheel: Work with Spaulding to obtain hinged RoHo cushion
- Hannah Lyons and Virginia Capasso: Review LG’s transcription of the oral wound care plan (attached) and provide additions and corrections as needed
- Barabara Cashavelly and MGH staff: Provide copy of discharge plan to M, LG and family. Discharge plan to include a list of contact names at Spaulding (including phone numbers and E-mails)
- Mary Campbell: Develop plan to coordinate M’s upcoming appointments to minimize number of transports between Spaulding and MGH. LG and M will provide Mary with all appointments they know of.
• Peter Dowling: Arrange ambulance/transfer staff to meet with Mi to discuss the transfer plan, pain issues and cushioning
• Hannah Lyons: Help oversee comfortable transfer to Spaulding on the day of transfer
• Mark Scheel: Bear in mind M is concerned about being immuno-compromised and is requesting a single.
MW’s Wound Care Plan
As told to LG by Hannah Lyons, RN and Virginia Capasso, RN, PhD.
8/8/2011

• He must be off the sore for 20 hours a day. Usually they prefer 23 hours a day with spinal cord patients, but they want M to sit up and eat.

• Ideally he should never lie flat on his back. He needs to tip one side of his pelvis so pressure is not flat on sacrum. He needs to move or be moved every 2 hours while in bed. He should be in a Clinitron Rite-Hite bed (so-called sand bed).

• The 4 hours he’s allowed in a chair must be broken up into 1 hour increments with shifts in position every 20 minutes. He must sit on a RoHo cushion.

• He may sit up on the edge of the bed, being careful not to put pressure on the sacrum. The limit is 1 hour, and he must shift position every 20 minutes.

• He may walk as many times as he likes; walking is encouraged.

• Whenever he moves, he should lift himself up as much as possible to avoid slide and shear. This is a bit difficult with his cardiac surgery restrictions to protect the sternal incision.

• Continue with wet/dry daily dressings and monitor debridement.

• Have plastic surgery evaluate dressing type with a goal of helping red granulation.
COMMUNICATION WITH WIFE AFTER DISCHARGE TO SPAULDING HOSPITAL

-----Original Message-----
From: Lyons, Hannah Felton,R.N.
Sent: Friday, August 12, 2011 9:23 AM
To: LG
Subject: RE: Notes of MW wound/transfer meeting

Lisa,

Thank you for giving me an update! I am so glad M is doing well. Thank you too for your kind words. It was a privilege to be a part of M's team and gratifying when teamwork and collaboration come together with a positive outcome!

Take care and best wishes to all of you,
Hannah

-----Original Message-----
From: LG
Sent: Friday, August 12, 2011 9:19 AM
To: Lyons, Hannah Felton,R.N.
Subject: Re: Notes of MW wound/transfer meeting

Hello Hannah,

The transfer to Spaulding went very well, and M is now fully engaged in PT and OT, which marks good progress for him. He is happy to hear about the conversation with Dr. Walker--kudos to you and Francie.

Thank you for getting Nicole up to speed; she saw M on Wednesday and things seem to be on track.

I'd like to say again how much I appreciate your compassion and caring. M's brother and sister also sing your praises, and even though the last week at MGH had its difficulties, we want you to know that we hold you in high regard.
Best wishes,

L
Date: 7/24/2012  Time: 5:10:24 PM  1/1
Access: LNA DL PICC (placed 7/9, dsg changed 7/23); lumens w/ +flush/BR, no s/s of IV complications. Flushed per policy.
CC: 51 y/o M w/ h/o metastatic melanoma adm 7/5 to Neurosurg for T11-L1 fusion and decompression, transferred from EUL 16 for continued pain control.
PMH: HTN, h/o multiple systemic tx's, bil hip replacement ('07), neck tumor debulking 6/12, sacral tumor debulking 7/12.
Oncology: Pt. received XRT today, unable to complete Monday 2/2 pain. Pt. scheduled for XRT @10a tomorrow.

Knowledge Deficit: A&Ox3. All meds/interventions explained to pt prior to adm. Pt verbalizing understanding/in agreement w/ POC. Brother Erik (ICU attending at Tufts) @ bedside this shift and supportive; cell phone number on whiteboard in rm-please call w/ any changes/questions. Pt. would consider cordotomy if pain remains an issue. Pt's goal is to be able to get OOB to chair, pain free, and not be sedated by med unless pain is unable to be controlled else wise. Palliative care following. Continue to assess for learning needs and educate appropriately.

