وزارة الصحة
Ministry of Health

A PRACTICAL GUIDE TO IMPLEMENTING A HOME-BASED PALLIATIVE CARE PROGRAM

INTRODUCTION

This handbook is a cooperation between the Palliative Care leads experts and Doctorate General of Home Healthcare in the Saudi Ministry of Health (MOH) and the Saudi Society of Palliative Care (SSPC) informs this guidance on how to create a

Home-based palliative care program in a medical facility. This cooperation developed the Palliative Care at Home program and evaluated it in a randomized control experiment. This handbook covers home-based palliative care program development because the assessment is ongoing.

Definition of Palliative Care and why should palliative care spread in the home and community?

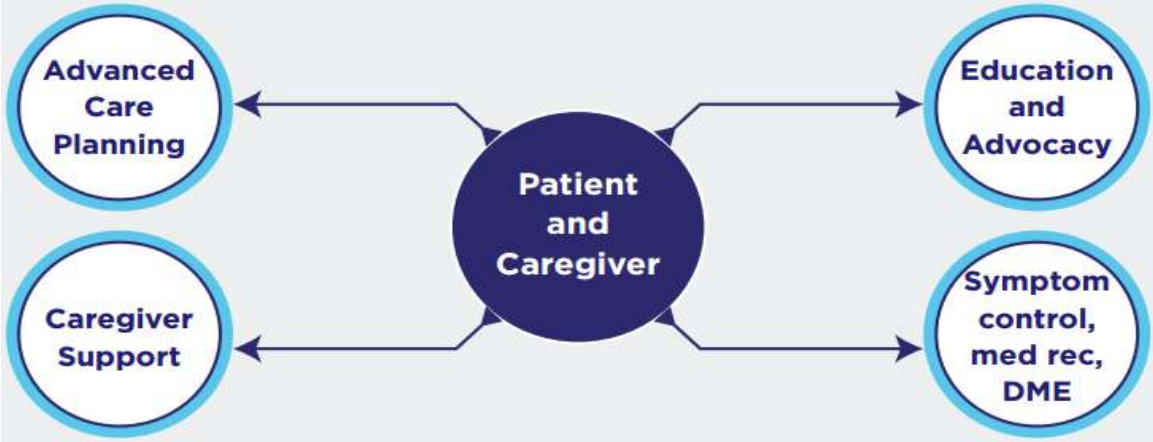
According to Center of Advanced Palliative Care (CAPC); "Palliative care is specialized medical care for people living with a serious illness. This type of care is focused on providing relief from the symptoms and stress of the illness. The goal is to improve quality of life for both the patient and the family"1. A multidisciplinary team provides palliative care in the hospital or at home and community to improve quality of life (2-4). Palliative care has grown substantially in hospitals during the past decade. For example, in 2023, more than 90% of Saudi health clusters has developed Palliative Care services (5). This number represents 19 out of 20 health cluster in Saudi Arabia. Unfortunately, home and community palliative care has not grown as swiftly. Thus, when not in the hospital, critically ill patients are mostly cared for by their families without professional medical aid.

Home and community palliative care is limited despite its benefits. Home-based palliative care reduced symptoms, decision-making and communication, understanding and dealing with disease, and hospitalizations by 70%, according to a Kaiser Permanente research (6,7). Also, Sutter Health's "advanced illness management" pilot program, which emphasizes advance care planning, symptom self-management, medication reconciliation/management, and careful physician follow-up, reduced hospitalizations by 54% (8,9). Instead, restricted compensation mechanisms (paying for social work or nurse time) under present fee-for-service models and the operational difficulty of home and community-based palliative care may explain the absence of it (10).

Home-based palliative care programs can now expand due to recent health care reforms toward value-based care. Health care and health systems' incentives shift from volume to high-value treatment at the proper level and place when they take on more risk-bearing contracts. Home or community-based palliative care reduces emergency department visits and hospitalizations and is favored by patients (11). Thus, palliative care professionals may build value-based home-based programs to handle high-cost, severely sick patients.

PALLIATIVE CARE AT HOME MODEL

This guideline program delivers 6-month in-home palliative care to very sick patients. The program objectives that Home visits are: (1) alleviate patients' symptoms suffering; (2) enhance the overall quality-of-life (QOL) for patients; enhance patient participation in advance care planning (ACP); (3) lighten the load on caregivers; and (4) Reduce unnecessary utilization of health care services. The guideline allow providers collaborate with the patients' current primary care providers to provide an additional layer of care. Thus, it is a paradigm of co-management (Figure shown below *adopted from Mount Sinai; A Practical Guide to Implementing a Home-Based Palliative Care Program*).



The programs' interdisciplinary care model recruit Community health workers (CHWs), registered nurses, social workers, and specialists in palliative care. This cost-effective staffing approach utilizes health care providers' talents and provides high-quality patient care. The CHWs educate, advocate, and assist caregivers in patients' homes. The CHWs' capacity to bridge the health care system and the community is one of the numerous benefits of including them into a home-based palliative care team. The CHWs is better at building trust and understanding than traditional healthcare providers, making patients feel more comfortable asking questions and voicing concerns.

Chapter 1

GETTING STARTED

Creating a new program is thrilling. Knowing where to start can help you save time and acquire community needs data. Needs assessments can organize information and aid decision-making. A needs assessment will reveal your objectives for creating a community palliative care program, your organization's readiness to adopt it, and the market's need for it. This data can assist you define your organizational culture, leadership participation and support, resource availability, patient population needs, and market potential. We will discuss brainstorming and stakeholder involvement in this section.

What is your motivation to start a program?

Define your community-based program's value proposition and why you want to launch it. Before approaching stakeholders, consider program design, regional limits, patient populations, and the business case. Defining your services, staffing strategy, palliative care paradigm (co-management or principal provider), referral sources, and income streams are further factors. Business case brainstorming and definition materials are available. Here are resources to help you starting planning and define the needs assessment:

1. (https://www.strategyzer.com/canvas/business-model-canvas) helps you define your value proposition, customer stream, and critical resources and activities.
2. Membership in https://www.capc.org/
3. https://ctb.ku.edu/en/toolkits
4. https://ctb.ku.edu/en/table-of-contents/assessment/assessing-community-needs-and-resources/swot-analysis/main

Remember, stakeholders and community resources may change the organization's concept. However, defining your program's framework will help you explain it.

Patient Population

Community-based palliative care initiatives serve critically ill individuals with various diseases. Consider your patient group and desired goals while creating your program. List your skills, expertise, and patient needs as a brainstorming exercise. This exercise may reveal patient care gaps and your worth. Let us say, if you have noticed that Cancer patients have high readmission rates in your health care system and miss appointments in your palliative care clinic, you might start with a home-based program. Another example, because 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, you may want to develop a home-based program that serves a wider patient population. Identifying partners and stakeholders requires defining your program's patient population and where patients receive

care. Hence, if you wish to start a Cancer co-management program, engage with doctors and specialists who see a lot of these patients and are eager to co-manage.

Involve Relevant Parties or Stakeholders

When designing a program with the goal of closing care gaps, it might be helpful to consult with relevant parties and gather their views and viewpoints. To begin, you should identify key community members who have a stake in the success of your program because they can have an impact on its direction, because they can benefit from your services, because they have expertise or perspective in community-based care delivery, or because they can provide you advice. Leadership in your institution, local healthcare providers (such cancer centers or primary care physicians), and patients/families are all examples of stakeholders. Likewise, national membership organizations like Saudi Society for Palliative Care (SSPC) or fellow professionals in the field of palliative care may be able to offer guidance.

