Mount Sinai

west health

A Practical Guide to Implementing a Home-Based Palliative Care Program

Foreword

The number of Americans aged 65 and older is growing rapidly. In fact, in just 10 years there will be more Americans over the age of 65 than under age 18 for the first time in our country's history. Additionally, adults who reach 65 are living longer than ever at an average of over 20 additional years. Unfortunately, most seniors will develop one or more serious chronic illness and/or experience functional or cognitive impairments as they age. Finding ways to provide care for seniors that address their serious and chronic illnesses while emphasizing quality of life is vital. We believe that palliative care can and should play a huge role in meeting these goals. Palliative care is already a lifesaver for seniors with serious illness because it reduces seniors' pain and suffering while supporting shared medical decision-making and emphasizing quality of life.

Regrettably, the US healthcare system is not set up to embrace palliative care principles when caring for seniors in a way that meets their needs and desires, particularly the desire to age in place. Instead, the system relies almost exclusively on addressing individual acute exacerbations of conditions as they occur and less on taking a holistic and pre-emptive approach to care that incorporates seniors' wishes. For example, currently most seniors see multiple physicians and specialists for management of their chronic medical conditions and are sent to hospitals and long-term care facilities for exacerbations of their acute diseases—leading to confusion and fragmented care. We believe seniors with serious illness deserve better care that is delivered when and where they need it. Home-based palliative care can be the solution.

Home-based palliative care is an innovative care model that can meet the needs of seniors while allowing them to remain at home. This model utilizes an interdisciplinary team to deliver high quality care focused on alleviating pain and other symptoms of serious illness, coordinating patient and family care, and ensuring that treatments are aligned with seniors' goals. To date, home- and community-based palliative care has not been widely available to patients who desperately need it. This is, perhaps, not surprising given that home-based medical care can be operationally challenging, logistically complex and expensive to administer under traditional fee-for-service Medicare. For home-based programs to expand, they must be able to provide high-value care in a cost-effective manner to the most appropriate patient population. This is not a simple task. That's why West Health Institute and Icahn School of Medicine at Mount Sinai partnered to develop and evaluate a cost-effective home-based palliative care program to serve seniors that proactively identifies patients and determines their care goals and needs, ensures that their needs are met and high quality care is received, and maximizes time spent at home (instead of in healthcare institutions).

In this guide, we describe this innovative model that utilizes a care delivery team of specially trained community health workers, social workers, nurses, nurse practitioners and doctors who work as an interdisciplinary team to deliver quality palliative care in seniors' homes. We cover a range of topics in this guide to help you start your own program and evaluate its impact, including: conducting a needs assessment; identifying your business case; hiring and training clinical staff; identifying appropriate patients; implementing clinical workflows; and evaluating success.

As the US population continues to age, home-based palliative care will become increasingly important to ensure community-dwelling seniors with serious illness are able to receive high-quality care that addresses their medical and psychosocial needs – all while maximizing doctor-patient continuity and supporting shared decision making. We are extremely proud to share this guide and excited to partner with you as we take these vital next steps to advance healthcare and successful aging.

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Just the Facts

Fact #1:

More than

20%

of the US population is projected to be aged 65 or older by 2030.

• Ortman, J. M., Velkoff, V. A., & Hogan, H. (2014). An aging nation: the older population in the United States (pp. 25-1140).
• https://www.census.gov/library/stories/2018/03/graying-america.html

Fact #2:

Americans with five or more chronic conditions make up

12% but account for

of the population

41%

of total health care spending

• Buttorff C., Ruder T, and Bauman M, Multiple Chronic Conditions in the United States. Santa Monica, CA: RAND Corporation, 2017. https://www.rand.org/pubs/tools/TL221.html.

Fact #3:

Cancer patients who received early community-based palliative care reported higher quality of life and less depressive symptoms.

• Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, Dahlin CM, Blinderman CD, Jacobsen J, Pirl WF, Billings JA, Lynch TJ. Early palliative care for patients with metastatic non-small-cell lung cancer. N Engl J Med. 2010 Aug 19;363(8):733-42.
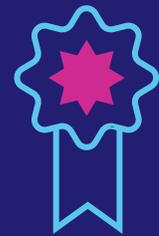
Fact #4:

HOME-BASED PALLIATIVE CARE

can reduce healthcare costs by

45%

• Brumley, R., Enguidanos, S. M., & Cherin, D. (2003). Effectiveness of a home-based palliative care program for end-of-life. Journal of Palliative Medicine, 6(5), 715-724.

Fact #5:

90%

of patients who receive home-based palliative care are highly satisfied with the care they receive

• Brumley, R., Enguidanos, S., Jamison, P., Seitz, R., Morgenstern, N., Saito, S., & Gonzalez, J. (2007). Increased satisfaction with care and lower costs: Results of a randomized trial of in-home palliative care. J Am Geriatr Soc, 55(7), 993–1000. doi:10.1111/j.1532-5415.2007.01234.x

Fact #6:

Home-based palliative care reduced hospital admissions by

34%

which saved an Accountable Care Organization **$12,000** per patient in the last 3 months of life.

• Lustbader D, Mudra M, Romano C, Lukoski E, Chang A, Mittelberger J, Scherr T, Cooper D. The Impact of a Home-based Palliative Care Program in an Accountable Care Organization. J Palliat Med, 2016; 20(1):23-28.

Introduction

This guide describes the implementation of a home-based palliative care program within an academic medical center using insights from an ongoing collaboration between the Gary and Mary West Health Institute and the Icahn School of Medicine at Mount Sinai. The scope of this collaboration included developing Mount Sinai's Palliative Care at Home program and its subsequent evaluation via a randomized control clinical trial. Because the evaluation is currently ongoing, this guide focuses on the steps needed to develop a home-based palliative care program.

What is Palliative Care, and why should it expand in the Home and Community?

Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve the quality of life for both the patient and the family (definition taken from https://www.capc.org/about/palliative-care/). Palliative care is delivered by a multidisciplinary team aimed at improving quality of life and can be delivered either in the hospital or in the home and community (1-3). Over the past decade, palliative care has expanded rapidly in the hospital setting. For example, in 2015, 90% of hospitals with >300 beds reported the presence of a palliative care team (4). This number represents a 150% growth in just 10 years (5; see reportcard.capc.org). Unfortunately, palliative care has not expanded as quickly in the home or community settings. As a result, when seriously ill patients are not in the hospital, they spend most of their time at home being cared for by their families without the assistance of formal health care providers.

The lack of palliative care in the home and community is in stark contrast to its positive impact. For example, a Kaiser Permanente study found that patients who received home-based palliative care showed improved symptoms, decision making and communication, understanding and coping with illness, and a 70% reduction in hospitalizations (6,7). Similarly, Sutter Health's pilot program of "advanced illness management," which focuses on advance care planning, self-management of symptoms, medication reconciliation/management, and close physician follow-up, demonstrated a 54% reduction in hospitalizations of those who received their care (8,9). Instead, the lack of home and community-based palliative care is likely due to both limited reimbursement mechanisms (payment for time with social work or nurse) in existing fee-for-service models and the operational complexity of delivering care in the home (10).

Despite limitations in existing fee-for-service models, recent shifts in the health care landscape towards value-based care models have created opportunities for the expansion of home-based palliative care programs. As health care and health systems begin to take on more risk-bearing contracts, their incentives shift from providing a greater volume of care to providing more high-value care at the right level and in the right place. Research has shown that providing palliative care in the home or community setting prevents unnecessary emergency department visits and subsequent hospitalizations and is often preferred by patients (11). Thus, palliative care providers have an opportunity to further develop home-based palliative care programs to manage the care of high-cost, seriously ill patients within a value-based environment.

Mount Sinai Palliative Care at Home Model

Mount Sinai's Palliative Care at Home (MSPCAH) program provides in-home palliative care to patients with serious illness over a 6-month period. The program's goals are to perform home visits that **(1)** reduce patients' symptom burden; **(2)** improve patients' overall quality of life; **(3)** improve patients' engagement with advance care planning; **(3)** reduce caregiver burden; and **(4)** decrease potentially unnecessary health care utilization. MSPCAH providers work in collaboration with patients' current primary care providers to add an additional layer of support. In other words, the MSPCAH program is a co-management model (figure below).

MSPCAH's interdisciplinary care model utilizes community health workers (CHWs), registered nurses, social workers, and specialty palliative care trained providers. This staffing model was designed to be cost-effective and provide high-quality patient care that maximizes health care professionals' skills, enabling them to operate at the top of their licenses. The CHWs spend the majority of their time with the patient in their home and provide disease education, advocacy, and caregiver support. There are many benefits of incorporating CHWs within a home-based palliative care team, critical among these being their ability to bridge the divide between the health care system and the community. As members of the community and peers, CHW may be better positioned to foster trust and understanding than traditional providers, thereby increasing patients' comfort in expressing concerns and questions.
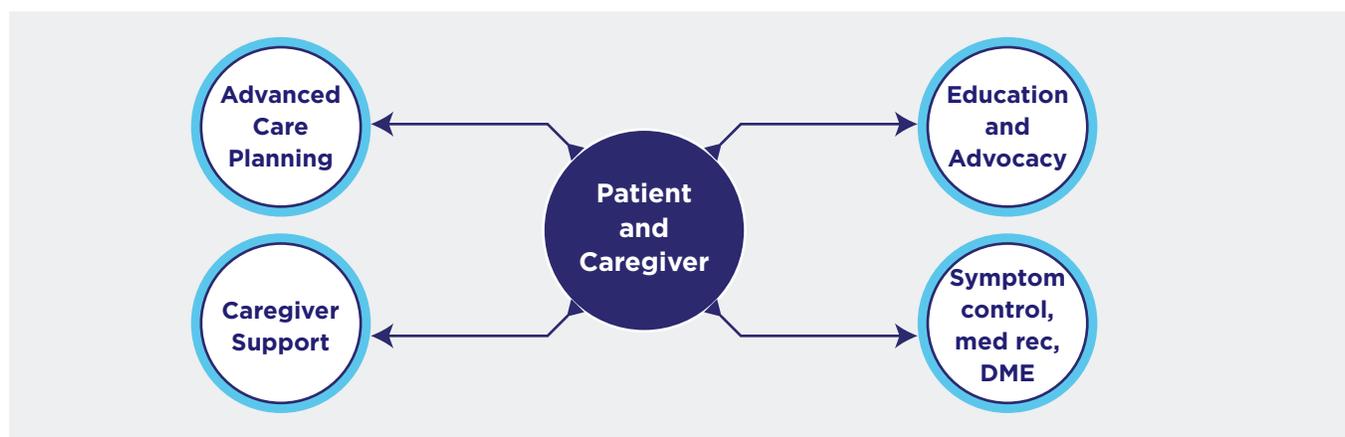
Chapter 1:
Getting Started

Embarking on the development of a new program can be exciting. Understanding where to start in the process can help you use your time efficiently and gather information necessary to design your program to meet the needs of the community. Needs assessments can provide a systematic way for you to gather information and help you make decisions. In conducting a needs assessment, you will gain insights into your motivations for developing a community palliative care program, your organization's readiness and willingness to implement community-based palliative care, and whether there is enough demand in your market for these services. Specifically, this information will help you understand and define your organizational culture, leadership engagement and support, resource availability, patient population needs, and market opportunities. In this section, we outline areas to consider as you brainstorm ideas and begin to obtain stakeholder input.

Why do you want to start a program?

Spend time defining why you want to start a community-based program and develop your value proposition. Think through program design, geographic boundaries, patient population(s), and the business case before speaking to stakeholders. Additional considerations can include defining your services, staffing model, type of palliative care model (co-management or primary provider), potential referral sources, and revenue streams.

There are several resources available to help you brainstorm and define your business case. The business model canvas is an example of a tool that can help you organize your business model and define your value proposition, customer stream, and key resources and activities. If you are a member, the Center to Advance Palliative Care (CAPC) has excellent worksheets

and advice on conducting a needs assessment. The Community Tool Box and the associated SWOT analysis, as well as the Population Needs Assessment by Dartmouth-Hitchcock, are also excellent resources for conducting needs assessments. Remember, the business plan may evolve as you begin speaking with stakeholders and identifying community resources. However, defining a framework of your program will help you to better communicate the idea to others.

Patient Population

Community-based palliative care programs address the needs of seriously ill patients, which can include patients with a wide range of diagnoses and conditions. As you begin defining your program, think about the patient population you want to serve and what outcomes you want to achieve for these patients. As a brainstorming activity, list your experience, skill sets, and observations of patient need. This activity may help you realize the gap in care for patients and the value you can bring. For instance, maybe you want to start with establishing a home-based palliative care program for congestive heart failure (CHF) patients as you have noticed that CHF patients have high readmission rates in your health care system, and these patients are missing appointments in your palliative care clinic. Or maybe you want to develop a home-based program that addresses a broader patient population because you have noticed that patients with functional limitations and high social determinants of health needs are coming into the emergency department where you work for issues that could be addressed in a community setting. Defining the patient population for your program and understanding where patients receive their care will be helpful in identifying partners and stakeholders you may want to engage. For instance, if you want to establish a co-management program for patients with congestive heart failure, you will likely want to partner with providers and specialists who have a high number of these patients and are willing to participate in a co-management role.

Engage Stakeholders

Seeking out stakeholders and obtaining their advice and perspective can be valuable in building a program that is focused on filling gaps in care. Start by identifying stakeholders in your community that can influence your program development, have knowledge or perspective in delivering community-based care, could benefit from your services, or whose advice could be helpful. These stakeholders are leaders in your organization, local health care providers (such as Accountable Care organizations, cancer centers, or primary care providers), and patients/families. Similarly, you may be able to obtain advice from national membership organizations such as CAPC or colleagues in the palliative care field.