Discharge Planning: Inpt hospice vs hospice house in the future once pain is able to be controlled/what is needed to control it. Pt. lives in Staten Island, has 12 y/o son. Supportive brothers, one in Boston/one in NY. CM following. Continue to assess pt discharge needs and facilitate a safe D/C.

Alteration in Comfort: Pt. w/ shooting/burning pain to R groin/ lower back, c/o L shoulder pain today after being repositioned. States pain is well controlled when lying down, exacerbates w/ movement- much improvement seen since yesterday/start of new epidural mixture. Pt. able to sit up more today/take pills. Continues on high concentration dilaudid PCA, see CAS for orders; basal stopped today 2/2 drowsiness. RN boluses PRN, none required this shift. Pt. w/ Bupivacaine/dilaudid/clonidine epidural infusing @10ml/hr throughout shift, increased to 12ml/hr @1700 by pain service; settings to be adjusted by Pain Service only. Epidural mixture not in epidural library of PCA machine-verified w/ pharmacy, please see 7/24 CNS note. Epidural medication under omninell as "special epidural" under stocked meds. Please call pharm and have them mix a new cassette after you remove a cassette from omninell (only stocked 1 @ a time). Continues on IV decadron. Neuro surgery, palliative care, and chronic pain team following. Pt. anxious @times, yzids ordered standing/PRN. Pt. w/ dry mouth, mouth moisturizer adm PRN. Plan: Continue to monitor/assess for discomfort, tx accordingly.

Risk for Falls: Pt. bedbound @this time, numbness to lower extremities bilaterally. TID heparin. Pt. refusing TEDs/pneumo boots. Able to turn w/ assistance; pt w/ pain w/ repositioning/unable to tolerate turning Q2H. Wound 300 mattress trialed today-pt having more pain w/ it so he was switched back to a regular mattress. Pt c/o d-limited by pain/inability to get OOB. OT following. Call light w/in reach, pt demonstrating proper use. Bed in low/locked position; frequent visual checks made, slipper socks on. Fall precautions maintained, sign on door/chart. Plan: Continue to assess mobility status and maintain fall precautions.

Alteration in F/E/N: Labs QOD, due in AM. Pt. able to take pills whole w/ ensure. SLP following, recommending putting pt in reverse trendelenberg to take pills/drink; pt able to sit up and take pills today. Pt. drinking ensure this shift, IV's @75cc/hr. Foley intact/draining adequate amounts of clear yellow urine. BM 7/23 s/p sub-Q methylphenidate, sm soft BM this shift. Pt. ordered for injection QOD x3. BS+/-4 fluid. No peripheral edema noted. PIP/CSM. Cardiac meds held this AM as BP's have been in 120's and pt on increased pain meds at this time-OK per NP-plan to continue to monitor, ? D/Cing tomorrow. Plan: Monitor F/E/N and intervene PRN.

Alteration in Skin Integrity: Epidural site visualized this shift, dsg intact, site benign. Serosanguinous drainage noted under dsg expected per Pain Service. Staples to back incision intact, no s/s of infection/no drainage; open to air. Pt. refusing to turn this shift 2/2 pain. Unable to tolerate wound 300 mattress. Outlined area on R groin where tumor is visible, blister-like in appearance. Similar appearing area noted on R lateral thigh. No drainage noted from either area. Pt. corvox intact, barrier cream applied. Ensure for nutrition. Plan: Continue to assess skin and tx accordingly.
Nursing Progress Note  

Enter name and unit number on both sides of EVERY sheet. Addressograph plate to be used when available. Name and unit number to be written distinctly when plate is not available.

Signature should be legible and include name, licensure & pager #

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Discharge Planning: Imp hospice vs hospice house in the future once pain is able to be controlled/what is needed to control it. Pt. lives in Staten Island, has 12 y/o son. Supportive brothers, one in Boston/one in NY. CN following. Continue to assess pt discharge needs and facilitate a safe D/C.

Alteration in Comfort: Pt. w/ shooting/burning pain to R groin/lower back, c/o L shoulder pain today after being repositioned. States pain is well controlled when lying down, exacerbates w/ movement-much improvement seen since yesterday/start of new epidural mixture. Pt. able to sit up more today/take pills. Continues on high concentration dilaudid PCA, see CAS for orders; basal stopped today 2/2 drowsiness. RN boluses PRN, none required this shift. Pt. w/ Bupivacaine/dilaudid/clonidine epidural infusing @10ml/hr throughout shift, increased to 12ml/hr @1700 by pain service; settings to be adjusted by Pain Service only. Epidural mixture not in epidural library of PCA machine-verified w/ pharmacy, please see 7/24 CNS note. Epidural medication under omnicell as "special epidural" under stocked meds. Please call pharm and have them mix a new cassette after you remove a cassette from omnicell (only stocked 1 @ a time). Continues on IV decadron. Neurosurgery, palliative care, and chronic pain team following. Pt. anxious @times, zydis ordered standing PRN. Pt. w/ dry mouth, mouth moisturizer adm PRN. Plan: Continue to monitor/assess for discomfort, tx accordingly.