Use this website to help you before meet your stakeholders http://www.qualres.org/HomeInte-3595.html. Think about your discussion goals. Start by describing your program's high-level details, gaps it may fill, and stakeholder issues. Who you are talking to will determine these questions. These are examples you may benefit from:

1. If you are conversing with a coworker who is created program in a different field, for instance, you might be curious about the obstacles they faced and the solutions they found. You might also get more honest comments on how your program is made.
2. When talking to possible health care partners, like primary care providers or senior leadership, spend time figuring out how your suggested program fits with their mission(s) and how it can help them with their problems. For example, could your suggested program help solve X's top priority, which is a high rate of readmissions? Or be cost-effective in your organization? Then, you must discuss it with the Population health representatives.

Do not forget to find out how your superiors may feel about your program. Make advantage of and offer statistics to back up your value proposition if you have access to them.

TIP: Use the SMART goals structure to describe the goals of your program. The SMART goals structure can help you say what you want to say and show your plan to people in your group and community who are important to it.

Use Data to Understand Your Local Community

Collect information about your own health system to learn about the people who use it and the ways in which palliative care can make the lives of patients better. If your health system has a strategic office or office for managing the health of the whole community, they may be able to help you with statistics. In a similar way, public sources like the Saudi Health Council, National Palliative Care Network or the Directorate of Home Healthcare may be able to help. Ask questions like, "What is your health care organization's readmission rate?" Is it more expensive for some diseases, is there a hole in the community care model of the health system that a community-based palliative care program could fill? Find out if and how you might be able to help alleviate these problems. This information from your internal health system or partners in the health system can help you talk to your top leadership. Using data from your health system can also help you plan for the growth of your program in a smart way. Use data to find out how many possible patients live in your business area and how much this group is expected to grow over the next five years.

The MOH Statistical Yearbook (https://www.moh.gov.sa/Ministry/Statistics/book/Pages/default.aspx) and your Cluster of Health may be able to help you learn more about the people who live in your suggested area.

Planning Resources and Finances

Resources may include space, personnel, medical supplies, and a variety of other factors. Financial modeling is a tool that enables you and your organization's leadership to obtain objective insights and plan for the future strategically. To create a financial model for a home- and community-based palliative care program, it is necessary to comprehend the revenue and expense details associated with providing palliative care at home.

When launching a new program, it may be necessary to rely on estimates or projections. These data will presumably consist of (but should not be limited to):

Operational Expenses:

Rented floor with a private meeting room for talking about patient care in confidence and an office with computer access.

- Computers, software, and internet access
- Workplace furniture
- Home visits equipment;
    - Sphygmomanometer / BP monitor
    - Temperature measure
    - Bandages
    - Special bags / jumpsuits for bed bugs or other sanitary issues
    - Hand sanitizers

  - Gloves
  - Containers for the tablets and documents
- Smart phones and tablets
- Printer, scanners and fax-machine
- Identification cards and membership for organization
- Brochures and educational materials
- Transportation funds
- Utilities
- Medical supplies
- Uniforms

Delivery and Clinical Team Costs:

- Salaries and benefits
- 24/7 phone service
- Payment fees
- Onboarding time
- Telemedicine or software costs, if applicable.
- Paramedic hiring, if applicable

Financial Model Expenses example

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	$	$	$

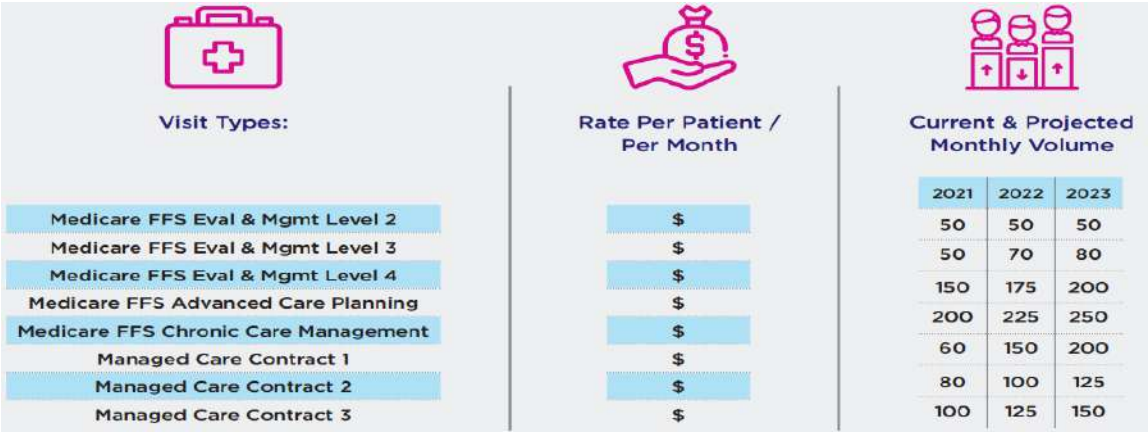
Annual Salary Expenses

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

After that, think of the program's sources of income. Now you have the target population and the staff. You can figure out when the program will be able to run on its own.

- Sources of income, such as real payments from bills
- Fees for home visit and telemedicine billing—how often will a billing provider see each patient every episode (planned and unplanned)?
- Membership contracts with the service
- Coding for chronic care control
- Coding for Advance Care Planning (ACP)

- **Example Financial Model Revenue Categories**



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	$			

TIP: Set a standard time period for figuring out prices, such as a year or a range of years. Use at least one full year's worth of real costs whenever possible to make better predictions. A financial model can be made with an Excel worksheet.

The way forward …

Goals, Limitations, and Influencers

Now, it is time to start putting together the financial plan. Set both short-term and long-term goals for your program as a first step. Plan out these sources of income and costs to help you figure out how your growth plan will work over a number of years. Financial influencers can be modified to increase income or lower costs. Manipulate your financial model's influencers can show how little modifications will affect your program's financial success. Examples for this steps:

1. Goals: Getting 10% of the market in the first year you are open. To do this, you might need to find 8 new patients per month and hire new staff once you have 50 patients.
2. Influencers: the amount of managed care contracts you handle, billable visits, staff personnel, and clinical call center expenditures.
3. Limitations: Staff-to-patient ratios may change as patient census rises. Your program's staff-to-patient ratios and goals should be reasonable given practical restrictions.

TIP: Cost modeling with a regular growth rate may be simpler. You may predict a 3% yearly rise in rent, employee salaries, and utilities.

Scenario Analysis

Next, based on forecasts of shifting critical levers like revenue sources and costs, three scenarios are usually created to anticipate financial outcomes over a few years. Your job is to define each scenarios for each influence and change the influencers' values to keep situations viable. Depending on your comfort, preparation, and team's goals, your organization's "Baseline," "Moderate," or "Aggressive" will vary. These scenarios are:

1. Baseline – over the next few years, a "baseline" scenario assumes little change in profits or costs. It predicts future practice financials.
2. Moderate – a prediction with "Moderate" income and expense adjustments requires more work, such as negotiating with managed care organizations, increasing patient population, or decreasing a major cost.
3. Aggressive – scenario is created with high revenue and cost objectives that need major program structure adjustments.

Additional Benefits

Launching a palliative care program requires consideration of expenditures that may not affect your bottom line but may affect the health system financially or in quality measures. Like, can minimize duration of stay, emergency department utilization, or hospice referrals. Take advantage when you are interviewing leaders so that you will be able to learn how your program may improve patient care or the health system. Tracking the benefits of a community-based palliative care program beyond revenue recognition will assist prove the business case.