Do your homework before interviewing stakeholders. Consider the goals of the conversation for you. Start with outlining the high-level details of your program, gaps that the program may fill, and have a clear list of questions to ask the stakeholder. These questions will be different depending on who you are speaking with. For instance, if you are speaking with a colleague who has developed a program in another area, you will likely want to know their challenges and how they overcame them. You may also be able to obtain more candid feedback on your program design. When speaking with potential health care partners such as primary care providers or senior leadership, spend time identifying how your proposed program will align with their mission(s) and how it can alleviate their pain points. For instance, could your proposed program help in addressing a high readmission rate that is a priority area for X in your health system. Or, could your program help better meet the needs of expensive and complex patients served via value-based contracts in your health system? If so, that would be important to describe to your Vice President of Population Health (or equivalent). Remember to ask questions about how stakeholders may feel about your program, where they believe synergies exist, and what outcomes would be considered a success to them. If available, use and present data to support your value proposition.

If you do not know what the priority areas are for some or all of your stakeholders, you can directly ask them. You can also review the health system's strategic planning documents or search for press releases or news articles about the health system to understand its initiatives, roadmaps, and gaps in care delivery, which can provide you insights that will help you tailor your message appropriately.

TIP:

Define the goals of your program using the **SMART goals framework.** The SMART goals framework can help you articulate your message and present your plan to stakeholders in your organization and community.

Use Data to Understand Your Local Community

Speaking with stakeholders in the community can provide key information for your program development. Similarly, collecting data on the geographic area you plan to serve can help you to understand potential referral sources and to identify potential partners and competitors. These data include types of health care providers such as hospitals, home health, assisted living, health systems, Accountable Care Organizations, and Program for the All-inclusive Care for Elders clinics. Moreover, collecting demographic information on the community such as average age, insurance composition, race, ethnicity, and religion can help to understand the community and their unique needs. For instance, if your geographic area serves a non-native English-speaking population, hiring staff who are bilingual and culturally competent will be important. Similarly, if the payer mix in your service area is dominated by one insurance company, see if you can arrange a meeting with representatives from the insurance plan to discuss partnership options. Data sources such as the US Census Bureau and your state Department of Health may be helpful in understanding the demographics of your proposed geographic area. Many states, but not all, have statewide information available for public use. California Office of Statewide Health Planning and Development and New York Statewide Planning and Research Cooperative System are two examples.

Collect data on your own health system to understand the patient population and areas where palliative care can improve the patient experience. If you have a strategic office or population health management office within your health system, they may be able to assist you with data. Similarly, public sources such as the Center for Medicare & Medicaid Services may be able to help. Ask questions such as: What is the readmission rate for your health care organization? Is it higher for certain conditions, particularly those conditions that cause CMS penalties? Is there a gap in the health system's community care model that a community-based palliative care program might fill? Identify if and how you may be able to help lower these pain points. This information from your internal health system or health system partners can be helpful when speaking with your senior leadership. Additionally, using data from your health system can also help to strategically plan for your program's growth. Use data to identify how many potential patients are in your service area and what the predicted growth of this population will be in the next five years.

Resource and Financial Planning

You have defined your value proposition and gotten support from leadership, congratulations! Now what? At this stage, it is time to start thinking through the operations, starting with the resources you need and how you will pay for them. Resources can include space, staff, medical supplies, and numerous other components to delivering care. Financial modeling is a tool that allows you and your leadership to gain objective insights and strategically plan for the future. Creating a financial model for a home- and community-based palliative care program requires understanding the details of the revenue and expenses associated with delivering palliative care in the home.

The first step is to identify the operational resources needed and determine the quantity, amount, and whether it is a start-up cost or ongoing cost for each resource. For your financial model, these resources will become the expenses of the program. Begin to list expenses in the same data frequency, such as monthly or weekly. Whichever frequency you choose, make sure it is consistent across all expenses and revenues. If you are starting a new program, you may have to work with estimates or projections. These data will likely include (but should not necessarily be limited to):

Operational Expenses:

Rented space that includes a meeting space that is private for confidential discussions of patient care and an office space with computer access

- Computers, software, and an internet connection

- Office furniture

- Home visit bags that include:

  - Blood pressure cuff

- ■ Thermometer

- ■ Bandages

- ■ Ziploc bags for bed bugs or other sanitary issues

- ■ Jumpsuit for bed bugs or other sanitary issues

- ■ Hand sanitizer

- ■ Gloves

- ■ Bag that has space for documents and tablets

- Phones, tablets, and data plans

- Color printer, scanner, and fax machine

- Membership to professional organizations or training organizations

- Marketing materials

- Travel funds (i.e., subway or bus passes, taxi fare)

- Utilities

- Medical Supplies

- Uniforms for the team

Clinical Team and Delivery Expenses:

- Staff salary, including fringe benefits

- 24-hour phone coverage

- Community paramedic deployment (if applicable)

- Billing and collection fees

- Onboarding time

- Telehealth service fees or software fees (if applicable)

Annual Costs of Fixed Expenses

	2021	2022	2023
Rent	$	$	$
Telephone	$	$	$
Printing	$	$	$
Utilities	$	$	$
Services	$	$	$
Dues	$	$	$
Training	$	$	$

Annual Costs of Variable Expenses

	2021	2022	2023
Medical Supplies	$	$	$
Billing & Collection Fees	$	$	$
Mileage	$	$	$
Office Supplies	$	$	$
Software	$	$	$
Travel	$	$	$
Telehealth Service Fees	$	$	$

Annual Salary Expenses

	2021	2022	2023
Office Mangers	$	$	$
Care Coordinators	$	$	$
Nurses	$	$	$
Physicians	$	$	$
	$	$	$

Example Financial Model Expense Categories

The next step for financial planning is to consider the revenue streams for the program. As you think through the number of patients that you will recruit into the program and a targeted census, you can identify when the program will be self-sufficient and sustainable.

- Revenue streams, including actual reimbursement from billing

- Fee-for-service home visit and telehealth billing, i.e., how often will each patient be seen by a billing provider per episode (both scheduled and urgently)

- Per member per month for Managed Care Contracts

- Chronic care management coding

- Advanced care planning codes

Visit Types:	Rate Per Patient / Per Month	Current & Projected Monthly Volume		
		2021	2022	2023
Medicare FFS Eval & Mgmt Level 2	$	50	50	50
Medicare FFS Eval & Mgmt Level 3	$	50	70	80
Medicare FFS Eval & Mgmt Level 4	$	150	175	200
Medicare FFS Advanced Care Planning	$	200	225	250
Medicare FFS Chronic Care Management	$	60	150	200
Managed Care Contract 1	$	80	100	125
Managed Care Contract 2	$	100	125	150
Managed Care Contract 3	$			

Example Financial Model Revenue Categories

TIP:

Define a baseline timeframe to assess costs such as a calendar year or span of years. For better predictive modeling, use at least one full year of actual costs, whenever possible. An excel spreadsheet can be used to develop a financial model.

Planning for the Future:

Goals, Constraints, and Levers

Once you have determined the revenues and expenses for your program, it is time to begin building the financial model. Start with setting some short-term and long-term goals for your program. For instance, you may have a goal of reaching 10% of the market in the first year of operation that might require recruiting 8 new patients per month and hiring new staff after reaching a census of 50 patients. Plan out these revenue and expense levers to help you model your growth strategy over multiple years. Financial levers are components that can be adjusted to change financial outcomes with the goal of increasing revenue and/or decreasing cost. The levers in your financial model can be manipulated to demonstrate how incremental changes will influence your program's future financial performance. Examples of levers include the number of managed care contracts you service per month, the number of billable visits completed per month, the total number of staff members, and your monthly clinical call center costs. As you consider the growth of your program, you will want to keep in mind operational constraints. For instance, increasing patient census will likely impact staff-to-patient ratios. Deciding on the staff-to-patient ratios for your program and setting goals that are realistic relative to operational constraints will produce a more robust model.

TIP:

In some cases, it might be easier to model costs at a standard growth rate. For instance, you might use a standard 3% annual increase in costs such as rent, staff salary, and utilities in your model.

Planning for the Future:

Assessing Scenarios

Once you have identified your goals and levers, you can begin to populate your model with data (either real-world data or estimates if starting a new program) to build different scenarios for growth planning. Typically, three scenarios are developed to forecast financial outcomes over a period of a few years based on projections of changing key levers such as revenue sources and costs. Define scenarios that range from "Baseline"

to "Moderate" to "Aggressive" for each of the levers and adjust lever values accordingly, making sure the scenarios are still feasible to implement and execute. "Baseline" or "Moderate" or "Aggressive" will differ for every organization based on your comfort, readiness, and what your team decides is attainable. A "Baseline" scenario is often built with little to no change in your current revenues or costs over the coming years. It serves as a baseline to predict how the current practice financials will look in the next few years. A "Moderate" scenario is a projection built with changes in revenue and cost that require additional work, such as larger increases in patient census, contracting with managed care organizations, or reducing a large cost. Finally, an "Aggressive" scenario is built with large targets for revenue and large reductions in cost that would require significant changes in program structure.

Other Gains

Other important components to consider when launching a palliative care program are costs that might not impact your bottom line but may be impactful to the health system either financially or in terms of quality metrics. For instance, could your program help to reduce length of stay or unnecessary emergency department use or help increase hospice referrals at the appropriate time? As you speak to stakeholders and leadership during your needs assessment, gain an understanding of how your program may alleviate their pain points or elevate the health system by providing excellent patient-centered care. Begin to track these metrics. Keeping track of the additional benefits of a community-based palliative care program will help to make the business case beyond strict revenue recognition.

Chapter 2:
Clinical Team Roles and Responsibilities

A key component to your staffing model is defining your team, roles and responsibilities, and identifying patient census and staff-to-patient ratios for delivering care. In this section, we describe the MSPCAH team and some components to clinical delivery. As you consider hiring members of the team, consult your health systems' human resources department for information on job descriptions, salary ranges, fringe benefits rate, and department/reporting structures.

Licensing

An important note: several states' regulations require on licensing for delivery of care in the home. Several states' regulations require a home health license to deliver medical care in the home. Check with your state laws and legal team on whether a home health license is needed for your program development. For instance, the New York Public Health article 36 Home Health Services required

a home health license for the registered nurse to provide care in the home, which the Mount Sinai Health System did not have at the time of program development. To comply with regulations, the team developed a partnership with an agency. The full details of the staffing model are described below.

MSPCAH Staffing Model

The staffing model is visually represented as a pyramid on the following page. Lower levels of the pyramid demonstrate more direct patient contact/ higher staff to patient ratio. CHWs, who form the foundation of the pyramid model, are responsible for day-to-day care coordination, symptom monitoring, disease education, communication with patients, and patient advocacy within the team and across the health care system. At a ratio of 20 patients per CHW (20:1), CHWs have the highest staff-to-patient ratio. They also have the most frequent contact with patients through telephone calls and home visits. Social workers (SW; 60:1)) and registered nurses (RN; 40:1) form the next level of the pyramid. They split their time between office support, patient care coordination and in-home psychosocial support (SW) and medical care (RN). The physician (MD) and advanced practice nurse (APN; 50:1) form the top of the pyramid and are responsible for oversight of the care plan and the team's operations, and typically spend the least amount of time in the home. Additionally, the APN is available to visit patients with complex clinical needs or urgent cases and can also provide advice on complex family meetings. The MD is available to the APN on a case-by-case basis and leads weekly interdisciplinary team (IDT) meetings ("see IDT section").