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| 7/24/2012 | 5:10:24 PM | 0700-1900 | DN/DNI | NP | NKDA | Fall | LVA DL PICC | 51 y/o M w/ h/o metastatic melanoma | 7/5 to Neurosurg for T11-L1 fusion and decompression, transferred from ELL 16 for continued pain control. | HTN, s/p multiple systemic txes, bil hip replacement ('07), neck tumor debulking 6/12, sacral tumor debulking 7/12. | Pt. received XRT today, unable to complete Monday 2/2 pain. Pt. scheduled for XRT @10a tomorrow.

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Enter name and unit number on both sides of EVERY sheet.
Addressograph plate to be used when available. Name and unit
Number to be written distinctly when plate is not available.
Signature should be legible and include name, licensure & pager #.

Date: 7/25/2012 Time: 7:02:11 PM
Shift: 0700/1000 Code: DNR/DNI Service: NP Allg: NKDA Precautions: Fall
Access: L VIA DL PICC (placed 7/9, dsg changed 7/23); lumens w/ +flush/BR, no s/s of IV complications. Flushed per policy.
CC: S 1 y/o M w/ h/o metastatic melanoma adm 7/5 to Neurosurg for T11-L1 fusion and decompression, transferred from ELL 16 for continued pain control.
PMH: HTN, s/p multiple systemic tx’s, bil hip replacement (07), neck tumor debulking 6/12, sacral tumor debulking 7/12.
Oncology: Pt. received XRT today, scheduled for last XRT session @1420 tomorrow.

Knowledge Deficit: A&Ox3. All meds/interventions explained to pt prior to adm. Pt verbalizing understanding/in agreement w/ POC. Brother Erik (ICU attending at Tufts) @bedside this shift and supportive; cell phone number on whiteboard in rm-please call w/ any changes/questions. Pt. depressed, stating he just wants to die. Denies suicidal ideation. RN support given. Friends in this shift, 1 will be staying overnight; pt seems to be in better state w/ friends. Neurosurgery in, not recommending codotomy @this time-recommending intrathecal therapy. No further plans @this time. Palliative care following. Continue to assess for learning needs and educate appropriately.

Discharge Planning: 7 intt hospice vs hospice house in the future once pain is able to be controlled/what is needed to control it; pt wishes to remain close to Boston/his doctors. Pt. lives in Staten Island, has 12 y/o son. Supportive brothers, one in Boston/one in NY. CM following. Continue to assess pt discharge needs and facilitate a safe D/C.

Alteration in Comfort: Pt. w/ shooting/burning pain to R groin/lower back. Pain is well controlled when lying down, exacerbates w/ movement—much improvement seen start of new epidural mixture. Pt. able to sit up today to take pills, unable to tolerate sitting up for long periods of time. Continues on high concentration dilaudid PCA, see CAS for orders. RN boluses PRN, none required this shift. Pt. w/ Bupivacaine/dilaudid/clonidine epidural infusing @12ml/hr at start of shift, increased to 14ml/hr @1030 by pain service (see holding parameters); dosing to be adjusted by Pain Service only.

VS recorded per protocol—please see front of green book. RR 22. Epidual mixture not in epidural library of PCA machine-verified w/ pharmacy, please see 7/24 CNS note. Epidural medication under omnicef as “special epidural” under stocked meds. Please call pharmacist and have them mix a new cassette after you remove a cassette from omnicef (only stocked 1 @ a time). Continues on IV decadron. Neurosurgery, palliative care, and chronic pain team following. Pt. anxious @times, zydls standing/PRN. Pt. w/ dry mouth, mouth moisturizer adm PRN w/ good effect. Plan: Continue to monitor/assess for discomfort, tx accordingly

Risk for Falls: Pt. bedbound @this time, numbness to lower extremities bilaterally R>L. TID heparin. Pt. refusing TEDs/pneumo boots. Able to turn w/ assistance; pt w/ pain w/ repositioning/unable to tolerate turning Q2H. PT c/c’d limited by pain/inability to get OOB. OT following. Call light w/in reach, pt demonstrating proper use. Bed in low/locked position; frequent visual checks made, slipper socks on. Fall precautions maintained, sign on door/chart. Plan: Continue to assess mobility status and maintain fall precautions.