Chapter 2

CLINICAL TEAM ROLES AND RESPONSIBILITIES

All palliative care providers share a responsibility for communication and information transfer (There should be a smooth transfer of medical information between the different health professionals responsible for patient care)

Home care nurse

- developing an individualized home-based care plan for each patient;
- in some cases, providing treatments and instructing the family in this task;
- facilitating access to supplies and medicines;
- visiting the patient's home according to a regular schedule in order to anticipate problems and if possible prevent them; reporting problems to a higher level and providing follow-up;
- training the patient and family in care and comfort-giving procedures and checking that they are being carried out;
- routinely conducting comprehensive assessment of the patient's physical, psychosocial and spiritual needs, and communicating the findings to providers at all three levels of health care;
- Based on the assessments, paying particular attention to ensure the availability of treatment, including for pain management.
- answering questions, providing information and keeping records;
- encouraging the family to keep the patient involved in their daily life as much as possible;
- Helping/supporting/guiding the family in nursing care and care of bedridden patients (if training has been received).

Home care - social worker

- developing an individualized home-based care plan for each patient;
-
- facilitating access to supplies and medicines, connect the patient with supporting resources and charities;
- visiting the patient's home according to a regular schedule in order to anticipate problems and if possible prevent them; reporting problems to a higher level and providing follow-up;
- advice the patient and family in care and comfort-giving strategies to prevent burnout and checking that they are being carried out;
- routinely conducting comprehensive assessment of the patient's physical, psychosocial and spiritual needs, and communicating the findings to providers at all three levels of health care;

- Based on the assessments, paying particular attention to ensure the availability of treatment, including for pain management.
- answering questions, providing information and keeping records;
- encouraging the family to keep the patient involved in their daily life as much as possible;
- Helping/supporting/guiding the family in nursing care and care of bedridden patients (if training has been received).

Home care- physical therapist

- developing an individualized home-based care plan for each patient;
- in some cases, providing education and instructing the family in this task;
- Facilitating access to supplies (walker, wheel chair, etc.) and medicines (muscle relaxant, pain killer upon positioning. .etc.);
- visiting the patient's home according to a regular schedule in order to anticipate problems and if possible prevent them (e.g. joint stiffness, muscle contracture …etc.); reporting problems to a higher level and providing follow-up;
- training the patient and family in care and comfort-giving procedures (exercises) and checking that they are being carried out;
- routinely conducting comprehensive assessment of the patient's physical, psychosocial and spiritual needs, and communicating the findings to providers at all three levels of health care;
- answering questions, providing information and keeping records;
- encouraging the family to keep the patient involved in their daily life as much as possible;
- Helping/supporting/guiding the family in nursing care and care of bedridden patients (if training has been received).

Roles of staff nurses at primary, secondary and tertiary care facilities

- supervising and monitoring the work of auxiliary nurses and nursing aides
- Coordinating and act in a liaison role between the community care system and secondary and tertiary care institutions.
- Teaching and training auxiliary nurses ,nursing aides and volunteers
- Provide specialist nursing procedures such as care of lymphedema and stoma.
- Ensure documentation of home care.

Roles of physicians at primary and secondary care facilities

- visit the community from time to time to train home-based care workers and community health workers and to learn about the conditions in which they work and in which their patients live;
- participate in palliative care training and services organized at secondary facility levels;
- support and supervise the community team and provide the patient with treatment and care;
- prescribe analgesics, including oral morphine, and medicines for the symptomatic treatment of other problems;
- supply medicines to the patient or caregivers for use either immediately or when needed;

- prescribe, provide, supervise, support and maintain supplies for the community health workers who do home visits;
- advise and educate the patients, families and community carers on how to prevent and manage common problems such as contractures and bedsores;
- refer patients to higher facilities for acute problems that are best managed there;
- help arrange transportation for patients to these locations;
- provide short-term inpatient care for severe symptom management;
- Provide distance supervision and assistance through telephone consultations.

Roles of providers at tertiary care level, including the hospital

- Provide inpatient care, including radiotherapy and other treatments available only at this level, for patients with intractable pain and other symptoms.
- Provide outpatient emergency care, if feasible and if agreed by the patient and family, for symptoms causing great distress. Using national protocols, patients are maintained pain-free as far as is possible, using appropriate strong opioid dosages if necessary.
- Report back to, and may hold distance consultations with, referring providers.

The role of the family in palliative care

- With the help of health workers, the family will be involved in joint decision-making, will be kept informed of medical decisions, including changes in carers and treatment, and should be guided in best practices of palliative care.
- The patient's family and other carers can be taught to provide home-based care.

Table 1. Trained health workers able to perform palliative care tasks safely and effectively

	Medical doctor	Non-physician clinician	Nurse	Community health worker
Pain management				
Conduct pain assessments(s)	x	x	x	x
Treat mild, moderate and severe pain using chronic pain management guidelines, including oral morphine	x	x	x	
Teach the patient and caregiver how to give pain medicine, including oral morphine	x	x	x	x
Prevent, recognize and treat the side-effects of pain medications	x	x	x	
Advise on non-pharmacological methods of controlling pain	x	x	x	x
Treat extreme, non-responsive pain appropriately, including through the use of steroids where indicated	x	x		
Symptom management				
Manage other common symptoms (weight loss, nausea, fever, diarrhoea, trouble sleeping, anxiety etc.)	x	x	x	
Psychosocial support and end-of-life care				
Counselling, psychosocial and spiritual support	x	x	x	x
Support for patient at end of life	x	x	x	x
Support for caregivers, family members and children	x	x	x	x
Supervision				
Supervise non-physician clinicians, nurses and community health workers in above activities	x			
Supervise nurses and community health workers in above activities	x	x		
Supervise community health workers in above activities	x	x	x	

Source: WHO guidelines on task-shifting *(33)*.

Chapter 3

CLINICAL CARE DELIVERY

Clinical Care Delivery

Palliative care service in Kingdom of Saudi Arabia (KSA) started since 30 years ago. In 2016 Ministry of Health (MOH) launched the Palliative Care/Last Phase Initiative as part of the Transformation of Healthcare - Vision 2030 **[13].** By 2030, the Cancer care in KSA is expected to grow by five to 10-fold due demographics changing, with the age group most affected by cancer being the middle-aged and elderly **[14].**

Most of our patients want to remain at home at the end of their lives but we have wide variations in Community in KSA. In some areas we have well established home care delivered by a multidisciplinary team trained in palliative care, including doctors, nurses, community health workers, stoma care and volunteers, but in other areas patients must travel from village every few weeks at best to a distant hospitals.

The Preferred Place of Care Plan is a recommended tool for high quality terminal care. **(15, 16).** Wishes are not legally binding in KSA. Patient's wishes and plan of care should be frequently updated and revised**. (17-19)**

Current Models of Home Care in KSA is Palliative care consultation service provides care to people with chronic, life-limiting health problems such as cancer, advanced cardiac, renal and respiratory diseases, HIV/AIDS and chronic neurological disorders, in the home in which the patient lives. It is best delivered by a multidisciplinary team trained in palliative care, including doctors, nurses, community health workers and volunteers.

Our plan to implement guidelines for clinical delivery model in KSA, based on the domains described in the National Consensus Project for Quality Palliative Care. **[20],** which is a highly recommended resource for designing a palliative care program.