A Pyramidal Staffing Model of Specialty Trained Providers -per every

Physician

+ Access to 24/7 telephonic advice and Community Paramedicine

Advanced Practice Provider

Nurse (1 FTE) + social Worker (1 FTE)

Community Health Worker (2 FTE)

Supported by the Administrative Assistant and program Manager.
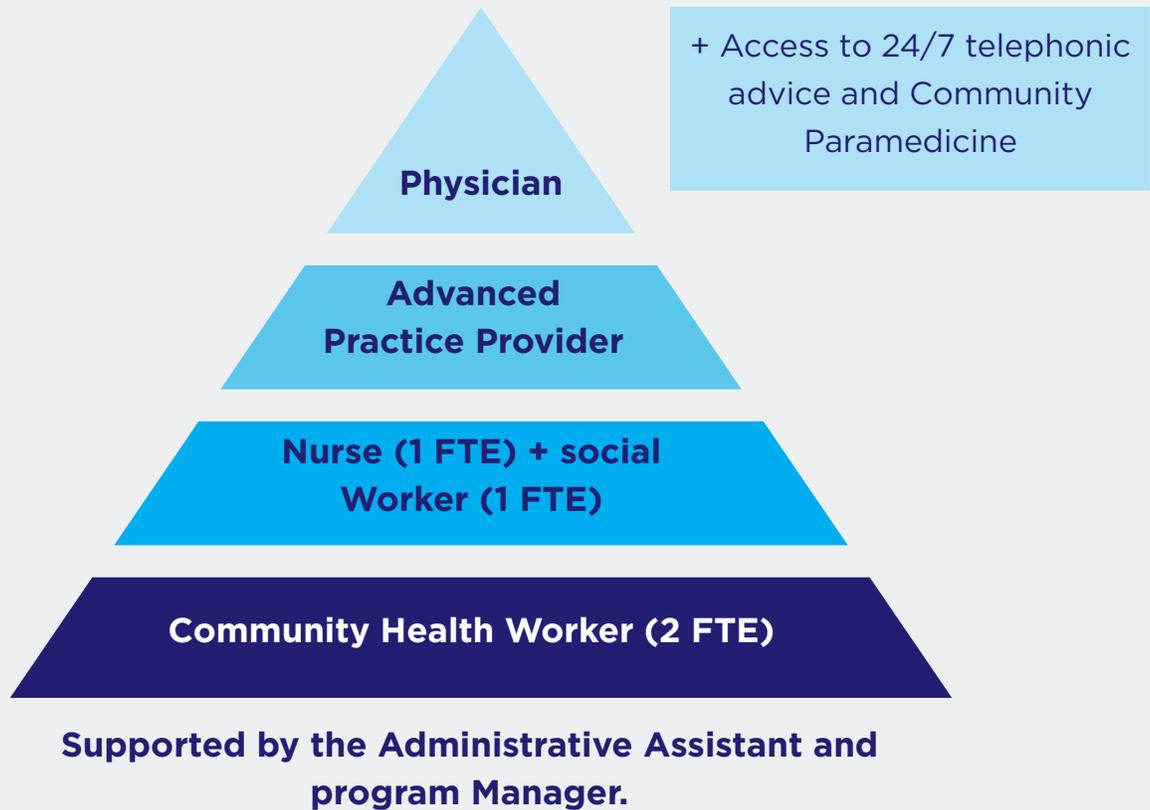
Community Health Workers (CHW)

Primary responsibilities of the CHW's role include empowering the patient to facilitate shared decision making and care planning, providing patient and caregiver education (e.g., medication management, disease trajectories), and communicating the patient's perspective and wishes to the palliative care team. The CHWs spend the most time with the patient either by visiting them in their home or via conversations over the phone. Other responsibilities of CHWs include:

1. Serve as a link between the community and health and social care services to expand patients' access to services and improve the quality of care delivered

2. Proactively identify patient and caregiver needs using validated instruments – assessing symptom management needs and home assessment needs

3. Coordinate care, including scheduling appointments and providing reminders and follow-up after appointments/hospitalizations

4. Monitor treatment adherence and confirm access to medications

5. Connect patients with community-based resources and assist with screening/enrollment procedures for such resources

6. Provide psychosocial support, which may include supportive counseling and motivational interviewing

7. Promote personal empowerment and patient/caregiver participation in health care, including navigation of the health care system

8. Promote literacy and techniques for management around health and social care problems

9. Advocate for patients and caregivers (e.g., at appointments, during hospitalization)

There is large variability in the educational training, job requirements, and certification for the role of CHWs across states. In general, individuals with a high school diploma, experience in motivational interviewing or health coaching and experience as home health aides are a good fit for the CHWs role in this palliative care model. Depending on your patient population, hiring CHWs who are bilingual might be necessary (see "Direct Hire or Work with Vendor" for more on staffing).

TIP:

Several organizations such as the *National Association of Community Health Workers*, the *Association of State and Territorial Health Officials*, the *Centers for Disease Control and Prevention* and the *National Academy for State Health Policy* provide information and resources on training, certification, and basics for states that have laws governing CHWs. Similarly, several states have local organizations and professional societies for CHWs that could be helpful when assessing and establishing the responsibilities for the role.

Social Worker

The Social Worker (SW) is a key member of the team whose role is to address patients' psychosocial needs, facilitate advance care planning conversations with patients and families, and serve as a connection to relevant community resources. The SW is responsible for conducting patient home assessments and training and overseeing CHWs. Additionally, the SW assists with Medicaid applications, if applicable. The Mount Sinai program selected a SW with experience in home care delivery, palliative care, and a Master of Social Work degree.

Nurses

A licensed, registered nurse with experience in palliative care, geriatrics, and/or hospice care is an ideal candidate for this role. The nurse will assess and render care to patients in their home environment and develop care plans with the interdisciplinary care team. Specific job responsibilities include:

1. Assistance in the development, implementation, and evaluation of standards of care and professional practice in collaboration with members of the health care team and in accordance with institutional policies and regulatory agency requirements.

2. Assessment and evaluation of patient needs for, and responses to, care rendered and application of sound nursing judgment in patient care management decisions. This includes assuming responsibility for undertaking a structured intake assessment and ongoing in-person and telephonic assessments according to the care plan and guided by patients' needs.

3. Provision of direct, continuous care for a specific caseload of patients through the application of evidence-based nursing processes.

4. Coordination of patient care activities based on established priorities, including teaching, counseling, and communication with others involved in the patient's care, and directs/delegates appropriately to members of the health care team.

5. Effective and professional communication with patients, caregivers, and members of the health care team about the patient's plan of care, including presenting cases at the weekly interdisciplinary team meeting.

Advanced Practice Nurse

The Advanced Practice Nurse (APN) is responsible for day-to-day clinical care delivery and operations. The APN works autonomously, has clinical oversight of the patients in the program, and provides clinical care for complex cases. The APN role coordinates clinical care with the primary care physician and/or specialists: (i) when patients are enrolled in the program, (ii) when changes to treatment plans are recommended by the palliative care team, (iii) when/if patients are admitted to the hospital, and (iv) at discharge from the program. The APN takes a lead role in triaging clinical cases, such as assessing patients with acute symptom exacerbations, following up on calls from overnight or off-hours and liaising with emergency department or hospital providers in the event that a patient is admitted to the hospital. Identifying a candidate who has experience working with palliative care and/or geriatrics patients and feels comfortable making autonomous clinical care decisions is key.

Tip:

Workforce shortages, high demand for talent, and the relatively recent expansion of palliative care in the community have made it difficult to find experienced professionals. Due to the limited palliative care workforce, this position may be the most difficult job position for the team to fill. As you consider hiring and employing an APN within your practice, you may want to allocate more time to find the right person and list this position first. Consider developing a mentoring program that provides training and active oversight to the APN during their first months on the job if you cannot find someone with the exact experience you need.

Physician

The ideal physician for a home-based palliative care program is one who is board-certified in palliative care and comfortable with, and skilled at, providing program oversight and clinical guidance on complex cases. The physician must be available for face-to-face, phone, or video check-ins when needed. Depending upon the number of patients served, the program may only require a physician who can fill this role on a part-time basis. For the MSPCAH program, the physician is available at 10% effort. This level of effort was chosen because it allows the program to provide appropriate patient care while utilizing people at the top of their license and skill level and remains conscious of cost. The program physician should meet with the clinical team on a weekly basis. The team at Mount Sinai recruited a physician from within their primary care program.

Administrative Support

Coordinating in-home visits, orders for durable medical equipment and referrals can be a full-time task, and, as such, hiring strong administrative scheduling support is an important part of program success. If possible, consider hiring someone with previous administrative experience in your health system since this person will already understand how to navigate the nuances of your system and may have experience with software systems in your organization.

Operations Manager

The operations manager is responsible for administrative tasks and continuous check-ins, plural with the team to identify barriers and work to alleviate these barriers. This individual will identify space, order supplies, assist with scheduling, and identify solutions to enable the clinical staff to work at the top of their license.

Pharmacist

The inclusion of a (consultant) pharmacist on your team can promote patient medication management and increase staff knowledge of medication, as shown in a recent study (12). In this study, a pharmacist provided educational material to palliative care staff, performed medication management in the home, provided education to patients and caregivers on how to administer medication, assisted in the creation of symptoms management protocols for staff and liaison with health care professionals to ensure continuity of care (12). Starting with one of these core principles with a consultant pharmacist or obtaining educational literature that might be available could improve patient and family understanding of their medication.

Tip:

The *American Society of Health-System Pharmacists (ASHP)* has guidelines for a pharmacist's role in palliative care. The *Society of Pain and Palliative Care Pharmacists* is working with palliative care organizations to advance pharmacists on palliative care teams. *CAPC* also has articles providing tips for involving a pharmacist on the IDT.

The MSPCAH team engaged a pharmacist to develop guidelines for clinical staff around medications. The pharmacist also provided education material to CHWs to enhance their understanding of common medications associated with palliative medicine (i.e., pain management) and how to educate patients and caregivers about their medications.

Around the Clock Access

Optimally, a 24 hour/ 7 day a week phone line will be available for patients of any home- and community-based palliative care program. As a new program, MSPCAH physicians staffed their phone line to understand the types of medical conditions and medical situations received via the call line. This helped them to define appropriate policies and procedures for call response. After an extended period, the call line was staffed with physicians within their Fellowship program.

Within the Mount Sinai hospital system, community paramedicine resources are available around the clock. The MSPCAH team utilizes community paramedicine for after-hours and weekend assistance with patients who need medical attention. The community paramedics have the option to deliver medications, perform limited therapies, or transport the patient to the emergency room if necessary.

TIP:

A 24 hour / 7 day a week phone call line is a best practice and quickly becoming a standard of care for palliative care programs. Partnering with a service for coverage after hours could be an option to address patient needs and avoid emergency department visits during off-hours.

Direct Hire or Work with Vendor

One decision that must be made is whether to directly hire staff for your program or hire for roles through an agency or vendor. The MSPCAH team chose to work with a vendor to hire for the roles of CHW and registered nurse. The

MSPCAH team learned that their health system did not have a department to hire, train, and supervise CHWs. As such, the MSPCAH team decided partnering with a vendor would be the best option for the program. For the registered nurse, the Mount Sinai Health System did not have the proper license needed to allow for providing nursing care in the home (home health license), hence the need again to partner with a vendor.

As a first step to identifying vendors when hiring CHWs, its best to research potential vendors through internet searches and have discussions with any departments in your health system that may utilize CHWs. The MSPCAH team performed interviews with a local CHWs professional organization to understand the CHW scope of practice, desired attributes, and knowledge and competencies. If a similar organization exists in your area, a conversation with this type of organization can be beneficial to your understanding of the CHW role. After you have completed formative research on CHW job skills, speak with local agencies and ask specific questions about their vendor operations.

Some example questions and discussion starters for these types of interviews include:

- Please tell me about your program

- What populations have you worked with?

- How do you measure success?

- Are you familiar with palliative care?

- Have you worked with the serious illness population?

- What type of training do you provide CHWs? Is it ongoing?

- How do you work with partners?

- Are we able to interview and choose candidates?

- What happens if there is an issue with a candidate?

- Do you maintain the supervisor role for CHWs you refer?

- What areas in town do you serve?

- Do you have employees who are bilingual?

RFP

After speaking with vendors, there are several ways you can engage vendors. One option is developing a Request for Proposal (RFP), which can be sent to your preferred list of vendors. This option was used by the MSPCAH team. After carefully reviewing the responses to the RFP, a vendor was chosen. The team contracted with this vendor but retained control over candidate selection and hiring.

TIP:

Contracting with outside entities can require a significant amount of resources (legal, finance, and business teams, plural) and can be a time-consuming process. In addition, supervisory control of the employees is not within your control when contracting with a vendor. If you do choose to contract with an outside vendor for services, ask to interview candidates as part of the contract and spend time identifying the right candidate for your team.

Education and Training Program

Once you have hired staff, you will want to develop a strong training and educational program. Training and continual education for staff in palliative care concepts can be accomplished in a variety of ways such as online coursework or learning modules, role-playing of simulated patient cases, and case reviews or guest lectures within your program. The combination of didactic and real-world shadowing can be beneficial, if possible, for training new staff in home-based care and palliative care. This section describes the different training and educational opportunities that the MSPCAH team used.

Classroom Training

Developing and teaching a classroom curriculum for staff who have little experience in palliative care and the IDT approach can be helpful to the new learner.

Training could include the following components:

- Definition of palliative care (including the distinction between hospice and palliative care)

- History of palliative care and why it is important (may add patient story)

- Advance care planning and communication skills

- Description of your program and vision for the program

- Description of each staff member's role within the home-based palliative care IDT;

Classroom training may be the first step in the orientation of new staff to your program. It provides an opportunity for staff to meet their coworkers, ask questions, and learn specifics about your program and institution. The MSPCAH team conducted classroom training that took about one day to complete.

Online Modules

Educational and training requirements will vary depending on the level of palliative care knowledge in your team. Several online resources are available for clinicians and staff that provide curriculum for the novice learner as well as the more experienced learner. Online modules are available at CAPC, Vital Talk, California State University Shiley Institute for Palliative Care and professional societies such as the American Association of Hospice and Palliative Medicine and Hospice and Palliative Care Nurse Association. The MSPCAH team utilized CAPC training modules to train their staff. Newly hired MSPCAH staff members came together after completing module sections to discuss the content while facilitated by staff with more palliative care experience (i.e., palliative care doctor and social worker).

Role-playing Scenarios

Role-playing clinical situations to model behavior and provide best practices in communication techniques can be useful in teaching palliative care concepts and easing staff worries in dealing with difficult and complex situations. Role-playing sessions are typically conducted with a moderator (or teacher) and possibly another person who will act as the "patient." For example, you can model a clinical scenario with the patient having trouble adjusting to their limitations due to their disease progression and accepting their reduced level of function, resulting in refusal to accept services. In role-playing, you can encourage staff to use different communication techniques such as Ask-Tell-Ask to assist the patient in their understanding of their prognosis. When conducting a session, you may want to keep the session to a small group, perform pre-work to understand the level of knowledge of the people in the group and design session accordingly, discuss the role-playing exercise, understand the expectations of participants in the session and finally create a safe space for learning and provide goal-directed feedback. An article by Jackson and Back in the Journal of Palliative Medicine outlines a detailed approach to conducting a role-playing session and is a good resource to use. Other resources include Vital Talk and Ariadne Labs. The MSPCAH team utilized the experience of the social worker and the palliative care physician to conduct a role-playing session that assisted the CHWs in learning how to communicate with patients with serious illness and tips for talking with patients about their disease.