Alteration in F/E/N: Labs QOD, due 7/27. Pt. able to take pills whole w/ ensure. SLP following, recommending putting pt in reverse trendelenberg to take pills/drink if unable to tolerate sitting up; pt able to sit up and take pills today. Pt. drinking ensure this shift, IVFs @75cc/hr. Foley intact/draining adequate amts of clear yellow urine. S/p sub-Q, methylnaltrexone 7/23. Pt. w/ multiple loose BMs this shift, unaware of bowel movements—pt checked frequently. Plan to hold bowel meds tonight. Rectal bag attached this shift, no BM since. B5+4, -flatus. No peripheral edema noted. +PP/CSM. Cardiac meds D/C’d as SVP 100-120’s/increased in pain meds. Plan: Monitor F/E/N and intervene PRN.

Alteration in Skin Integrity: Epidural site visualized this shift, dsg intact, site benign-pain team did not want to change dsg @this time. Serosanguinous drainage noted under dsg, expected per Pain Service. Staples to back incision intact, no s/s of infection/no drainage; open to air. Pt. refusing to turn this shift 2/2 pain. Unable to tolerate wound 300 mattress this adm. Outlined area on R groin where tumor is visible, blister-like in appearance. Simlar-appearing area noted on R lateral thigh. No drainage noted from either area. Pt’s coccyx intact, barrier cream applied. Ensure for nutrition. Plan: Continue to assess skin and tx accordingly.

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Nursing Progress Note

Date: 8/8/2012  Time: 5:49:17 AM
Shift: 1900-0700  Service: NP/Red  Code Status: DNR/DNI
Access: LA DL PICC, 4 BR, - flush (drug change 7/30)

Reason For Hospitalization: Pt is a 51yo M with b/o mutation metastatic melanoma (d/o/d 11/2010), mets to groin, liver, lungs, lymph nodes, hip, spine, admitted 2/5 for T11-L1 fusion/decompression, continued inpt dx pain, here for continued pain control. Pertinent PMH: HTN, a/p multiple systemic therapies, a/p bilateral hip replacement 2007, a/p neck tumor debulking 6/12, a/p sacral tumor debulking 7/12, XRT completed 7/26/12

Problems:

Pain/Coping: Pt rating his pain 4-5/10 in his back, hip, and left shoulder most of shift. Continues on continuous Fentanyl/Dilaudid/Clonidine epidural currently infusing at 6ml/hr (only to be adjusted per Pain service). Epidural documentation in front of green book, no scanning in eMAR. Epidural medication in Omnicell as "special epidural" under locked morphology. One cassette is in Omnicell. Continues on high concentration Dilaudid PCA currently at 4mg bolus/0 min lockout/0 continuous, increased from 3mg to 4mg as pt woke up w/ increased pain. Dilaudid PCA will transition to a drip @ 3mg/hr this am @ 8am. IV Decadron BID for pain. Pt has no sensation in perineum. Lower extremities numb w/ slight sensation R>L, continues on neurotin, last dose to be given this am. Continues on zolpidem for anxiety. Neurosurgery, Palliative Care, and Pain Service following. Pt able to speak about his illness and states that he has made peace with his life and is ready to pass. Pt receiving palliative sedation per Pall/Care. Suggestion to be initiated this am @ 8am. Vicki Jackson to come and give loading dose of phenobarbital w/ drip to follow. Plan: Continue to assess pain level, tx accordingly and provide emotional support.

Alt in tissue perfusion: HCT 22.4; pt not to be transfused as not part of pt's goals. Denies SOB/COP, O2 sat >95% on RA. PAIN saline nph given x1 for increased jucy cough, pt reports feeling much better following nph tx. Plan: Continue to monitor labs and VS and treat accordingly.

F/T/N: NS KVO @ 10cc/hr. Regular diet ordered, consuming only ensure shakes @ this time w/pills. Pt likes to sit up @ 45 degrees when drinking/taking pills. Foley draining moderate amts amber colored urine. Abd slightly distended, + flatus, + BS x4. LBM 8/7. Most pills d/o/d on previous shift as pt will be sedated starting this am. Plan: Continue to assess nutritional and fluid status, labs, elimination. Provide bowel meds.
Optimum Care Consult  
August 7, 2012  
5:30 PM