First, we created a patient identification algorithm to find prospective patients for the home-based palliative care program. Candidates for the program are patients with serious illness, multi morbidity. Serious illness was defined 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 **(21).**

Based on this definition admission criteria is stated as below

Admission Criteria

For patients to be eligible for enrolment in the home palliative care program, they should meet the following criteria:

1/ Diagnosis of an incurable cancer, terminal condition, where disease-modifying therapies are no longer possible (refer to attached disease-specific criteria).

2/ Diagnosis of chronic degenerative conditions such as ALS, Parkinson's, Muscular Dystrophy, Myasthenia Gravis or Multiple Sclerosis. The patient must meet at least one of the following criteria (1 or 2A or 2B):

1. Critically impaired breathing capacity, with all: Dyspnea at rest, Vital capacity < 30%, Need O2 at rest, patient refuses artificial ventilation
   OR
2. Rapid disease progression with either A or B below: Progression from :

Independent ambulation to wheelchair or bed-bound status normal to barely intelligible or unintelligible speech normal to pureed diet independence in most ADLs to needing major assistance in all ADLs

AND

A. Critical nutritional impairment demonstrated by all of the following in the preceding 12 months: Oral intake of nutrients and fluids insufficient to sustain life Continuing weight loss Dehydration or hypovolemia Absence of artificial feeding methods

OR

B. Life-threatening complications in the past 12 months as demonstrated by ≥1: Recurrent aspiration pneumonia, Pyelonephritis, Sepsis, Recurrent fever, Stage 3 or 4 pressure ulcer(s)

3/ Renal failure but the patient is not seeking dialysis or renal transplant, Creatinine clearance*is < 10 cc/min (15 for diabetics) and Serum creatinine > 8.0 mg/dl (> 6.0 mg/dl for diabetics)

4/ Stroke or coma, the patient has Poor functional status PPS* ≤ 40% and Poor nutritional status with inability to maintain sufficient fluid and calorie intake with ≥1 of the following: ≥ 10% weight loss in past 6 months ≥7.5% weight loss in past 3 months Serum albumin < 2.5 gm/dl

5/ Prognosis of 6 months or less if the disease follows its natural course based on best clinical knowledge and judgment

6/ Do-not-resuscitate order completed by the primary physician per the approved DNR policy

7/ Patient and family acceptance to comfort goals of care and enrolment in the program

In case the above criteria are not fulfilled, yet the patient requires intensive pain and symptom management at home, the home palliative care team can provide temporary services with goals specified by the primary care team. Such consults will be evaluated on a case-by-case bases.

Discharge Criteria

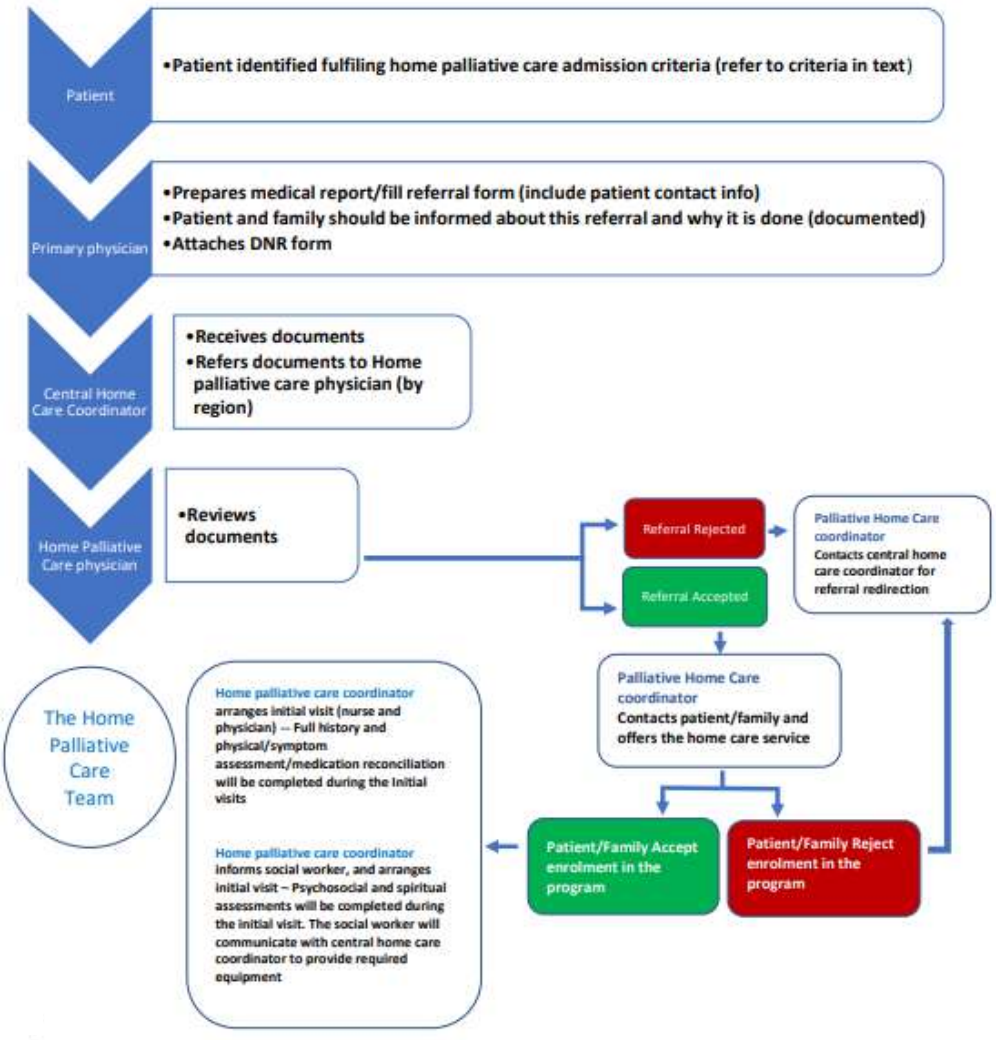
1. Death, Patient moves out of area or Patient and/or family no longer wish to continue receiving the service,