Shadowing

Observations from shadowing can be valuable learning experiences. As such, it might be beneficial to have team members shadow an existing home-based program such as a hospice or home health agency when starting a new program. If shadowing isn't possible, you may consider online resources such as those available through CAPC and the Home Centered Care Institute.

The MSPCAH team engaged with their health system in the following ways:

- New hires shadowed doctors and social workers from the Mount Sinai Visiting Doctors Program, which is their home-based primary care program. This included attending new patient intakes and visits with both SWs and MDs, as well as visits with existing patients, to understand the different types of visits.

- New hires shadowed two hospice nurses for a day and then shared their experiences by talking with the MSPCAH team about the emotional impacts of treating seriously ill patients.

- New hires observed the hospital Palliative Care Unit IDT. This led to them gaining an understanding of interdisciplinary communication.

Once your program is up and running, you will see periods of growth that require you to hire additional employees. When that happens, we recommend that you purposefully create opportunities for those new employees to shadow experienced employees. For instance, after the MSPCAH program was established and they began hiring new CHWs, those newly hired CHWs spent a few days in the field shadowing experienced CHWs, which helped them understand the role and the expectations.

Continuing Education

It can be beneficial to offer educational opportunities either through weekly prescheduled 2-hour sessions or half-a-day sessions per month to continue advancing staff knowledge. These educational sessions could include guest lecturers (such as experts in Alzheimer's Disease) or involve a review of case

studies that staff talk through to learn how to approach difficult cases. The MSPCAH clinical staff sought additional educational sessions to expand their learning and understanding of specific disease states. For instance, the staff wanted more information about the disease progression of Amyotrophic Lateral Sclerosis (ALS). Experts within the community and health system were identified by the team, and educational sessions were conducted. The major learning for the MSPCAH team was that establishing a team culture that promotes continuous learning and freedom to seek educational resources is beneficial to patients and raises the competency of the home-based program.

Chapter 3:
Clinical Care Delivery

In this section, we describe the MSPCAH clinical delivery model. The MSPCAH team based their processes of care on the domains described in the National Consensus Project for Quality Palliative Care, which is a trusted source for evidence-based clinical practice guidelines and is a highly recommended resource for use when designing a palliative care program. A high-level description of the program components and stages is shown below.

Intake Assessment

→

Ongoing Care

→

Discharge

Intake Assessment
- Two intake assessments are conducted in the home.
- Nurse + Community Health Worker complete medical in-home assessment
- Social Worker + Community Health Worker complete psychosocial in-home assessment

Ongoing Care
- Community Health Reasons Worker led with weekly phone calls or in-home visits
- In-home visits with Social Worker or Nurse occur according to patient's needs
- Weekly interdisciplinary review of patients to address ongoing needs

Discharge
- Death
- Hospice
- Long-term care
- Patient moves out of area
- End of program (patient transition to home-based primary care or usual providers)

Proactive Identification of Patients

First, the MSPCAH team created a patient identification algorithm to find prospective patients for the home-based palliative care program. Patients with serious illness, multimorbidity, and prior health care utilization were identified as potential candidates for the program. Serious illness was defined using Kelley et al.'s definition as a condition that carries a high risk of mortality, negatively impacts quality of life and daily function, and/or is burdensome in symptoms, treatments, or caregiver stress (14). Based on this definition, the following serious medical conditions were inputted into the algorithm.

Severe Medical Conditions Included in the Definition of "Serious Illness"

- Cancer (metastatic or hematologic)

- Renal failure, end-stage

- Dementia

- Advanced liver disease or cirrhosis

- Diabetes with severe complications (ischemic heart disease, peripheral vascular disease, renal disease)

- Amyotrophic lateral sclerosis (ALS)

- Acquired Immune Deficiency Syndrome

- Hip fracture

- Chronic obstructive pulmonary disease or interstitial lung disease (only if using home oxygen or hospitalized for the condition)

- Congestive heart failure (only if hospitalized for the condition)

Obtaining the data to construct the patient identification algorithm required understanding where the health system stores the data, how it can be obtained, and what data can be obtained. The MSPCAH team established a working relationship with the data warehouse team within the Mount Sinai Health System to facilitate the implementation of their case-finding approach. A data warehouse is a central repository for data that allows for the storage, retrieval, and analysis of data. At Mount Sinai, the MSPCAH team spent time with the data warehouse team to understand how it functions, the data that is available, what data elements are pulled from the systems, and what types of data were included. Over multiple discussions, the MSPCAH team began to understand the data warehouse workflow and how requests were fulfilled. The team had to adjust its patient identification plan based on the data elements that were available. As the team refined their approach, they built a relationship with the team and were able to create an agreed-upon schedule for regular data pulls that the data warehouse team would conduct to support patient identification. The first few data pulls resulted in several back-and-forth conversations to get the correct elements.

TIP:

If developing an algorithm is not feasible for your program, another resource is the Consensus Standards for Community-based Palliative Care created by the California Advanced Illness Collaborative. This document provides disease-specific clinical criteria that may be found in any EMR. It also includes guidelines for essential services and providers and how to measure and report outcome measures.

Once patients are identified, a chart review should be conducted. During the chart review, a physician or nurse from the palliative care outreach team looks for factors that might exclude the person from home-based care, such as enrollment in hospice, participation in a home-based primary care program, dialysis, death and/or enrollment in long-term care. From chart reviews, a list of eligible candidates for home-based palliative care is created and used to reach out to the patient's primary care providers. The outreach team contacts the patient's provider and the patient to ask about enrollment in the program. If the patient agrees to enroll in the program, several assessments are completed, a visit is scheduled, and the patient's provider is notified. A detailed flow chart of patient enrollment is provided below.

Patient Identification
IDENTIFICATION AND ENROLLEMENT FLOW

Pall Care Outreach Team receives potential List of patients → Outreach team screens charts to refine identification → Outreach team reaches out to provider for consent to introduce program to patient → Outreach coordinator introduces program to patient and caregiver in clinic, by phone, or via mail → Outreach team performs assessment of physical, psychological, and social needs at time of enrollment

Administrative assistant schedules first visit ← APN reviews charts and structured assessments to determine exact timing of first visit ← APN receives referral and decides on acuity of need ← (If patient enrolls)

APN circulates pre-visit summary to clinical team → APN introduces program to co-managing provider by email → RN/SW/CHW preview the pre-visit summary and the electronic medical record ahead of first visit → First Visit

Visit Frequency and Scheduling Tips

All scheduling is completed by the administrative assistant. The scheduled visits begin with the initial intake assessments. Patients who enroll in the program have an initial intake assessment completed with a community health worker and a nurse. Information from these initial intake assessments is used to develop a care plan that is reviewed by the APN, the patient, and the IDT. The care plan is also shared with the patient's provider. After the initial assessment is completed, the CHW visits with the patient weekly. The SW and the CHW will also conduct an initial intake assessment (see Intake Visit) to assess the environment and psychosocial needs. Additional visits are conducted dependent on the patient's needs and acuity. A patient is discharged from the community-based palliative care program after 6 months or earlier if any of the following occur: enrolled in hospice, death, move into a long-term care facility, or move outside the geographical area of the program (see Diagram below).

The MSPCAH program enrolled patients across a large geographic area of Manhattan. As such, the team needed to be creative and efficient in scheduling enrollment and clinical care visits to avoid wasted time spent in cars or public transportation traveling from one side of the city to the other. A few tips from the team include:

	Find alternative working spaces.	The operations manager was able to obtain office space in downtown Manhattan office with computer access. This downtown space allowed team members to work between appointments eliminating a 30-minute journey back to the office and thus increasing efficiency.
	Visualize scheduling.	Using a map to plot out all the visits to reduce travel time.
	Be flexible in care team assignment.	To accommodate patients' needs, e.g., need for Spanish speaking care team member.
	Continual communication with the clinical team	To refine processes and identify their barriers, facilitators and needs. For example, the team identified trouble with completing administrative tasks when in the field. As a solution, one day a week was designated as IDT meeting and administrative work.
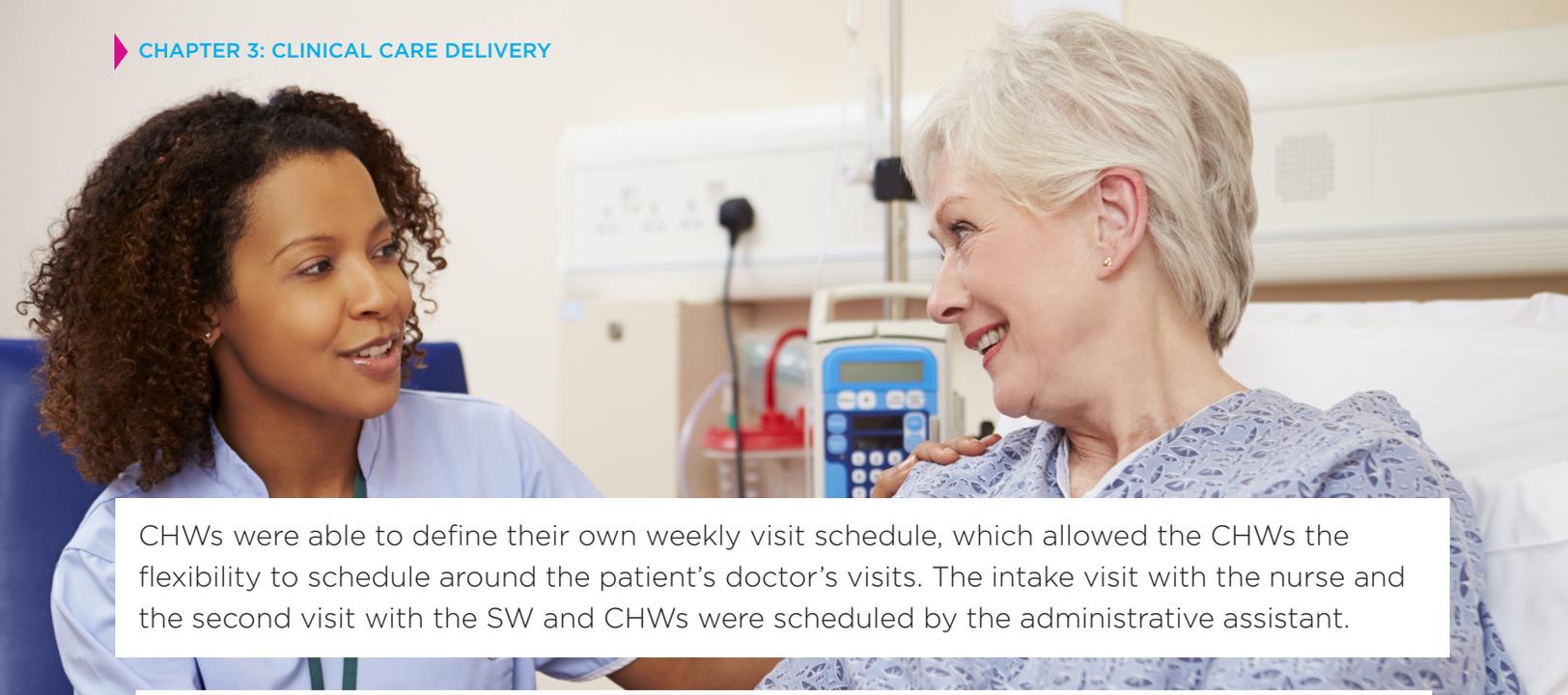
CHWs were able to define their own weekly visit schedule, which allowed the CHWs the flexibility to schedule around the patient's doctor's visits. The intake visit with the nurse and the second visit with the SW and CHWs were scheduled by the administrative assistant.

INITIAL VISIT

| RN/CHW/SW conduct initial visits at home | → | RN and CHW introduce program, use structured assessment template and address any patient and family concerns | → | APN oversees creation of an interdisciplinary care plan which is presented at the first IDT meeting | → | Care plan shared with co-managing provider |

SUBSEQUENT VISITS

| CHW makes contact once per week (telehealth or in person) to assess symptoms and other needs | → | SW and CHW conduct subsequent visits using structured assessment template | → | Visit frequency determined by patient and family acuity of need and agreed upon at weekly IDT |

Patient stay in program for 6 months unless:

| Patient discharged to hospice or end of life on program | Patient enters long-term care on permanent basis | Patient relocates outside geographic scope of the program |

Communication with Primary Care Providers (PCPs)

As a co-management model, the palliative team established communication with the primary care provider as soon as the patient was enrolled in the program. The APN contacted the patient's providers to inform them that the MSPCAH team would be going into the patient's home, and to ask how best to help the patient. As expected, communication was easiest when the patient's primary care provider was within the Mount Sinai system and shared the same EMR as the MSPCAH team. If the PCP was outside the system, the nurse practitioner had to call and fax the provider (see Appendix A for sample communication templates).

TIP:

Define your communication plan with other providers. How will you connect with primary care providers? What information will you communicate? What information will you seek? What is your plan for communication when an acute event occurs or at discharge? It is best to consider these questions prior to enrolling patients.

Typically, all communication was done through the EMR or faxes. However, at the outset of the program, the APN communicated with the PCP to inform them that, in the case of an urgent need for intervention, and in the event of non-response from the patient's primary care provider, the APN would intervene without the primary care provider's express permission. When the patient was discharged from the program, the APN sent a discharge note via the EMR or fax to let the PCP know.