Asked by [REDACTED] to consult regarding ethical consideration of the option of palliative sedation for [REDACTED], 51 year old man who was diagnosed with metastatic malignant melanoma in November 2010. [REDACTED] noticed a lump in his groin in March 2010, and a subsequent biopsy of it in November 2012 revealed metastatic poorly differentiated melanoma. In addition, he had noticed a nodule on his right thigh that was becoming larger and was ultimately identified as the primary site. Also in November 2010, diagnostic work up revealed that [REDACTED] had lung nodules, a right adrenal nodule and suspicions of metastatic disease in the abdomen. By December 2010, his disease was classified as Stage IV malignant melanoma. Presently, metastases include diffuse lesions in his liver, bone, spine, chest wall and soft tissue. [REDACTED] has received his care at Memorial Sloan Kettering, NIH Bethesda and MGH, and since diagnosis has received many therapies including Phase 1 clinical trials as far back as January 2011, and XRT for his cancer, and now is at end stage as metastatic lesions are increasing. On 5/3/12, [REDACTED] underwent C4-6 laminectomy and C3-6 instrumentation and fusion for spinal metastases, and, most recently s/p T11-L1 fusion and decompression on 7/6/12 for same.

Areas of pain for this patient are well documented by Palliative Care and oncology physicians and nurses who are providing direct care to him. A right hemi-pelvic mass and right groin mass causing severe pain and lymphedema has recently been treated with palliative XRT. [REDACTED] continued to complain of severe pain in R hip/flank/groin and proximal RLE which was intolerable such that the only position that he could assume to bear it was lying flat. Additionally, severe, intolerable sacral back pain has been a stubborn problem for this him. This intractable pain, despite epidural catheter delivering Bupivacaine/Hydromorphone/Clonidine led to the recommendation and decision for cordotomy on 7/29/12. While the patient admits that he has some relief post this procedure, he still requires the epidural administered medication regime, to be able to attain 30 degree elevation, and thus is still not in a place where he assesses his pain as ‘managed’. On Monday, August 6, the patient stated that, “If I lie totally still, I can handle it, but as soon as I move at all, it becomes very difficult to handle the pain.” He is bedbound, and is unable to control his bowels or bladder.

[REDACTED] has a construction business, in which he partners with his brother, [REDACTED]. Another brother, [REDACTED] is the patient’s health care agent and an enduring source of support to [REDACTED] during this illness. [REDACTED] has a twelve year old son, [REDACTED], who visited him this weekend, with the boy’s mother, who is the former partner of the patient. [REDACTED] has reached out to an estranged brother, [REDACTED], who came in to visit him.
Palliative Care consultation for [redacted] was initiated in May 2012 for back pain, and since that time, pain has been a chronic issue, as metastases continue to emerge, in spite of many different pain management strategies. [redacted] pain has been evaluated by [redacted] of Palliative Care over the past several months, both on an in and out patient basis. The primary reason for this month long hospitalization was uncontrolled pain, and during this time, the Palliative Care team has worked tirelessly and collaboratively with all team members, in partnership with Mr. [redacted] to find effective strategies for his pain control. Currently, the patient has an approximate two month prognosis, and his pain is reported by him as unbearable.

[redacted] stoicism may portray a sense of managing his pain, yet, when interviewed on August 6 by Optimum Care consultants, he expressed his sense of suffering through statements such as: “I can’t take it, the pain has gone on too long, if I move I’m in so much pain.” The patient stated: “I have tried everything that [redacted] recommended, including the epidural and the cordotomy. I honestly can’t stand it any longer; I’m at the end of my rope with this pain.” While he admits that these interventions have helped somewhat, [redacted] stated that the pain persists in a way that is unbearable to him overall. The patient also stated that he has lost control of his bowel and bladder, and this adds to his overall discomfort, distress and for him, a loss of dignity.

[redacted] of Palliative Care introduced the possible option of palliative sedation to [redacted]. Given his terminal prognosis, the acceleration of metastases and associated intractable pain, this is an option that he would like to have implemented. [redacted] talked with OCC about his desire to move forward with this procedure. [redacted] was present and participated in the discussion. OCC consultants asked the patient to describe the reasons why he wanted palliative sedation. His primary reported reason is the intractable pain. He stated, “While I lie here without moving, I can bear it, the moment I move ever so slightly, I feel the pain, even after having the cordotomy and with the epidural.” [redacted] stated that he has said goodbye to his son, who had visited this weekend. We asked if he considered himself a burden to his family, and he replied, “No”. [redacted] emphasized that [redacted] was absolutely not a burden, and agreed with OCC that this should not be a factor in [redacted] decision for palliative sedation. The patient recounted the highlights of his illness trajectory, dating back to November 2010. He stated, in between congested coughing, “I tried so many things for this, I really tried. I just can’t do any more.” The patient was asked if there were emotional burdens for which psychiatric-spiritual and/or trusted other counseling would help him. He replied, “No, I am good. I’m okay with that.” [redacted] stated that their brother, [redacted] wanted to come again, and the patient agreed. Other than the presence of these two brothers, the patient stated that he does not desire the presence of additional friends/family. He stated that he understands he will ultimately die while sedated.