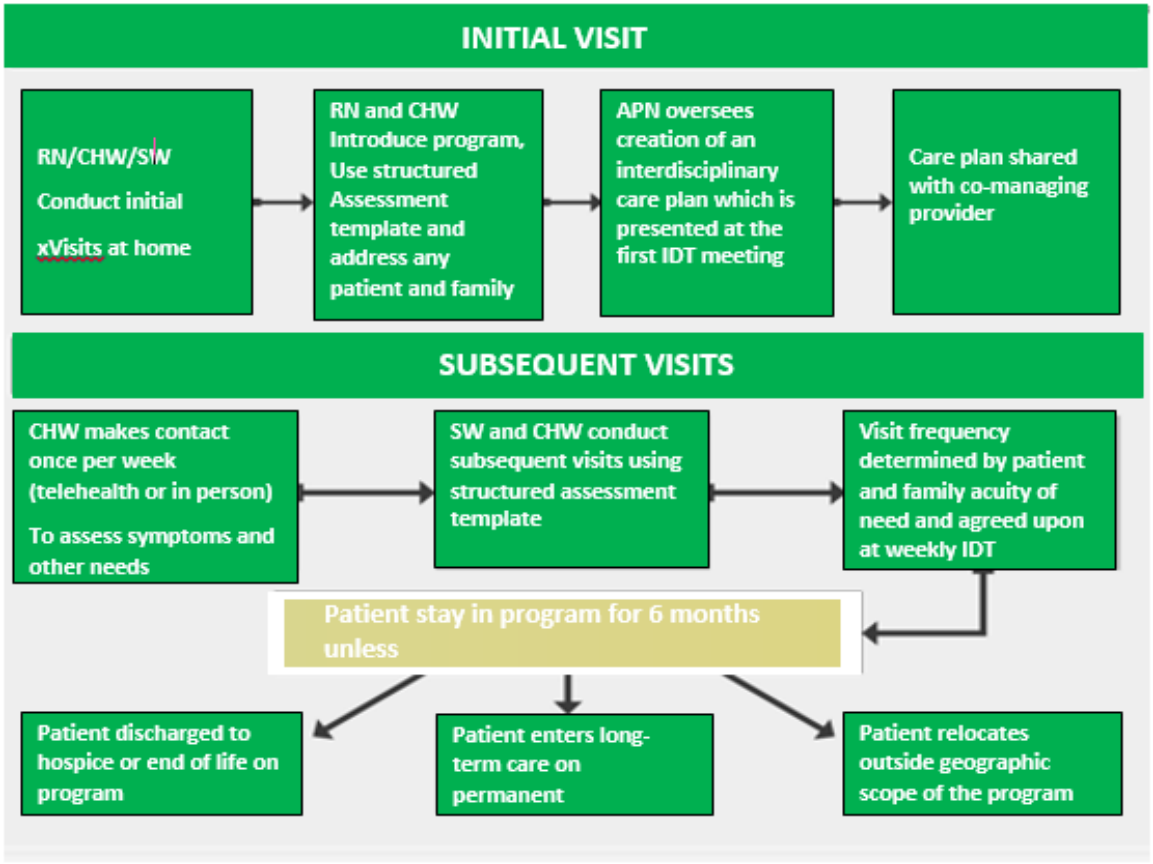
2. End of program Discharge to Hospice or Long-term care

3. Continuation of service jeopardies the safety of health care professionals providing it

It is difficult to estimate prognosis even when a patient is imminently dying. **(22)** Several symptom scores used as prognostic tools, we use the Edmonton Symptom Assessment Scale (ESAS-r). **(23)** and Palliative Performance Scale (PPSv2) **(24)**

Home-based Palliative Care Program Pathway




INITIAL VISIT
RN/CHW/SW
Conduct initial
xVisits at home
RN and CHW Introduce program, Use structured Assessment template and address any patient and family
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
Patient relocates outside geographic scope of the program

Initial Assessment

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: …….

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?

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 swallow

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

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

……
……
……

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

……
……
……

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

……
……
……

CAREGIVER SUPPORT:

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

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: …….

Advanced care planning: (ACP)

Advance care planning Advance care planning is a voluntary process of discussion about future care between an individual and their care providers, irrespective of discipline.

It is recommended nowadays to have an Advance Care Planning. **(25, 27).** Although making plans and strategies are part of Islamic traditions, KSA has no law permitting provisions for ACP and advance refusal of treatment.

Our policies to ensure that advance care planning is offered to adults at end of life, to ensure that each have a copy of their advance care plan available with them if admitted to care home and involved carers and family in advance care planning, at end of life if patient agrees.

An advance care planning discussion might include:

• The individual's concerns and wishes

• Their important values or personal goals for care

• Their understanding about their illness and prognosis

• Their preferences and wishes for types of care or treatment that may be beneficial in the future and the availability of these. Advance care planning is one part of the process of personalized care and support planning.

Decision making and illness understanding:

1. APP: Patient Rights and Responsibilities
2. Dealing with Life Threatening Emergencies in a Patient's Home
3. End-of-Life Care
4. Intravenous Patient Controlled Analgesia (IV-PCA) for Acute Pain Management
5. Medication Administration
6. Narcotics and Controlled Drugs
7. Nursing Screening/Assessment, Reassessment System and Documentation
8. Palliative Medicine Referrals
9. Referral to the Home Medicine Program
10. Clinical Consultation Form
11. Edmonton Symptom Assessment Scale (ESAS)
12. Multidisciplinary Patient and Family Education Record
13. Multidisciplinary Progress Notes
14. Pain Assessment/Reassessment-Nursing Services
15. Palliative Medicine Nursing Flowsheet: Patient Controlled Analgesia (PCA)
16. Palliative Medicine Physician Order: Patient Controlled Analgesia (PCA)
17. Report of Waste/Breakage/Loss of Narcotic and Controlled Drug
18. Richmond Agitation Sedation Scale (RASS) (Form No. 407/005)
19. Treatment Flow Sheet/Home Visit Physical Assessment/Pain Assessment/Reassessment

Chapter 4

EVALUATION

Evaluation and continuous improvement are important to the development and sustainability of the Home Palliative Care program. Executing the evaluation plan will help you identify and target areas for improvement to ensure quality care and patient and staff satisfaction. The evaluation plan is a systematic approach to collecting. Data and evaluating the results to determine if you are meeting your goals, providing beneficial patient care, and creating value for all stakeholders.

Getting Started

One approach to develop an evaluation plan and identify the right indicators to monitor is to use a logic model. This approach was used by the Centers for Disease Control (CDC) and the Agency for Healthcare Research and Quality (AHRQ) to assess the effectiveness of their programs.

The logic model provides a visual representation of the inputs, outputs, and impacts (short, medium, and long-term) that encourages you to think critically about what you want to achieve and how to get there. The logic model gives you a framework to think about the assets, activities, and stakes you have or need to achieve your goal and create an impact.

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

Patient Outcome and Process Metrics

An important part of the evaluation plan is to include the assessment and process measurements. These measures may be administrative and/ or clinical in nature, but are intended to measure the quality of care provided and the effectiveness of the care provided. For example, the 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

Note:

The National Quality Forum endorsed several measures to assess patient quality and convened experts to propose quality measures in areas where metrics are lacking. These guidelines can be helpful in considering what to consider when providing clinical care.

Operational measures of process are important metrics to implement in your program because these measures provide insight into 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 when there is a plan to review, discuss, and remediate processes when those processes fail. The Plan-Do-Study-Act (PDSA) is a simple and systematic way to study program problems and test solutions. When you start a program, it may be best to repeat the elements of the program, e.g. B. Planning and travel/visit times. The availability of data to support decision making will facilitate decision making and redirect the clinical team towards a shared goal.

As you begin to define quality metrics, review existing palliative care registries. National Palliative Care led by CAPC, Global Palliative Care Quality Alliance and Palliative Care Quality Network. Each of these registers has a different purpose and provides tools to implement data collection, benchmarking and process improvement project.

CLOSING

It is quite evidenced by most of health professionals and authorities worldwide, and due to sophisticated health care developments during the last century, population ages prolonged by the innovative models that provide high quality of care, Hence, the chronic illnesses care population are increasing dramatically. A fraction of the population is cancer patients which are also increasing in number worldwide, By 2030, the Cancer care in KSA is expected to grow by five to 10-fold due demographics changing, with the age group most affected by cancer being the middle-aged and elderly **[14].** with the modern notion that palliative care must be provided to cancer patients and family at same time of diagnosis till the end of life and even after death of the patient, these population changes and to improve quality of life with cost-effective management, mandatory to establish a well-trained professional home and community palliative care team.

The goal of this practical guide is to provide guidance, workflows, assessment, and real-world examples of program development implementations and evaluation of home-based palliative care program.

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APPENDICES

Appendix 1: Sample Templates for Communicating with Providers

Appendix 2: Brochure

Appendix 3: NURSING INTAKE ASSESSMENTS

Appendix 4: Social Worker Initial Assessment

Appendix 5: CHW Weekly Check-in

APPENDIX 1

Sample Templates for Communicating with Providers

Sample Letter Template:

Communication to Provider Asking Permission for Patient admission to palliative home health care (PHHC) services.