Engagement of PCPs varied. Some PCPs and oncologists were quite receptive to the program and responded to all electronic communication. For the most part, the PCPs read the notes and acknowledged electronic notes. This suggests that PCPs were paying attention to what was going on with the patient.

Initial Intake Visit

During two separate in-home visits, the nurse, CHWs, and social worker completed the intake assessment and discussions (see Appendix C for Nursing Initial Assessment and Appendix D for Social Worker Initial Assessment). These conversations took place to identify the following:

- Patient's health status, physical and psychosocial symptoms

- Physical and cognitive function

- Caregiver network and community support

- Home environment and safety

- Knowledge about their disease/ health literacy

- Health Care Proxy and Medical Orders for Life-Sustaining Treatment (MOLST)

- Food insecurity

- Financial trauma

- Additional stressors

- Benefits entitlement (esp. Medicaid eligibility)

- Engagement with health care professionals

In addition to the intake assessment, the nurse completed an *Integrated Palliative Care Outcome Scale (IPOS)*. Information from this scale informed clinical decision-making. The IPOS scale was used to understand patient self-reported pain and symptom burden as well as mood, practical concerns, and overall feeling of being at peace.

TIP:

The IPOS is a free downloadable assessment that only requires registration. It is available at *www.pos-pal.org*

The MSPCAH team also collected the following assessment tools: McGill Quality of Life questionnaire (15,16), FAMCARE 10 (17), ACP Preference Consistent Care, caregiver burden (Zarit Burden Interview (18)), and caregiver mental health (PHQ-9 (19)). These measures were collected at enrollment, at 6 weeks, at 3 months, and again at 6 months to evaluate the program. Additionally, patient measures on health care utilization and hospice use were collected at 3 months and 6 months after enrollment.

GENERAL:

Patient name: ....

Patient age: ....

Patient DOB: ....

Primary language: ....

Health insurance: ....

Allergies: ....

Nature of allergic reaction: ....

Living arrangement: ....

- Lives alone
- Lives with family. If so, specify: ....
- Lives with other non-family. If so, specify: ....
- Apartment building - walkup
- Apartment building - elevator
- Private house

Healthcare Decision Making: ....

- Emergency contact / caregiver name and contact #: ....
- Health Care Proxy name: ....
- MOLST or other advance directive? ....

PCP or lead provider contact information: ....

- Date of last appointment with PCP or lead provider? ....

Pharmacy name: ....

- Address and telephone #: ....

BACKGROUND/ MEDICAL HISTORY

Primary diagnosis (with dates) - include history and current status

Other diagnoses (with dates) - include history and current status

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Based Palliative Care Program
www.mountsinai.org

Clinical Pathways

The MSPCAH team utilizes two main pathways: active and monitoring. The pathways allow the team to match their patient's clinical needs with appropriate clinical care. Ultimately, this allows the team to provide high-quality care and helps make the program operationally efficient.

The active pathway is for patients with acute symptom crises and/or ongoing clinical concerns. All new patients are put on the active pathway when they enroll in the program. The active pathway involves weekly in-home visits from CHWs, potentially more frequent visits from clinical staff depending on clinical condition, and more in-depth discussions during IDT meetings. As patients stabilize and have fewer unmet needs, they transition to the monitoring pathway. The monitoring pathway is for patients who have symptoms managed, and whose goals of care have been reached. The monitoring pathway involves weekly phone calls from CHWs and briefer discussions of patients in IDT meeting.

Patients may transfer between pathway levels if there is an acute exacerbation or if a concern is raised by the team, the patient, or a caregiver. The IPOS is a key indicator for a change in pathway status—making it patient-driven. For example, if a patient in the monitoring pathway is requesting to see the team, has pain, or generally doesn't feel well (even if they can't explain why), a nurse visit is usually scheduled to check the patient's vital signs. The nurse will identify the symptoms causing trouble for the patient and work with the APN to make treatment recommendations. If necessary, the patient's specialist will be called. The APN will call the patient for as long as the exacerbation lasts, and the CHW will reach out to the patient the next day and make a visit. In this case, the team will change the patient to the active pathway and the IPOS will be done weekly. After the patient's symptoms are better controlled, the patient will be moved back to the monitoring pathway.

Patient Story

Mr. Pink's caregiver calls the clinic complaining of shortness of breath during regular business hours. The APN talks with the patient and caregiver over the phone to understand the severity and likely cause of the symptoms and develops a care plan. Based on the assessment, the APN instructs the caregiver to increase the frequency of nebulizer use to address the patient's symptoms. The APN provides the caregiver with education on what to expect over the next 24 hours and information on what to do if symptoms do not decrease or get worse. The APN schedules an urgent visit from the RN to the patient's home that day and then contacts Mr. Pink's pulmonologist via the EMR to inform them of the deterioration. The team moves Mr. Pink from the monitoring pathway to the active pathway. The APN calls Mr. Pink and his caregiver the next morning to make sure he is improving. The RN visits Mr. Pink again on the second day. The APN continues her calls to Mr. Pink and his caregiver every morning for a week to check how the treatment plan is going. After a week, Mr. Pink is stabilized, and the team moves him back to the monitoring pathway.

The pathways can also be adjusted for social complaints or concerns. For instance, if the patient has underlying agitation and anxiety that was not initially diagnosed (or is newly present), the team, particularly the social worker and CHW, will work with the patient to define a new care plan. If the plan goes well and the patient stabilizes, then the patient is moved to the monitoring pathway. The patient will remain on the active pathway until the patient and the team feel symptoms have improved.

ACTIVE PATHWAY

Tracking: Weekly brief IPOS and 6 weekly full IPOS

Contacts: Minimum weekly in person review and extra as needed by SW/RN. *ANP review for all on active pathway for 4 weeks*

IDT: Weekly full IDT review

Scores in any domain on IPOS (set threshold) OR Concerns raised by team members/ patient/ caregiver

Goals for care reached ("function" AND scores on IPOS) AND Team/ patient/ caregiver agrees transfer to monitoring pathway

MONITORING PATHWAY

Tracking: Weekly brief IPOS (by phone by CHW); 6 weekly full IPOS

Contacts: Minimum CHW weekly telephone

IDT: Weekly brief IDT review

Visits with CHW

CHWs have the most frequent home-based contact with patients. Their role is to facilitate patients' involvement in shared decision making, advocate for patients to the wider health care team, and educate the patient and their families. CHWs conduct an in-person visit weekly when the patient has been assigned to the active pathway and conduct weekly in-person visits or phone calls when the patient is assigned to the monitoring pathway. During these visits, CHWs ask about symptoms and overall wellness (see questions below and Appendix E) and spend time talking with patients, caregivers, and their families. Our experience suggests that CHWs are more likely to gain patients' trust than clinicians are. In the MSPCAH experience, as patients come to trust CHWs, they will often open up about their situation (for example, they may share that they are not taking their medications as prescribed and the reasons why as well as the reasons why they haven't brought this up with their doctors). In these situations, CHWs will encourage patients to be more transparent with their physicians and teach patients ways to self-advocate. In special situations (for example, a visit with an oncologist following a recent staging CT scan), CHWs may accompany patients to provider visits when patients have no one who can go with them to help advocate. This is a rare occurrence and is evaluated on a case-by-case basis.

Visit Date: ....

Present During Visit: ....

INTERVAL CHANGES:

- General health status / problems in the past week:
- Is the patient able to take all their medications as prescribed? Yes / No
- What problems do they have taking their medications as prescribed?
- Hospitalization / ED / office visits since last contact?
- Upcoming doctor visits / therapies / procedures?
- Status of outstanding referrals / durable medical equipment orders?

FUNCTIONAL STATUS:

Complete Palliative Performance Scale

PHYSICAL AND PSYCHOLOGICAL SYMPTOMS

In the last week has the patient had?

- Pain ....
- Shortness of breath ....
- Weakness / lack of energy ....
- Nausea ....
- Vomiting ....
- Poor appetite ....
- Constipation ....
- Sore or dry mouth ....
- Drowsiness ....
- Poor mobility ....
- Fall: No / Yes: Last Fall: .... Injuries? ....
- Other: ....

In the last 2 weeks, has the patient felt down, depressed or hopeless? In the last 2 weeks, has the patient had little interest or pleasure in doing things?

GOALS OF CARE/ADVANCED CARE PLANNING:

Prior to Today: (auto-populated from EMR)

....

....

Goals of care discussed today? Yes / No

- "Planning My Way" reviewed*...
- HCP discussed ....
- DNR/DNI discussed ....
- MOLST discussed ....
- End of Life Wishes ....
- Other: ....

CAREGIVER SUPPORT:

- Supportive counseling ....
- Disease education ....
- Medication education ....
- Community resource referrals ....

"Planning my Way" is a specific advance care planning template that the Mount Sinai Palliative Care at Home team uses. It is used with permission of the Cunniff Dixon Foundation. This line can be adapted based on whatever guide the team is using for patient care. Other such guides include "Prepare" (www.prepareforyourcare.com) or "Five Wishes."

Patient Story

Mr. Green is an 82-year-old male with end-stage heart failure. Mr. Green has significant breathlessness, fatigue, and anxiety. He is on home inotropes, but these are no longer helping to manage his symptoms to allow for an acceptable quality of life. In addition to symptom control, MSPCAH focused on caregiver support and advance care planning. After many visits by MSPCAH's CHW and the team, Mr. Green decided to embrace comfort-focused care and enroll in hospice. Below is a CHW's testimonial on how Mr. Green's transformed during his time on the program.

"During our visits, Mr. Green was able to open up more about his life, his love for his family, and his illness. He understood that his family loved him and that they were doing everything in their collective power to make sure he "lived." He believed that they had done enough, and though he appreciated their efforts, he was tired and scared, not of the end of life, but of how his family would react to his death. Mr. Green was able to share his hopes for the future and that he was exhausted from doctors' visits and preferred to be at home. He gave me permission to speak with his wife and daughter separately, and those discussions provided the family with a chance to get on the same page. We provided the support for Mr. Green and his family in making the decision to enroll in hospice. MSPCAH allowed the family to understand that quality health care does not stop with the doctor's visit but includes the support of an invested interdisciplinary team. I am just fortunate to be a part of something that allows me to build trust between the patient, their caregivers and me."

- *Community Health Worker, Mount Sinai Palliative Care at Home*

Patient Story

Mrs. Yellow is a 52-year-old female with multiple morbidities (COPD, CHF, uncontrolled diabetes), a recent cancer diagnosis, anxiety, and depression. She had significant issues around medication concordance and engagement with services. She had no goals of care in place when she enrolled in the MSPCAH program. Below is a CHW's testimonial on how Mrs. Yellow transformed during her time on the program.

 "I met her where she was, scared, insecure, and full of so many doubts about herself. I have watched in wonder how much she has grown over the past few months and how empowered she has become. She has someone in her life who is truly in her corner: someone who listens to her side of the story. She has gone from being quiet and a bit withdrawn to being very verbal and forthcoming about what she does and does not want for her care. She has stated many times that she just never realized that she was such an integral part of her own care. She has an amazing health care team, and now she can aid them in better caring for her."

- Community Health Worker, Mount Sinai Palliative Care at Home

IDT Meetings and Weekly Schedule

The IDT team meets every week for 2-4 hours to discuss the patients in the program, review patient care plans, make changes to patient pathways, and review the new and discharged patients. The CHWs, RN, and SW each provide reports in the IDT meeting. Responsibility for reporting on each patient's care plan is divided among the team. Whoever is assigned to a particular patient will report out the full data for that patient. Decisions on treatment plans are made during this meeting with input and consensus from all team members.

Some key tips

- Establish a culture where all teams members feel their opinion is respected.

- Emphasize the collaboration of all team members and build confidence in team members.

- Listen and provide feedback, especially to new team members. If team members are new to IDT meetings, it might be difficult for them to understand the level of detail to share with the group. Providing feedback could create a helpful teaching moment.

MONTITORING NEEDS AND REVIEWING CARE PLANS

| All patients reviewed at weekly IDT meeting | > | IDT reviews symptoms and conducts psychological, social, and goals of care documentation | > | Progress against care plan goals measured every 3 months (minimum standard or at change in patient's clinical condition) |

Accessibility to Staff for Medical or Social Issues

During the week, the MSPCAH team is available during normal working hours and calls are answered and triaged by the administrative assistant. For issues that arise during off-hours, a phone line is available for patients to receive medical advice from the on-call provider. As discussed in the Staffing section, the after-hours phone line was initially staffed with attending physicians and later by palliative care fellows. When a patient calls the medical line overnight, the provider answering the phone is usually able to address the patient's concern. The on-call provider will send a message to the MSPCAH team with information that includes who called the advice line, why they called, and the course of action recommended by the provider. The APN reviews each of these cases during business hours and makes phone calls to all patients to check in with them and see how they are feeling. If their condition isn't improved, the nurse or social worker will make a visit.

TEAM AVAILABILITY TO PATIENT AND CAREGIVERS

Team available between 8:30am and 4:30pm by phone

Calls triaged by the administrative assistant and routed to the APN or SW as appropriate

Out-of-hours calls handled by on-call provider who can provide telephone advice and dispatch community paramedicine as necessary

Hospital Admission

When a patient is admitted to the hospital, the CHWs visit them in the hospital the next day if it is a weekday or on the following Monday if admitted over the weekend. The APN will identify the hospital inpatient provider and coordinate care with this provider for when the patient is discharged.

For admission to the hospital for a medical issue, the nurse will visit patients within a few days to ensure that they have everything they need in place when discharge occurs and that follow-up appointments are made. The discharge process is not simple and the MSPCAH team assists in the coordination of care after a hospital visit.