Today, an interdisciplinary meeting was held on Lunder 9, with the patient’s attending physician, [redacted], Palliative Care physician [redacted], Primary Nurse [redacted] RN and many other
team members, including nurse practitioners, social work, nurses and oncology chaplain. and described the patient’s oncologic history, including diagnosis/treatment, and pain history with detail regarding the effectiveness and ineffectiveness of pain treatment strategies, which have included interventions as cordotomy. explained the decision making process leading to palliative sedation. described her relationship with , and validated his stoicism in the face of pain, but, the continuing presence of it with moving even slightly or with required care. described the OCC interview, and ethical justification for the OCC’s position to support palliative sedation for this patient, based upon Palliative Care specialists’, attending physician’s and primary nurse’s assessment of persistent suffering despite implementation of aggressive treatment options including epidural catheter delivered medications and cordotomy. All professionals had opportunity to speak about their concerns, and ask questions.

Analysis:

This patient has lived with Stage IV malignant melanoma for 2.5 years. He has taken advantage of cutting edge chemotherapy trials and radiation therapy at Memorial Sloan Kettering and MGH, and even traveled to NIH for treatment. Once a strong man over 200 lbs, proud in his role as a contractor and father, his weight and strength have dwindled over the trajectory of his illness. In the window of a two month prognosis, his disease burden is high, and metastases are accelerating. His pain has required technological intervention, including epidural and cordotomy, which, while providing some, but not near adequate relief, have also come replete with their own adverse effects, including incontinence. He remains unable to move without severe pain. Beneath his stoicism, he is weak, congested and in pain.

Palliative sedation is now an acceptable option for , who has done his best to stave off an aggressive disease which is now terminal, with multiple areas of metastases causing pain. He is well informed about this decision, and thus, we believe this is an autonomous decision for him which can be honored, as it is both ethically and legally permissible, and is the only remaining therapy to protect him from the continued harms of pain and symptoms that are unrelieved by advanced combinations of medications and technologies.

Recommendations:

- Review the procedure for palliative sedation with the patient and his family caregivers. Key professionals to provide support to patient and his brothers, and continue to encourage dialogue amongst them.
- Consider the patient’s son; while there are no plans for his return, assure follow up with appropriate professionals.
- Continue to review the case assessment, justification, and procedure for palliative sedation with professional caregivers with ample time for discussion, as the decision for ‘palliative sedation’ is a
weighty decision, and not a commonly utilized protocol. To this end, professionals who are caring for the patient, as well as those on the periphery may need education and support.

- Palliative care professionals to work with oncology interdisciplinary team to assure seamless care of [redacted] at this time, as he approaches the end of his life after a prolonged illness trajectory.

Respectfully submitted,

[redacted] MD

[redacted] RN PhD
Nursing Progress Note

Date: 8/7/2012  Time: 6:16:11 PM  Service: NP

Code Status: DNR/DNI

IV access: DL PICC left arm (dressing changed 8/6)

Precautions: fall

Allergies: none known

Reason for Admission: 51 year old man with hx of mutant metastatic melanoma (dx/d 11/10), mets to groin, liver, lungs, lymph nodes, hip, spine, admitted 7/5 to Neurosurg for T11-L1 fusion and decompression, continued inpatient d/t pain, transferred from EL 16 for continued pain control.

Pertinent PMH: HTN, s/p multiple systemic therapies, s/p bilateral hip replacement 2007, s/p neck tumor debulking 6/12, s/p sacral tumor debulking 7/12, s/p XRT (completed 7/26)

Problems:

Knowledge Deficit: pt A + O X 3, though sometimes needs information repeated. Plan of care for today and for tomorrow reviewed with pt, who states understanding and agreement. Plans also reviewed with his supportive brother Erik, the ICU attending MD at Tufts, who is very involved in pt's care. Continue to assess learning needs, educate as appropriate.