Dear Dr. [insert provider name]

We are writing to inform you that your patient [insert name and Medical Record Number MRN] who is admitted to hospital has been identified to fit our admission criteria for PHHC services. Further information about these services are attached to this email [attach information about your program to email].

We are waiting for your permission to approach the patient to introduce these PHHC services. If you agree (please answer Yes or No all)?

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

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 Provider Asking for Permission for Outreach Patient

Dear Dr. [insert name]

We sent this letter to inform you that your patient [name/ MRN] has enrolled to receive our palliative home health care services for patients with serious illness led by [name of HHC leadership]. Further information about these services are attached to this email [attach information about your program to email].

We will continue to update you about your patient's progress for the entire time that he/she receives these services. If we need to make any significant changes in the plan of care, we will notify 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 based National Saudi guidelines for symptoms and other palliative care related problems management.

It would be helpful for us if you kindly indicate for us your preferred mode of communication and the corresponding contact information: an Email, Cell-phone, Hospital phone or Social media please

Is there anything else we should know about this patient (e.g., social, financial, family dynamics and/or home-living situation that affect health status?

Thanks for your time and consideration. We look forward to working together. Please let us know if 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

1) Symptom {case summery}
2) Treatment successes and failures during time on program:
3) Current status:

Caregiver Education and Support

1) Caregiver needs identified
2) Actions taken: z
3) Current caregiver status:

Social Needs

1) Social needs identified:
2) Actions taken:
3) Current social care needs and outstanding issues:

Advanced Care Planning

1) Illness understanding at program enrollment:
2) Goals of care discussions during time on program
3) Current illness understanding
4) Current documentation of advance directive:

Recommendations for ongoing assessment:

Sample Letter Template:

Communication to Primary Care Provider when Patient Dies

Dear [Dr. / NP]

We are sorry to inform you that your patient [name, MRN] passed away today (date/time) at his/her home

Our Doctor [name] now is completing the death certificate which will be issued according to regulations and our Social Worker will provide bereavement support.

Please don't hesitate to contact us if you need more details or have any questions.

Thanks

Administrative Assistant [Program name)

APPENDIX 2

Brochure

الرعاية الصحية المنزلية
Home Health Care

Palliative Care

How does the program work?

I. 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

Athorough assesment of your needs, including symptoms, medications, support network, understanding of care,and whatever matters to you.

Development of care plantased around your needs and goals

Close collaboration with the other health providers involved in your care.

II. 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 prefrences.

Who will I see on the care team?

The care team will include registred nurse, a social worker, and a community health worker. they will be supported by a nurse practitioner and apalliative care physician. out of normal hours you can contact a palliative care physician for advice.

APPENDIX 3

Nursing Intake Assessments

Initial assessment Template:

Nursing

☐ New Referral Hospital Assessment
☐ Reassessment Initial Home Visit
☐ Reassessment Post Readmission to Hospital
☐ New Referral Initial Assessment at Home (Home bound Patient)
☐ Reassessment (60 days)
☐ Discharge From Home Care Service
☐ Reassessment Post Presentation to Emergency Unit
☐

Patient History

Diagnosis

Past Medical History

Reason for Referral

Lifestyle History

☐ Not Applicable (Child)

Smoking ☐ Non Smoker ☐ Ex Smoker ☐ Smoker Packs per day

Alcohol ☐ Never drink ☐ Drank in the past but do not drink now ☐ Drink casually Type of alcohol bottle per day

Exercise ☐ Never exercised ☐ Exercised in the past but not now ☐ Does exercise Type of exercise hours per day

Weight kg

Height cm

BMI

Recent Allergy

Any Drug Allergy ☐ No ☐ Yes Specify

Other Allergy

☐ Food ☐ No ☐ Yes Specify
☐ Environment ☐ No ☐ Yes Specify
☐ Others ☐ No ☐ Yes Specify

Laboratory and Other Investigations (Done)

Blood

Urine / Swab

Other Investigations

Physical Symptoms/ Psychological Symptoms/ Functional Status/ Nutrition:

Physical symptom assessment:

Date:		Time:	
Diagnosis: Pain Management Symptom Management Subcutaneous Infusion			
Potential/Actual Risk			
Pain Related to disease process			
Ineffective pain management			
Nutritional deficit related to poor oral intake			
Nausea and/or vomiting related to medication/treatment			
Constipation related to medication/immobility/decrease food or fluid intake			
Breathlessness related to disease process			
Psychosocial issues related to terminal prognosis			
Measurable Goals (By Review Date)			
Will maintain adequate level of comfort as evidenced by no signs and symptoms of unrelieved pain or distress			
Verbalizing relief of pain with ordered medications.			
Will function at optimal level within limitations imposed by disease process			
Verbalizing satisfaction with level of comfort			
Will demonstrate adjustment to end of life situation by verbally expressing feelings about death with family or social worker			
Expressing through words or actions understanding of what is happening (example dying process)			
Patient Assessment			
Presence of pain		Presence of nausea	
Pain Score		Presence of vomiting	
Pain assessment tool used		Presence of constipation	
Pain relieve with medication		Frequency	
Narcotics		**Caregiver Assessment**	
Regular dose		Management of patient's pain	
Breakthrough dose		Management of patient's nutrition	
Number of breakthrough dose taken today		Coping psychologically	
Narcotic supply enough till next visit		Coping with patient's care	
Patient Caregiver Education			**Advice given**
Ensure that patient taking analgesia as prescribed			
Ensure that there is sufficient pain medication to last till next visit			
Advise activity or movement 1 hour after taking pain medication			
Advise to increase fluids as tolerated			
Advise to take stool softeners for constipation			
Encourage mobility as tolerated			
Take anti emetics 30 minutes before taking food			
Take small frequent meals			
Advise taking juice or liquid nutrients			
Nurse's Name, Designation and Stamp:			
Signature:		Badge Number:	

Pain assessment

Pain Score ☐ 10

Pain Assessment Tool Used

☐ Numerical ☐ Wong-Baker Faces ☐ FLACC ☐ ABBEY

Presence of pain	Location	Provoking factor	Quality	Radiation	Time
☐ No ☐ Yes	☐ Head ☐ Chest ☐ Limbs ☐ Abdomen ☐ Back	☐ Food ☐ Rest ☐ Movement ☐ Palpation ☐ Other	☐ Dull ☐ Sharp ☐ Burning ☐ Colicky ☐ Other	☐ No ☐ Yes	☐ Gradual ☐ Sudden ☐ Constant ☐ Intermittent ☐ Other:

Comment:

Head

Vision ☐ Normal ☐ Visually Impaired ☐ Cataract | Blind ☐ Trauma | Other _____

Pupil Size Right ☐ mm Left ☐ mm **Response** Right ☐ Left ☐ **Equal** ☐ No ☐ Yes

Hearing ☐ Normal ☐ Diminished ☐ Loss ☐ Use hearing aid

Comment:

Speech ☐ Normal ☐ Impaired ☐ Unable to talk ☐ Tracheostomised ☐ Nil
☐ Slurred ☐ Aphasic ☐ Incoherent ☐ Other _____

Swallowing ☐ Normal ☐ Impaired ☐ Normal gag reflex ☐ Poor gag reflex ☐ No Gag reflex
☐ Other _____

Appearance ☐ Normal ☐ Abnormal, specify: _____ Head Circumference (Infant): _____