For admission to the hospital for a social issue, the social worker will visit the patient and make sure any necessary appointments are made. After discharge, if patients are stable, they go back to their usual CHW visit schedule. If patients are not stable, the APN will prescribe a certain number of nursing visits for medical issues until patients are stable (pain managed, blood pressure stable, etc.), or the social worker will visit more frequently if needed.
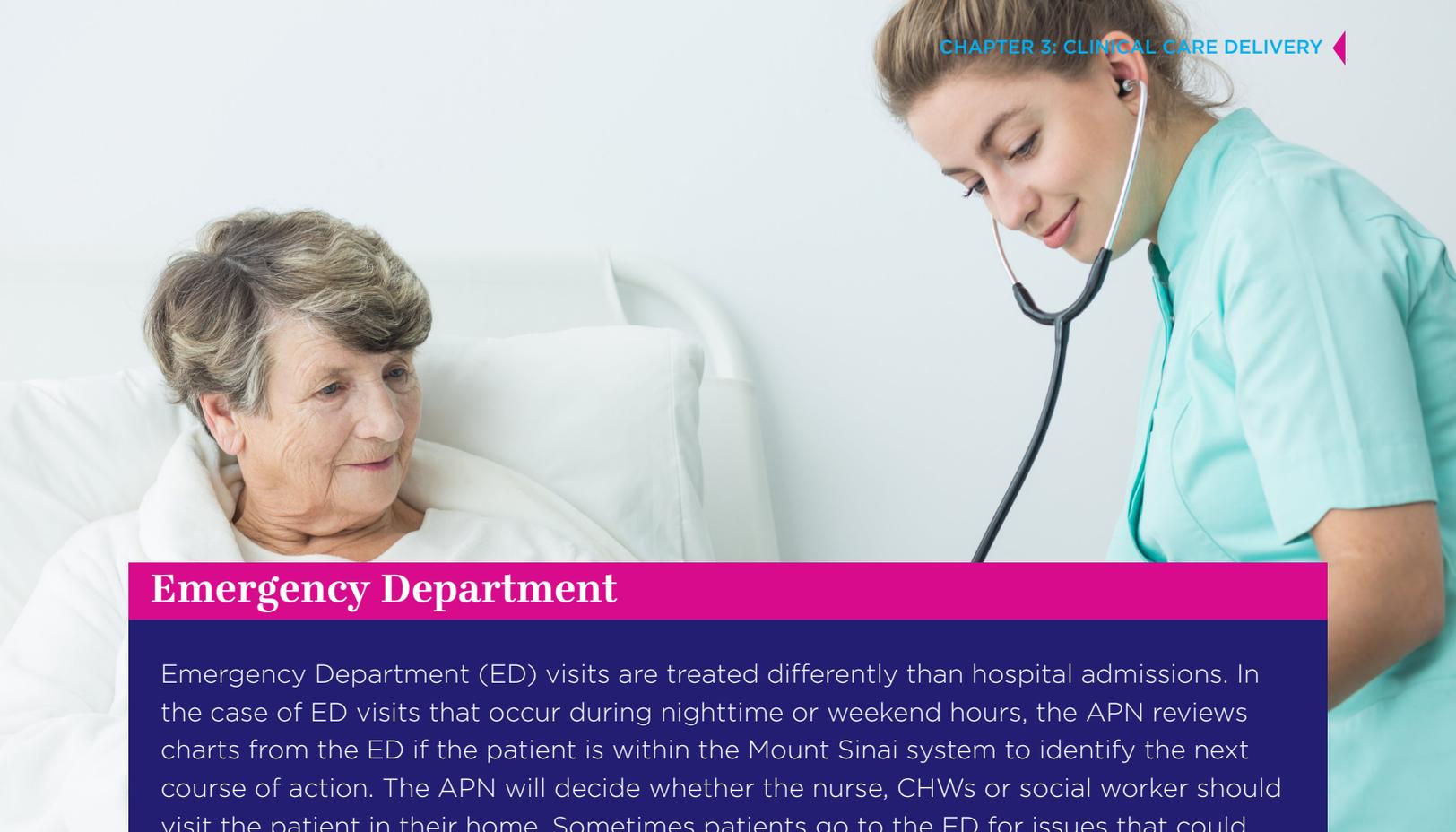
Emergency Department

Emergency Department (ED) visits are treated differently than hospital admissions. In the case of ED visits that occur during nighttime or weekend hours, the APN reviews charts from the ED if the patient is within the Mount Sinai system to identify the next course of action. The APN will decide whether the nurse, CHWs or social worker should visit the patient in their home. Sometimes patients go to the ED for issues that could be resolved in the home. If the team feels the patient needs to visit the ED, CHWs may go with the patient to ED or meet them at ED Additionally, the MSPCAH team will call the hospital to help coordinate care for their patient when they arrive at the ED.

Patient Story

Mrs. Purple and her family have received information about her congestive heart failure, including what symptoms to expect and how to manage the condition. Mrs. Purple's understanding of her illness is limited. When Mrs. Purple begins to feel bad, she goes to the ED as she has no plan for how to manage her congestive heart failure. The ED doctor educates Mrs. Purple again on how to self-manage her disease and discharges her. After a number of hospital admissions, Mrs. Purple enrolls in the MSPCAH program. The MSPCAH team works to help Mrs. Purple and her wider family better understand her condition and how to manage it. In conjunction with Mrs. Purple's primary care provider, the team also works to improve her understanding of heart failure as a life-limiting illness and assist in helping her to make decisions for her care around her values. During the weekly visits, the CHW talks with Mrs. Purple and her husband to provide emotional support.

TIP:

Receiving timely notification that one of your patients is in the hospital is easiest when your patient goes to a hospital within your system. In that case, an alert can be sent to you directly via the EMR. However, you often cannot control where your patients choose to seek care. Thus, it is important to educate your patients to notify you when they are admitted to a hospital or are visiting an ED. Continual reminders about the 24-hour phone line and clear patient education material with the phone number displayed (i.e., magnets, brochures, flyers, etc.) are essential.

Advance Care Planning and POLST

Appropriate advance care planning and advance directives form an essential part of any community-based palliative care program. As discussed in the Education and Training Program section, there are numerous resources to train your staff to conduct difficult and meaningful conversations with patients about their illness. The MSPCAH team utilized resources available through Planning My Way, a project of the Cunnoff-Dixon Foundation. Other resources such as Five wishes and Respecting Choices are available and provide tips and techniques for discussing advance care planning. The Centers for Disease Control has compiled a list of public resources for advance care planning.

For the MSPCAH team, the conversations about advance care planning, health care proxy, and Medical Orders for Life-Sustaining Treatment (MOLST) are often the most difficult to schedule as the amount of time the patient and family may need can vary. Additionally, having all of the important members of the family present during that conversation can be a challenge to coordinate. The social worker introduces the concept of a health care proxy and MOLST during the initial intake visit. These visits range from 90-120 minutes.

Chapter 4:
Evaluation

Evaluation and continuous improvement are important to the growth and sustainability of your home-based palliative care program. In implementing an evaluation plan, you will be able to identify areas of improvement and address these areas to enable high-quality care and patient and staff satisfaction. An evaluation plan is a systematic approach to collect data and assess outcomes to determine whether you are meeting your goals, providing beneficial care to patients, and creating value for all stakeholders.

Getting Started

One approach to developing an evaluation plan and identifying the correct metrics to track is with a logic model. This approach has been used by the Centers for Disease Control (CDC) and the Agency for Healthcare Research and Quality (AHRQ) to evaluate the effectiveness of their programs. The logic model provides a visual display of inputs, outcomes, and impacts (short-, mid-, and long-term) that prompt you to think critically about what you want to achieve and how you will get there. The logic model will provide a framework to think through the resources, activities, and participation you have or need to meet your goals and create an impact.

Inputs	Outputs	Outcomes	Impact		
Resources	Activities	Participation	Short Term	Mid Term	Long Term

Patient Outcome and Process Metrics

A key component of the evaluation plan is the inclusion of outcome and process measures. These measures can be administrative and/or clinical but are defined to measure the quality of care being delivered and the efficiency of delivering that care. For instance, clinical measures could include:

- Percent of patients referred to hospice

- Percent of POLST forms completed within X days of enrollment in the program

- Number of hospitalizations per month

- Number of emergency room visits per month

- Percentage of patients with controlled pain

- Percentage of patients with improved symptoms

- Number of deaths in preferred place

- Number of patients with completed screenings (i.e., depression, anxiety, pain, etc.)

- Patient or proxy survey of experience

TIP:

The National Quality Forum has endorsed several measures to assess patient quality and had convened experts to suggest measures of quality in domains lacking metrics. These recommendations could be useful, as you consider what is important to your clinical care delivery.

Operational measures of process are important metrics to implement in your program as these measures will tell you about the patient and staff experience. Operational measures could include:

- Number of on-time appointments

- Number of patients seen in X days after enrollment

- Number of completed intake forms

- Number of phone calls returned within X amount of time

- Amount of travel time between appointments

- Percent completion of paperwork within X days
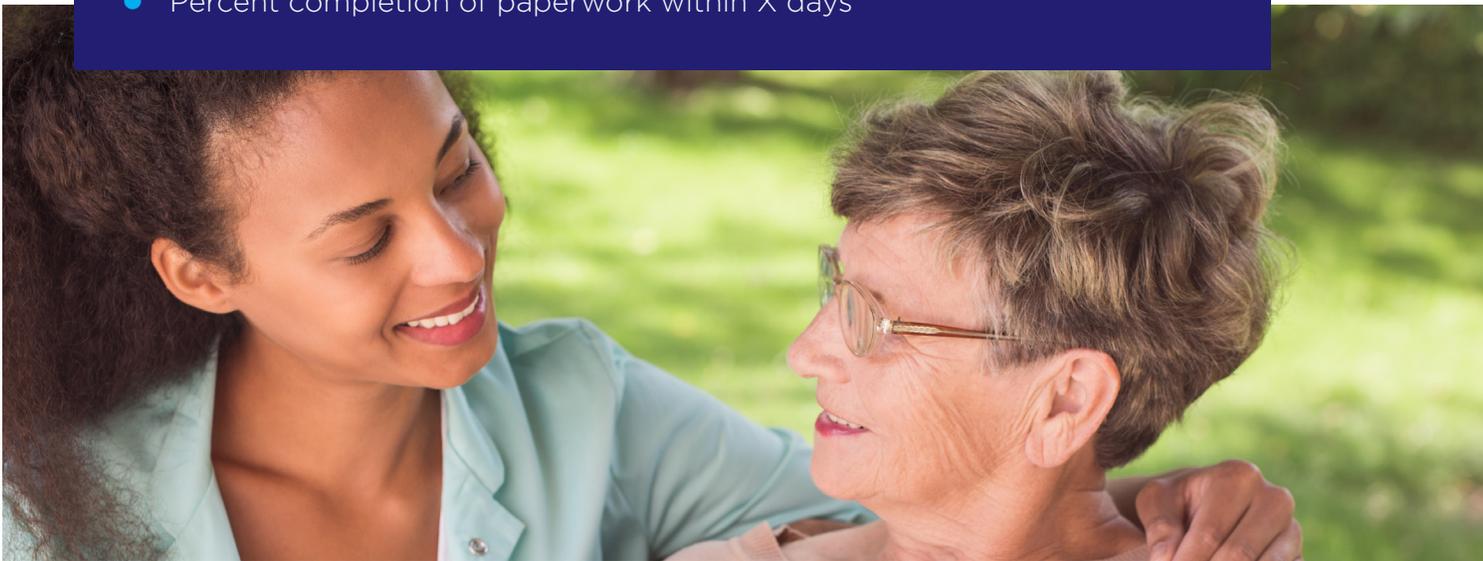
The measures are only useful if there is a plan to review, discuss, and address processes when these processes are not working. Plan-Do-Study-Act (PDSA) is an easy systematic way to investigate problems within your program and test solutions. When starting a program, it might be best to iterate on program elements such as scheduling and travel/appointment times. Having data to drive these decisions will make the decision process easier and align the clinical team toward a shared goal.

As you begin to define quality metrics, look at the registries that exist for palliative care. The National Palliative Care led by CAPC, Global Palliative Care Quality Alliance, and the Palliative Care Quality Network. Each of these registries has a different focus and offers tools for implementing data collection, benchmarking, and process improvement projects.

Closing

As the population ages, the demand for palliative care in the home and community will continue to grow. Innovative models that provide high quality care for seniors (particularly those with multiple chronic conditions) and that allow health care professionals to work at the top of their abilities/licenses will be essential to expand palliative care into the community. In developing a staffing model that employs community health workers trained in palliative care and motivational interviewing, we were able to connect to patients as peers and address their needs. Our goal with this guide was to provide guidance, workflows, assessments and real-world examples of program development implementation and evaluation of a home-based palliative care program. As the landscape shifts to value-based care, there is real opportunity to deliver high quality palliative care in the home.