Pain: pt with 4-5/10 pain in left shoulder, left hip, back, ribs, groin. Pain is reduced when lying flat but never completely relieved. Right hip/flank pain is diminished since cordotomy 8/3, but pain in general has increased. On continuous epidural infusion of Bupivacaine 0.25 % + hydromorphone 200mcg/ml + clonidine 2mcg/ml, running at 6ml/hr. See epidural policy in front of pt's green book. Epidural medication in Omnicell as "special epidural" under stocked meds. Please call Pharmacy to restock when cassette is removed. Casette changed at 1815. Also continues on High Concentration dilaudid PCA 10mg/mL set at 3mg demand dose / 10 minute lockout / 0mg basal rate, 63mg used 8/6 1720 to 8/7 1815. Continues on IV decadron and neurontin. Plan is for initiation of palliative sedation with pentobarbital 8/8 AM. Will be initiated by Vicki Jackson MD, med orders already written. Dilaudid PCA to be changed to gtt at 3mg/hr in AM. Neurontin doses to be tapered tonight and 8/8 AM. Neurosurgery, Palliative Care, and Pain Service following. Plan: Continue to assess pt's pain level with a goal of 4/10 or less, intervene appropriately.

Alteration in Respiratory: saline nebs available for junky nonproductive cough, pt reports feeling better for several hours after treatment. Continue to assess for uncomfortable symptoms and treat accordingly.

Alteration in FEN: pt taking pills with Ensure, looking forward to only 2 pills tonight. Sipping water throughout day. He is unable to sit up enough to eat and says he is not interested in eating. NS at KVO with PCA. Foley draining clear amber urine. Bowel meds given this AM, now doec'd. BM X 1 this afternoon, consistency of peanut butter. Pt w/o feeling in perineal area, so frequent monitoring for stool. Continue to offer water tonight, monitor for stool.

Alteration in Mobility: pt unable to get OOB, to sit at greater than about 45 degrees, or to reposition independently d/t pain and epidural effects. He prefers to lie on his back with only minimal repositioning. General Care order that turning be done only if pt requests it. He can move upper extremities, though left arm is increasingly weak. Has some movement and sensation in left leg and minimal movement or sensation in right. Bed in low locked position, call bell in reach and pt using appropriate, frequent visual checks. Continue to assess safety, assist as needed.

Name: [Redacted]

UNACCEPTABLE ABBREVIATIONS: Applies to all handwritten and electronic 'free text' entries

| QD | QOD | MS | MSO2 | MgSO3 | hs | ss | mg | IU | IU | os | qn | bt |
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| .5 (i.e., use 0.5mg) | 1.0 (i.e., use 1mg) | Apothecary Symbols (e.g., amp, grain)
Nursing Progress Note

Enter name and unit number on both sides of EVERY sheet. Addressograph plate to be used when available. Name and unit number to be written distinctly when plate is not available.

Signature should be legible and include name, licensure & pager #

Date: 8/7/2012   Time: 6:16:11 PM

Alteration in Skin Integrity: back and buttocks visualized when pt was turned after BM. General care order in CAS that pt is to be repositioned/turned only at his request. He has skin breakdown (tears and nonblanching purple areas) at sacrum. Area cleansed and Mepilex sacral dressing changed this afternoon because it was soiled with stool. Healed surgical incision along thoracic spine, open to air. New surgical incision at T2 covered with CDI dressing. Epidural catheter in place, covered with tegaderm, no redness, swelling, tenderness. Pt shifting pressure slightly while awake with changes in bed angle, refusing repositioning with pillows. Could not tolerate Wound 300 mattress or Gaymar cushion under buttocks while in bed. Tumor is visible in form of blistered-looking skin on right groin and right and left lateral thigh. Palpable mets in right chest wall. No drainage noted from any of these areas. LE edema, R> L, scrotum also very edematous. Left arm PICC site appears benign. Continue to monitor skin if pt tolerates.

Coping: palliative sedation with pentobarbital to be initiated by Vicki Jackson MD 8/8 AM. See notes in chart re care team meeting this AM to talk about process. Pt’s brother Erling arrived this afternoon, will spend the night with pt. He and brother Erik plan to be present for initiation of sedation. Brothers both very supportive of plan. Pt has 12 year old son (Gunnar) who visited last weekend; per pt, he is aware that his father is dying. Zydus administered as scheduled SL q8hrs, also available PRN. Palliative Care and SW following. Support and presence offered, pt states gratitude. Continue to assess coping skills, offer support.

Name:

UNACCEPTABLE ABBREVIATIONS: Applies to all handwritten and electronic ‘free text’ entries

| QD | QOD | MS | MSO4 | MgSO4 | hs | ss | µg | U | IU | os | qn | bt |
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| .5 (i.e., use 0.5mg) | 1.0 (i.e., use 1mg) | Apothecary Symbols (e.g., amp, grain) |
7/5/2012 11:27:42AM

7/5 Chart reviewed & I met pt briefly. He tells me he lives alone, does not know why he’s at MGH. He has h/o dementia & prostate cancer. I spoke w/team 4 Dr Marine Lipartia. Also met w/Liz Parker Soc Service & Barb Maxey from Prime Care. Concerns were raised on pt’s last admission if he was safe to be home alone, but 24/7 caregivers were initiated. However on 7/5 an incident occurred at the bank, pt’s HCP Joel Davidson was called & went to bank. HCP/Joel fired the caregiver, took pt home & left pt home alone. The VNA arrived a short time later & found pt home alone, & VNA called 911, pt was brought to MGH. The Social Worker in ED filed an Elder at Risk report.