Mouth: ☐ Normal ☐ Ulcer ☐ Bleeding ☐ Odour

Lips: ☐ Normal ☐ Cracked ☐ Dry ☐ Other

Nose: ☐ Normal ☐ Flaring ☐ Discharges ☐ Other

Comment for Head Assessment:

Neck

Appearance ☐ Normal ☐ Jugular vein distension ☐ Enlarged Thyroid ☐ Surgical wound

☐ Tracheostomy brand _____ Size _____ Date Trached _____

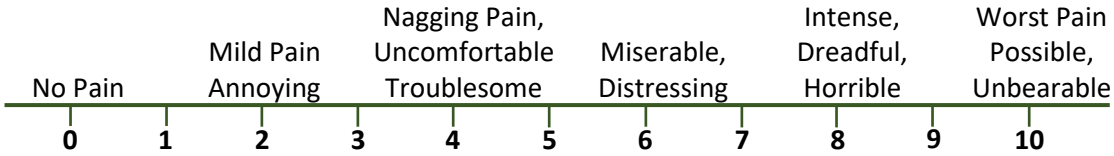
Date Inserted _____ Due date for change _____ ☐ Cuffed ☐ Un-cuffed

Comment for Neck:

PAIN RATING SCALES

FACES SCALE

NUMERIC SCALE



FLACC SCALE

	0	1	2
FACE	No particular expression of smile	Occasional grimace or frown, withdrawn, disinterested	Frequent to constant frown, clenched jaw, quivering chin
LEGS	Normal position or relaxed	Uneasy, restless, tense	Kicking or legs drawn up
ACTIVITY	Lying quietly, normal position, moves easily	Squirming, shifting back and forth, tense	Arched, rigid or jerking
CRY	No crying (awake or sleep)	Moans or whimpers, occasional complaint	Crying steadily, screams or sobs, frequent complaints
CONSOLABILITY	Content, relaxed	Reassured by occasional touching, hugging or “talking to”. Distractible	Difficult to console or comfort

Edmonton Symptom Assessment System shall be completed for in-patient at initial assessment and every week

The ESAS-r shall be completed for palliative care patients at home as follows:

Each time the patient is contacted by telephone or in person

Weekly if symptoms are in good control, and there are no predominant psychosocial issues

Edmonton Symptom Assessment System: (revised version) (ESAS-R) -English

No Pain	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Pain**
No Tiredness *(Tiredness = lack of energy)*	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Tiredness**
No Drowsiness *(Drowsiness = feeling sleepy)*	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Drowsiness**
No Nausea	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Nausea**
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Lack of Appetite**
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Shortness of Breath**
No Depression *(Depression = feeling sad)*	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Depression**
No Anxiety *(Anxiety = feeling nervous)*	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Anxiety**
Best Wellbeing *(Wellbeing = how you feel overall)*	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible Wellbeing**
No _____ **Other Problem** *(for example constipation)*	0	1	2	3	4	5	6	7	8	9	10	**Worst Possible** _____

Completed by (check one)

☐ **Patient**

☐ **Family Caregiver**

☐ **Healthcare professional caregiver**

☐ **Caregiver assisted**

Name: _____ **Date:** _____

Signature: _____ **Time:** _____

"BODY DIAGRAM ON PAGE 2"

تقييم أعراض ادمونتون
(نسخة مراجعة)

Edmonton Symptom Assessment System: (revised version) (ESAS-R) – Arabic

لا يوجد ألم	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد تعب *(التعب = نقص الطاقة)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد شعور بالنعاس *(النعاس = الشعور بالنوم)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد غثيان	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد نقص في الشهية	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد ضيق في التنفس	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد اكتئاب *(الاكتئاب = الشعور بالحزن)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد قلق *(القلق= الشعور بالإضطراب العصبي)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
الشعور التام بالصحة والسعادة *(ما تشعر به عموماً)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن
لا يوجد _____ *أي مشكلة أخرى (الإمساك على سبيل المثال)*	٠	١	٢	٣	٤	٥	٦	٧	٨	٩	١٠ أسوأ شعور ممكن

تم تعبئة النموذج من قبل (اختر واحداً):

- ☐ المريض
- ☐ مقدم الرعاية الصحية من أسرة المريض
- ☐ مقدم الرعاية الصحية في المستشفى
- ☐ بمساعدة مقدم الرعاية الصحية

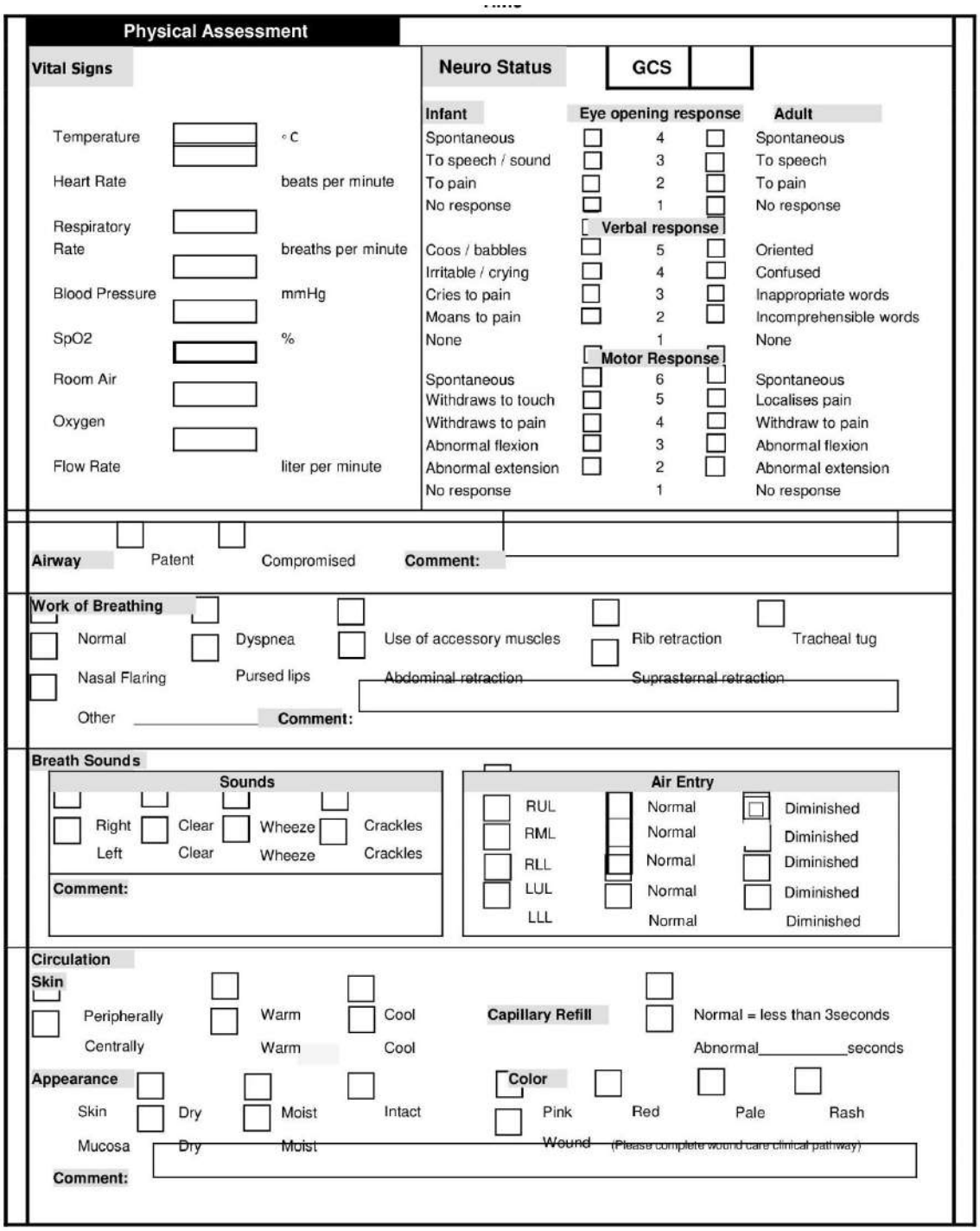
اسم المريض _____ التاريخ _____

التوقيع _____ الوقت _____

"رسم توضيحي للجسم من الجهة الخلفية"