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Resources

Membership Organizations, Committees and National Organizations

Center to Advance Palliative Care

https://www.capc.org/

California Advanced Illness Collaborative

https://coalitionccc.org/public-policy/california-advanced-illness-collaborative-caic/

Society for Pain and Palliative Care Pharmacists

https://www.palliativepharmacist.org/site_home.cfm

US. Census Bureau

https://data.census.gov/cedsci/

National Association of Community Health Workers

https://www.healthconnectone.org/nachw-progress-and-purpose/

Association of State and Territorial Health Officials

https://www.ruralhealthinfo.org/toolkits/community-health-workers/4/training/certification

National Academy for State Health Policy

https://www.nashp.org/state-community-health-worker-models/

Vital Talk

https://www.vitaltalk.org/

California State University Shiley Institute for Palliative Care

https://csupalliativecare.org/

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American Association of Hospice and Palliative Medicine

http://aahpm.org/

Hospice and Palliative Care Nurse Association

https://advancingexpertcare.org/HPNA/Default.aspx

Ariadne Labs

https://www.ariadnelabs.org/

Home Centered Care Institute

https://www.hccinstitute.org/

Toolkits and Resources

The Business Model Canvas from Strategyzer

https://www.strategyzer.com/canvas/business-model-canvas

The Community Tool Box: Resource for Readiness Assessment, Needs Assessment and SWOT (Strengths, Weakness, Opportunities and Threats) analysis and Logic Models

https://ctb.ku.edu/en/toolkits

Dartmouth Hitchcock Health : Resources on Population Needs Assessment.

https://med.dartmouth-hitchcock.org/documents/population_needs.pdf

Robert Wood Johnson Foundation: Information on Interviewing

http://www.qualres.org/HomeInte-3595.html

Centers for Disease Control and Prevention: Community Health Workers resource

https://www.cdc.gov/dhdsp/programs/spha/chw_training/index.htm

Logic Model Guide: W.K. Kellogg Foundation

https://www.wkkf.org/resource-directory/resources/2004/01/logic-model-development-guide

Agency for Healthcare Research and Quality: Resource List

https://www.innovations.ahrq.gov/guide/indexoftools

Centers for Disease Control and Prevention: Program Evaluation

https://www.cdc.gov/eval/guide/index.htm

Institute for Healthcare Improvement: PDSA cycle guide

http://www.ihi.org/resources/Pages/Tools/PlanDoStudyActWorksheet.aspx

Reports

National Consensus Project for Quality Palliative Care

https://www.nationalcoalitionhpc.org/ncp/

Consensus Standard for Community-based Palliative Care

https://coalitionccc.org/2017/11/final-version-community-based-palliative-care-consensus-standards-available-now/

American Society of Health-System Pharmacist: Guidelines for Pharmacist's Role in Palliative Care and Hospice Care

https://www.ashp.org/Pharmacy-Practice/Policy-Positions-and-Guidelines/Browse-by-Topic/Medication-Therapy-and-Patient-Care?loginreturnUrl=SSOCheckOnly

Clinical and Research Assessments

Integrated Palliative Care Outcomes Scale

https://pos-pal.org/maix/ipos_in_english.php

McGill Quality of Life Questionnaire

http://www.npcrc.org/files/news/mcgill_quality_of_life.pdf

FAMCARE 10

http://www.npcrc.org/files/news/famcare_scale.pdf

Zarit Burden Interview

https://dementiapathways.ie/_filecache/edd/c3c/89-zarit_burden_interview.pdf

Patient Health Questionnaire

http://www.med.umich.edu/1info/FHP/practiceguides/depress/phq-9.pdf

Advance Care Planning

Planning My Way from Cunnoff-Dixon Foundation

https://www.planninghealthcaremyway.org/

Five Wishes

https://fivewishes.org/

Respecting Choices

https://respectingchoices.org/

Centers for Disease Control and Prevention: Advance Care Planning Resources

https://www.cdc.gov/aging/pdf/acp-resources-public.pdf

Quality Reporting

National Quality Forum Palliative Care Measures

https://www.qualityforum.org/Topics/Palliative_Care_and_End-of-Life_Care.aspx

CAPC National Palliative Care Registry

https://www.capc.org/national-palliative-care-registry/

Palliative Care Quality Collaborative

https://www.palliativequality.org/

Palliative Care Quality Network

https://www.pcqn.org/

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Appendix A:

Sample Templates for Communicating with Providers

Sample Letter Template: Communication to Provider Asking for Permission for Outreach Patient

Dear Dr. [insert provider name]

We are writing to inform you that your patient [insert patient name and health system identification number, if applicable] has been identified through a data query as being a potential fit for our palliative care at home support services, an innovative care model for patients with serious illness led by [insert palliative care at home care team leadership names]. Further information about these services are attached to this email [attach information about your program to email].

We are seeking your permission to approach the patient to introduce these home-based palliative care support services. Are you agreeable (please answer Yes or No all)?

- For the palliative care at home team to send the attached leaflet to the patient and follow up by telephone? *[see Appendix B for example leaflet]*

- For the palliative care at home team to introduce these services at an upcoming appointment?

- For the palliative care at home team to introduce these services should the patient be admitted to hospital?

If yes to any of the above, please let us know the patient's primary language. If you would rather we didn't contact your patient, we'd be grateful if you could let us know why, so that we can refine our patient identification approach.

Please know that should your patient enroll in our palliative care at home support services, we will reach out to notify you, and will continue to keep you aware of the patient's progress. This includes keeping you informed of any recommendations we have with regards to changing your patient's medications.

Many thanks for your time and consideration. Please reach out should you have any additional questions.

[insert contact information, including name, title, email address, physical address, and phone-number]

Sample Letter Template: Communication to Notify Provider of Patient Enrollment in Home-based Palliative Care

Dear Dr. [insert provider name]

We are writing to inform you that your patient [insert patient name and health system identification number, if applicable] has enrolled to receive our palliative care at home support services, an innovative care model for patients with serious illness led by [insert palliative care at home care team leadership names]. Further information about these services are attached to this email [attach information about your program to email].

We will continue to keep you aware of your patient's progress for the entire time that [insert pronoun] receives these services. We will only recommend changes to your patient's care plan, including any changes in medications, following a comprehensive evaluation. If we need to make any significant changes, we will reach out to engage you and ask for permission. However, if we do not hear back from you within 24-hours, our team will move forward with our recommendations, which follow evidence-based guidelines for treatment of symptoms and other palliative care related problems.

With this in mind, it would be helpful if you could address the following questions:

- Can you please indicate your preferred mode of communication with us and provide the corresponding contact information?

    - Email

    - Cell-phone

    - Office phone

    - Any of the above

- Is there anything else we should know about this patient (e.g., social determinants of health – financial hardship, complex family dynamics, and/or a challenging home-living situation due to another reason)?

Many thanks for your time and consideration. We look forward to working together. Please reach out should you have any additional questions.

[insert contact information, including name, title, email address, physical address, and phone-number]

Sample Letter Template: Communication to Primary Care Provider when Patient is Discharged from Home-based Palliative Care

Referring provider:

Date of admission to program:

Date of discharge:

Discharge disposition:

Brief Clinical History: ***

Areas addressed during time during program:

Physical and Psychological Symptoms

- Symptom(s):
- Treatment successes and failures during time on program:
- Current status:

Caregiver Education and Support

- Caregiver needs identified:
- Actions taken:
- Current caregiver status:

Social Needs

- Social needs identified:
- Actions taken:
- Current social care needs and outstanding issues:

Advanced Care Planning

- Illness understanding at program enrollment:
- Goals of care discussions during time on program:
- Current illness understanding:
- Current documentation of advance directive:

Recommendations for ongoing assessment: ***

Sample Letter Template: Communication to Primary Care Provider when Patient Enrolls in Hospice

Dear [Dr./ NP]

[PATIENT'S NAME, MRN] was under the care of Mount Sinai Palliative Care Team between [DATE] AND [DATE].

They were enrolled in [agency name] hospice on [DATE].

Please don't hesitate to contact us if you have any questions.

Best wishes,

Administrative Assistant

[Program name here]

Sample Letter Template: Communication to Primary Care Provider when Patient Dies

Dear [Dr./ NP]

We are sorry to inform you that [PATIENT'S NAME, MRN] passed away [this morning/ this afternoon/ tonight] in their home.

Our Medical Doctor [Doctor's name here] is completing the death certificate and our Social Worker will be contacting their caregiver [caregiver's name here] to provide any necessary bereavement support.

Please don't hesitate to contact us if you have any questions.

Best wishes,

Administrative Assistant

[Program name here]

Appendix B:

Brochure

Palliative care (pronounced pal-lee-uh-tiv) is specialized medical care for people with illness. This type of care is focused on providing relief from the symptoms and stress of a serious illness. The goal is to improve quality of life for both the patient and the family. Palliative care is provided by a specially trained team of doctors, nurses, and other specialists who work together with a patient's other doctors to provide an extra layer of support. It is appropriate at any age and at any stage in a serious or chronic illness, and it can be provided along with curative treatment.

Mount Sinai Palliative Care at Home is an innovative program developed by the Mount Sinai Health System that provides home-based palliative care for patients with serious illnesses.

Mount Sinai Palliative Care at Home is:

Holistic: We treat the whole person, tailoring care to his or her medical, emotional and social, and spiritual needs.

Home-based: We come to the patient to provide care in an environment that is familiar and comfortable.

Highly Skilled: We deliver specialized palliative care through a team of dedicated and highly skilled professionals

My care team includes:

_____
_____
_____
_____
_____
_____

Contact Us:
212-241-0699
Office hours are 8:30am until 4:30pm.
Phone support available 24/7 for emergencies.

Mount Sinai Hospital
Mount Sinai Beth Israel
Mount Sinai West
Mount Sinai St. Luke's

Mount Sinai | **Palliative Care at Home**

Specialized Care
for People with
Serious Illness

Mount Sinai

How does the program work?

INTAKE

Timing
Around one week after enrolling, the care team will call you to schedule a convenient time for the initial visit in your home.

What to Expect
- Initial visit by one to two members of the care team
- A thorough assessment of your needs, including symptoms, medications, support network, understanding of care, and whatever matters to you
- Development of a Care Plan based around your needs and goals
- Close collaboration with the other health providers involved in your care
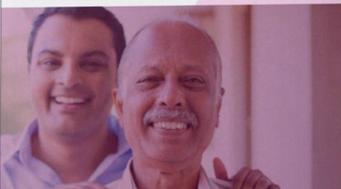
MONITORING

How often will I see my care team?
The care team will check in with you every week by telephone or in person. They will also visit you in your home; how often depends on your needs and preferences.

Who will I see on the care team?
The care team includes a **registered nurse (RN), a social worker (SW), and a community health worker (CHW)**. They will be supported by a nurse practitioner (NP) and palliative care physician. Out of normal hours, you can contact a palliative care physician for advice.

FAQ:

Q: Will I get to keep my current doctors?

A: Yes. Our team of palliative care specialists works with your existing care team to add a layer of additional support.

DISCHARGE

What will I receive at the end of this program?
We will give a summary of the care you have received and further information to you and your PCP at the end of the program.

Mount Sinai
Palliative Care at Home

Appendix C:

Nursing Intake Assessments

Initial Assessment Template: Nursing

General:

Patient name: ....

Patient age: ....

Patient DOB: .... / .... / ....

Primary language: ....

Health insurance: ....

Allergies: ....

Nature of allergic reaction: ....

Living arrangement:

☐ Lives alone

☐ Lives with family. If so, specify: ....

☐ Lives with other non-family. If so, specify: ....

☐ Apartment building – walkup

☐ Apartment building – elevator

☐ Private house

Healthcare Decision Making:

- Emergency contact / caregiver name and contact #: ....

- Health Care Proxy name: ....

PCP or lead provider contact information:

- Date of last appointment with PCP or lead provider? ·············· / ··············/ ··············

Pharmacy name: ···

- Address and telephone # ···

Background/ Medical History ···

- Primary diagnosis (with dates) – include history and current status

  ···

  ···

  ···

  ···

- Other diagnoses (with dates) – include history and current status

  ···

  ···

  ···

  ···

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Physical Symptoms/ Psychological Symptoms/ Functional Status/ Nutrition:

Physical symptom assessment:

☐ **Complete Integrated Palliative Care Outcome Score (IPOS)**

Pain Assessment:

- When did the pain begin? ....

- Where is the pain? ....

- Is it there all the time or does it come and go? ....

- How often do you get the pain? ....

- How long does it last? ....

- How would you describe the pain? ....

  (e.g., ☐ Sharp ☐ Dull ☐ Burning ☐ Shooting ☐ Stabbing)

- Does it travel anywhere? ....

- What makes the pain better or worse? ....

- What relieves the pain? ....

- How does the pain affect your function / mood / sleep? ....

  ....

  ....

- On a scale of 1-10 how severe is the pain: ....

  - Now: ....

  - On average in the last 24 hours: ....

  - At its worst in the last 24 hours: ....

  - At its best in the last 24 hours: ....

Current Pain Regimen:

- If opioids, has an opioid risk assessment been documented? ☐ Yes ☐ No

Cognitive Assessment:

- ☐ Complete mini-Cog in Electronic Medical Record

Psychological Assessment:

Patient Health Questionnaire 2-item (PHQ-2) + Generalized Anxiety and Depression 2-item (GAD-2)

● In the last 2 weeks how often have you been bothered by the following problems:

PHQ2:

Feeling down, depressed or hopeless:

Not at All	Several Days	More than half the Days	Every Day
0	1	2	3

Having little interest or pleasure in doing things:

Not at All	Several Days	More than half the Days	Every Day
0	1	2	3

GAD2:

Feeling nervous, anxious or on edge:

Not at All	Several Days	More than half the Days	Every Day
0	1	2	3

Feeling that you are not able to stop or control worrying (if applicable)?

Not at All	Several Days	More than half the Days	Every Day
0	1	2	3

Note: Complete PHQ-9 (incorporates suicidality questions) if score on the PHQ2 is > 3. Complete GAD7 if GAD2 score is > 3.