MGH Soc Worker Liz Parker has met pt, & she will call HCP/Joel & also consult w/other Team members. No discharge plans yet. Per Liz, pt might need Psych eval to determine capacity. Liz will speak Team & Dr Lipartia, I have not called HCP yet, will wait until Soc service speaks w/HCP & then process. CM will cont to follow.
NURSING PROGRESS NOTE

Date: 7/05/12  Time: 1600

Mental Status: A&O x3; talking about how he is enjoying his hospital stay etc but wants to go home; occasionally with confused speech; pt with known worsening dementia and word find issues; pleasant and cooperative with care; Plan: continue to monitor and assess mental status and report any changes.

Coping: Pt admitted due to safety concerns at home; followed by social worker; social worker and MD in to speak with pt today; pt in pleasant mood; pt states "I am doing fine I am just waiting for them to let me leave today and go home"; calm and cooperative stating "I will stay here until the doctor says it is ok to go"; Plan: continue to monitor and assess coping; follow-up with social worker and MD about discharge planning and placement.

Mobility: OOB ambulating room independently; slow steady gait without assistance; frequent visual checks made; Plan: continue to assist with activity as tolerated; continue frequent checks.

Perfusion: Recently diagnosed with DVT of LLE; mild edema to LLE; palpable DP/PT pulses bilaterally; continues on PO Coumadin; INR 1.8 this AM; followed by AMS as outpatient; Plan: continue to monitor and assess distal perfusion; to receive 10mg PO Coumadin tonight; follow-up with AM INR.
Massachusetts General Hospital

Nursing Progress Note

Enter name and unit number on both sides of EVERY sheet. Addressograph plate to be used when available. Name and unit number to be written distinctly when plate is not available.

All entries in the patient record, written or electronic, will be authenticated by the author. Authentication will include the author's signature and credentials along with either a legible pager number or printed first and last name to assist in uniquely identifying the author.

Unacceptable Abbreviations: Applies to all handwritten and electronic 'free text' entries

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Apothecary Symbols (e.g., amp, grain)

0.5 (i.e., use 0.5mg) 1.0 (i.e., use 1mg)

Nursing Progress Note

Date: 07.10.12  Time: 0700

Risk for altered mental status: A+ Ox2-3 this shift. Very pleasant and cooperative in care. Pt keeps journal of date and time with events. Oriented to place and person however not oriented to time. RN re-oriented pt frequently as needed and ensured pt safety. SW is following. Pt resting comfortably throughout shift. Continue to monitor mental status and re-orient pt frequently. Maintain pt safety.

Discharge: Dic is pending care team meeting with HCP today. HCP? s need for 24/7 care. PAU with team regarding plan.
Nursing Progress Note

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**NURSING PROGRESS NOTE**

**Date:** 7/10/12  
**Time:** 1200 (12:00 pm)

**Mental Status:** Very pleasant and cooperative with care. A&Ox2. Oriented to self and place; disoriented to time/date. Does have difficulty with memory; repeating self often. Will often get fixated on certain subjects; i.e., his weight. He weighed himself 4 times today and recorded it in his journal. Easily re oriented. SW following; please read note in chart.

**Plan:** Continue to assess mental status; follow up with SW; family meeting today 4/10 SW; CM; HCP.

**Elimination:** Voiding small frequent amounts of urine q.s. Encouraged pt to use urinal; however forgetful at times. Flomax 10 mg qd. UA negative. Afebrile. Abdomen SNTND; continues on colace BID & Lactulose q.d. 4 BM this am.

**Plan:** Continue to monitor elimination status; I&Ds; alert team of any changes;

**Mobility:** OOB independently with guard assist walking laps in hallway. Slow steady gait. Plan: Continue to assist with mobility.

**Discharge:** SW/CM following. Family meeting held today with CM/SW/HCP to discuss plan of care. Pt will need to go home with 24/7 care by tomorrow; CM/SW looking into agencies with geriatric care available. Plan: Continue with discharge planning; follow up with CM/SW.

**Other:** Bone scan completed today to assess for metastasis. Plan: Follow up with results.

Revised: 7/18/07