References

Kroenke, K., Spitzer, R.L., Williams, J.B. (2003). *The Patient Health Questionnaire-2: validity of a two-item depression screener.* Medical Care, 41:1284–92.

Spitzer R., Kroenke, K., Williams, J. (1999). *Validation and utility of a self-report Version of PRIME-MD: the PHQ Primary Care Study.* Journal of the American Medical Association, 282, 1737-1744.

Kroenke K, Spitzer RL, Williams JB, Monahan PO, Löwe B. *Anxiety disorders in primary care: prevalence, impairment, comorbidity, and detection.* Ann Intern Med. 2007;146:317-25

Physical Function Assessment:

☐ Complete Palliative Performance Scale*:*

☐ Activities of Daily Life Assessment:

How is your vision?

    ☐ Good

    ☐ Difficult but no corrective eyewear

    ☐ Corrective lenses, effective

    ☐ Corrective lenses, difficult

    ☐ Blind

- How is your hearing?

....

- Do you need hearing aids? ☐ Yes ☐ No

- Do you have any other support services like Home Health Agency Service, Meals on Wheels, or transportation services? ☐ Yes ☐ No

- Have you fallen in the last 6 months? ☐ Yes ☐ No

If patient answers yes to above:

- ■ When? ....

- ■ What were you doing when you fell? ....

- ■ Were you using an assistive device when you fell? ☐ Yes ☐ No

- ■ Who was there with you?

- ■ Did you go to ER? ☐ Yes ☐ No

- ■ Were you hospitalized? ☐ Yes ☐ No

- ■ If so, what hospital were you admitted to and how many days were you hospitalized?

....

Nutritional Assessment:

- How is your appetite?   ☐ Good   ☐ Fair   ☐ Poor

- Any change in your appetite in the past 3-6 months?   ☐ Yes   ☐ No

- Have you lost any weight in the past 3-6 months?   ☐ Yes   ☐ No

- If so, how much? .... Does this bother you?   ☐ Yes   ☐ No

- How many meals do you eat a day? ....

- Do you eat a quarter, half, or all of your food? ....

....

Current medications and immunizations *(can pull from EMR, confirm with pt):*

List current medications and doses: ....

....

*For steroids, list duration of treatment

- Do you have any problems keeping track or taking any of your medications?

    ☐ Yes   ☐ No

- Does anyone help you manage your medications?   ☐ Yes   ☐ No

- Do you experience any side effects from any of your medications?   ☐ Yes   ☐ No

- Flu shot date: .... /............./ ....

- Pneumococcal shot date: .... /............./ ....

Decision making and illness understanding:

- Is anyone else involved either in your care or in helping you to make care decisions? (for example: a spouse, family member, friend, etc) ☐ Yes ☐ No ....

- What is your understanding of your illness? ....

- What helps you to cope? ....

Review of Symptoms:

- **Pulmonary:** ☐ Cough   ☐ Shortness of breath

- **Cardiovascular:** ☐ Palpitations   ☐ Chest pain   ☐ Edema

- **GI:**   ☐ Constipation   ☐ Diarrhea   ☐ Nausea   ☐ Vomiting
  ☐ Abdominal distension   ☐ Pale stool   ☐ Melena   ☐ Blood PR

  Last bowel motion: ....

- **Renal:**   ☐ Oliguria   ☐ Hesitancy   ☐ Frequency   ☐ Urgency
  ☐ Dysuria   ☐ Nocturia Incontinence

- **Neuro:**   ☐ Dizziness   ☐ Difficulty speaking   ☐ Weakness in arms / legs

- **Other:**   ☐ Insomnia   ☐ Difficulty swallowing   ☐ Cough while swallowing

Examination:

MRN: .... Date: .... / .... / .... Time: .... : ....

Person Completing the Assessment: ....

Vital Signs:

- BP: ....
- RR: ....
- Pulse: ....
- Temp: ....
- O2 saturations: ....
- BM: ....
- Weight: ....
- Height: ....

Skin:

- Color: ☐ Jaundice   ☐ Redness   ☐ Cyanotic

- Temp/moisture: ☐ Warm   ☐ Cold   ☐ Within normal limits   ☐ Dry
  ☐ Moist   ☐ Itchy

- Turgor: ☐ Within normal limits   ☐ Tenting

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Wounds:

Pressure ulcers: ☐ Stage I   ☐ Stage II   ☐ Stage III   ☐ Stage IV

Location ···································· **Treatment** ·······································

- **Pulmonary: (I)** Inspection: respiratory rate and effort, oxygen (continuous / intermittent, liters/minute, mode of delivery) **(II)** Auscultation: Diminished breath sounds, Wheezing / rhonchi, Crackles

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- **Cardiovascular: (I)** Auscultation: normal heart sounds? Any murmur? Peripheral edema?

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- **Neurology: (I)** Assess orientation: time, place, person; **(II)** Assess for evidence of focal weakness, atrophy, contractures

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Appendix D:

Social Worker Initial Assessment

Initial Assessment Template
Social Work

Name: ....

Age: ....

Gender: ....

Date of Visit: .... / .... / ....

Location of Visit: ....

Persons Present: ....

Current Advance Directives: ☐ No   ☐ Yes

Housing and Social Support Environment Review:

- What is your housing situation today? ....

- Do you have any problems with your housing? (e.g., mold, inadequate heat, bug infestation) ☐ No   ☐ Yes ....

- Are you worried that in the next few months, you may not have stable housing?
  ☐ No   ☐ Yes

Tell me about your family/other social supports *(this includes the quality of the relationship with them):*

- How often do they visit? ....

- How is your relationship with them? ....

- Do they help you with anything? ☐ No   ☐ Yes: ....

- Do you ever have to care for someone else? ☐ No ☐ Yes: ....

- Do you socialize much outside of your home? ☐ No ☐ Yes: ....

- Are you involved with any community groups? ☐ No ☐ Yes: ....

- Do you often feel as though you lack companionship? ☐ No ☐ Yes

- Aside from the people you mentioned, do you get any extra help from outside agencies? ☐ No ☐ Yes. If yes, from who? ....

- Doing what? .... How often? ....

- Home Attendant Agency Name: ....

- Hours per week: ....

- How long has your current HA / HHA worked with you? ....

- Do you feel you need help with anything inside or outside the home? ☐ No ☐ Yes:

....

Current Home Equipment Review:

- Commode: ☐ No ☐ Yes

- Hospital Bed: ☐ No ☐ Yes

- Cane: ☐ No ☐ Yes

- Walker: ☐ No ☐ Yes

- Wheelchair: ☐ No ☐ Yes

- Do you feel as though you need any additional equipment inside your home?

☐ No ☐ Yes. If yes, please explain: ....

....

Transportation Needs Review:

- How often do you get out of your home? ....

- Do you need anyone to help you get out of your home? ☐ No ☐ Yes

- Do you need any assistive devices when you are out of your home? ☐ No ☐ Yes

- What mode of transportation do you use? ☐ Public transportation ☐ Driving

  ☐ Some other arrangement: ....

- Do you have any difficulty using public transportation or driving? ☐ No ☐ Yes

- Do you use any transportation services? ☐ No ☐ Yes: ....

- In the last 12 months, has lack of transportation kept you from medical appointments or from getting the things needed for your daily life? ☐ No ☐ Yes

- Do you feel you need any additional transportation services? ☐ No ☐ Yes:

....

Utility Needs / Food Insecurity/ Financial Barriers to Medical Care:

- Do you have any problems paying utility bills? ☐ No ☐ Yes: ....

- In the last 12 months, has the electric, gas, oil or water companies threatened to cut off the supply to your home? ☐ No ☐ Yes: ....

- Do you have any problems affording food? ☐ No ☐ Yes: ....

- In the last 12 months, did you ever worry the food would run out before you had money to pay for more? ☐ No ☐ Yes: ....

- In the last 12 months, have you ever been in the situation when the food ran out and you didn't have money to buy more? ☐ No ☐ Yes: ....

- Do you or have you ever received food stamps or SNAP? ☐ No ☐ Yes: ....

- Do you have any problems affording the cost of your medications?

  ☐ No ☐ Yes: ....

- Do you have any other problems accessing your medications as needed?

  ☐ No ☐ Yes: ....

- Do you have any problems affording your co-pays or deductibles?

  ☐ No ☐ Yes: ....

- In the last 12 months, have you ever needed to see a doctor, but haven't been able to due to cost?

  ☐ No ☐ Yes: ....

Insurance:

- What is your income per month? (this is asked to determine Medicaid eligibility)

  ....

- Who is your medical insurer? ....

- Do you have long term care insurance? ☐ No ☐ Yes

- Have you ever served in the US military? ☐ No ☐ Yes

Health Literacy

- How confident are you filling out medical forms by yourself?

  ☐ Extremely   ☐ Quite a bit   ☐ Somewhat   ☐ A little bit   ☐ Not at all

- How often do you have problems learning about your medical condition because of difficulty understanding written information?

  ☐ Extremely   ☐ Quite a bit   ☐ Somewhat   ☐ A little bit   ☐ Not at all

- How often do you have someone help you read hospital materials?

  ☐ Extremely   ☐ Quite a bit   ☐ Somewhat   ☐ A little bit   ☐ Not at all

Illness Understanding and Advanced Care Planning:

- Have you discussed your health with your doctor?   ☐ No   ☐ Yes

- What did you understand about how things were going when you last had a chance to discuss with your doctor?

  ....

- How much information would you like to know about possible and/ or expected changes due to your illness?

  ....

- If your health becomes worse, what would be your most important goals and wishes?

  ....

- What are your biggest fears and concerns about the future because of your health?

  ....

- Does anyone else (e.g. family/friends/others identified in the assessment) understand your health priorities and important goals and wishes?

  ☐ No   ☐ Yes: ....

Spirituality/Religion:

Use FICA approach (below) – from Christina Puchalski MD

Faith:

- Do you consider yourself spiritual or religious?   ☐ No   ☐ Yes: ....

- Do you have spiritual beliefs that help you cope with stress/ difficult times? Or is spirituality something important to you? ☐ No ☐ Yes: ....

- What (else) gives your life meaning? ....

Importance:

- What importance does your spirituality have in your life? ....

- Has your spirituality influenced how you take care of yourself, your health?

  ☐ No   ☐ Yes: ....

- Does your spirituality influence you in your healthcare decision making?

  ☐ No   ☐ Yes: ....

Community:

- Are you part of a spiritual community? ☐ No   ☐ Yes: ....

- Is this of support to you and how? ☐ No   ☐ Yes: ....

Addressing Needs:

How would you like me, your healthcare provider, to address these issues in your healthcare?

....

....

Who would you call in an emergency? ....

Primary:

- Emergency Contact: ....

- Address: ....

- Mobile Phone: ....

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- Work Phone: ....
- Relationship: ....

Extended Emergency Contact Information:

- Emergency Contact: ....
- Address: ....
- Mobile Phone: ....
- Work Phone: ....
- Relationship: ....

TIME SPENT Completing Assessment:

- Start time: ....
- End time: ....
- Total time: ....

Appendix E:

CHW Weekly Check-in

Weekly Check-in Template
Community Health Worker

Visit Date: .... / .... / ....

Present During Visit: ....

Interval Changes:

- General health status/ problems in the past week: ....

- Is the patient able to take all their medications as prescribed? ☐ No ☐ Yes:

- What problems do they have taking their medications as prescribed?

....

- Hospitalization / ED / office visits since last contact? ☐ No ☐ Yes: ....

- Upcoming doctor visits / therapies / procedures? ☐ No ☐ Yes: ....

- Status of outstanding referrals / durable medical equipment orders?

....

Functional Status:

☐ Complete Palliative Performance Scale

Physical and Psychological Symptoms

In the last week has the patient had:

- **Pain** ☐ No ☐ Yes: ....

- **Shortness of breath** ☐ No ☐ Yes: ....

- **Weakness/ lack of energy** ☐ No ☐ Yes: ....

- **Nausea** ☐ No ☐ Yes: ....

- **Vomiting** ☐ No ☐ Yes: ....

- **Poor appetite** ☐ No ☐ Yes: ....

- **Constipation** ☐ No ☐ Yes: ....

- **Sore or dry mouth** ☐ No ☐ Yes: ....

- **Drowsiness** ☐ No ☐ Yes: ....

- **Poor mobility** ☐ No ☐ Yes: ....

- **Fall**: ☐ No ☐ Yes

- **Last Fall:**...................... ; **Injuries?** ☐ No ☐ Yes: ....

- **Other:** ....

In the last 2 weeks, has the patient felt down, depressed or hopeless?

☐ No ☐ Yes

In the last 2 weeks, has the patient had little interest or pleasure in doing things?

☐ No ☐ Yes

Community Health Worker Initial Assessment Template

Goals of Care/Advance Care Planning:

Goals of care discussed today?

- "Planning My Way" reviewed*   ☐ No   ☐ Yes
- Health Care Proxy discussed   ☐ No   ☐ Yes
- DNR/DNI discussed   ☐ No   ☐ Yes
- MOLST discussed   ☐ No   ☐ Yes
- End of Life Wishes   ☐ No   ☐ Yes
- Other:..

....

....

Caregiver Support:

- Supportive counseling
- Disease education
- Medication education
- Community resource referrals

*"Planning my Way" is a specific advance care planning template that the Mount Sinai Palliative Care at Home team uses. It is used with permission of the Cunniff Dixon Foundation. This line can be adapted based on whatever guide the team is using for patient care. Other such guides include "Prepare" (www.prepareforyourcare.com) or "Five Wishes."

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