Physical Function Assessment:

Complete Palliative Performance Scale



Physical Assessment

Vital Signs

Temperature		◦C
Heart Rate		beats per minute
Respiratory Rate		breaths per minute
Blood Pressure		mmHg
SpO2		%
Room Air		
Oxygen		
Flow Rate		liter per minute

Neuro Status **GCS**

Infant	Eye opening response	Adult
Spontaneous	4	Spontaneous
To speech / sound	3	To speech
To pain	2	To pain
No response	1	No response
Verbal response		
Coos / babbles	5	Oriented
Irritable / crying	4	Confused
Cries to pain	3	Inappropriate words
Moans to pain	2	Incomprehensible words
None	1	None
Motor Response		
Spontaneous	6	Spontaneous
Withdraws to touch	5	Localises pain
Withdraws to pain	4	Withdraw to pain
Abnormal flexion	3	Abnormal flexion
Abnormal extension	2	Abnormal extension
No response	1	No response

Airway Patent Compromised **Comment:**

Work of Breathing

Normal Dyspnea Use of accessory muscles Rib retraction Tracheal tug

Nasal Flaring Pursed lips Abdominal retraction Suprasternal retraction

Other **Comment:**

Breath Sounds

Sounds				
Right	Clear	Wheeze	Crackles	
Left	Clear	Wheeze	Crackles	

Comment:

Air Entry		
RUL	Normal	Diminished
RML	Normal	Diminished
RLL	Normal	Diminished
LUL	Normal	Diminished
LLL	Normal	Diminished

Circulation

Skin

Peripherally Warm Cool **Capillary Refill** Normal = less than 3seconds

Centrally Warm Cool Abnormal_____seconds

Appearance **Color**

Skin Dry Moist Intact Pink Red Pale Rash

Mucosa Dry Moist Wound (Please complete wound care clinical pathway)

Comment:

Palliative Performance Scale (PPS): Is a tool developed as an excellent communication tool for quickly describing a patient's current functional level. It appears to have prognostic value. PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient which is then assigned as the PPS% score.

Palliative Performance Scale (PPSv2) version 2 Form

☑	PPS Level	Ambulation	Activity and Evidence of Disease	Self-Care	Intake	Conscious Level
☐	100%	Full	Normal activity and work No evidence of disease	Full	Normal	Full
☐	90%	Full	Normal activity and work Some evidence of disease	Full	Normal	Full
☐	80%	Full	Normal activity and work Some evidence of disease	Full	Normal or Reduced	Full
☐	70%	Reduced	Unable Normal Job or Work Significant Disease	Full	Normal or Reduced	Full
☐	60%	Reduced	Unable to do hobby or house work Significant Disease	Occasional Assistance Necessary	Normal or Reduced	Full or Confusion
☐	50%	Mainly Sit or Lie	Unable to do any work Extensive Disease	Considerable Assistance Required	Normal or Reduced	Full or Confusion
☐	40%	Mainly in Bed	Unable to do most activity Extensive Disease	Mainly Assistance	Normal or Reduced	Full or Drowsy + or - Confusion
☐	30%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Normal or Reduced	Full or Drowsy + or - Confusion
☐	20%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Minimal to Sips	Full or Drowsy + or - Confusion
☐	10%	Totally Bed Bound	Unable to do any activity Extensive Disease	Total Care	Mouth Care Only	Drowsy or Coma + or - Confusion
☐	0%	Death	Not Applicable	Not Applicable	Not Applicable	Not Applicable

Name and Stamp: _____ **Signature:** _____ **Date:** _____ **Time:** _____

Palliative Performance Scale (PPSv2) [Internet]. 2017 [accessed June 23/2023]. Available from: http://palliative.info/resource_material/PPSv2.pdf

Psychological Assessment:

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

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.

Cognitive Assessment:

Complete mini-Mental State Examination (MMSE)

Mini-Mental State Examination (MMSE) Form

Diagnoses	

Category	Item	Score guide	Score
Orientation 1 point for each answer	Ask: what is the:	1 = Date 1 = Day 1 = Month 1 = Year 1 = Season or Time	/5
	Ask: Where we are:	1 = Country 1 = City 1 = Hospital 1 = Ward or room number 1 = What city is the Kabba in?	/5
Registration Score 1,2,3 points according to how many are repeated	Name three objects give the patient one second to say each. Then ask the patient to repeat all three after you have said them. Repeat until the patient learns the three.	1 = Cup 1 = Book 1 = Table	/3
Attention& Calculation 1 point for each correct subtraction	Ask the patient to: begin from 100 and count backwards by 7. Stop after 5 correct answers.	1 = 93 1 = 86 1 = 79 1 = 72 1 = 65	/5
Recall 1 point for each correct answer	Ask the patient to: name the three objects from above	1 = Cup 1 = Book 1 = Table	/3
Registration 			/2
			/1
			/3
			/1
			/1
			/1
Total Score			/30

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 swallow

Examination:

Physical Assessment

Vital Signs

Temperature		◦C
Heart Rate		beats per minute
Respiratory Rate		breaths per minute
Blood Pressure		mmHg
SpO2		%
Room Air		
Oxygen		
Flow Rate		liter per minute

Neuro Status

GCS

Infant	Eye opening response		Adult
Spontaneous	4		Spontaneous
To speech / sound	3		To speech
To pain	2		To pain
No response	1		No response
	Verbal response		
Coos / babbles	5		Oriented
Irritable / crying	4		Confused
Cries to pain	3		Inappropriate words
Moans to pain	2		Incomprehensible words
None	1		None
	Motor Response		
Spontaneous	6		Spontaneous
Withdraws to touch	5		Localises pain
Withdraws to pain	4		Withdraw to pain
Abnormal flexion	3		Abnormal flexion
Abnormal extension	2		Abnormal extension
No response	1		No response

Airway ☐ Patent ☐ Compromised **Comment:**

Work of Breathing

☐ Normal ☐ Dyspnea ☐ Use of accessory muscles ☐ Rib retraction ☐ Tracheal tug

☐ Nasal Flaring ☐ Pursed lips ☐ Abdominal retraction ☐ Suprasternal retraction

Other _____ **Comment:**

Breath Sounds

Sounds				
	Clear	Wheeze	Crackles	
☐ Right	☐	☐	☐	
☐ Left	☐	☐	☐	

Comment:

Air Entry		
☐ RUL	☐ Normal	☐ Diminished
☐ RML	☐ Normal	☐ Diminished
☐ RLL	☐ Normal	☐ Diminished
☐ LUL	☐ Normal	☐ Diminished
☐ LLL	☐ Normal	☐ Diminished

Circulation

Skin

	Warm	Cool	
☐ Peripherally	☐	☐	
☐ Centrally	☐	☐	

Capillary Refill ☐ Normal = less than 3seconds ☐ Abnormal_____seconds

Appearance

	Dry	Moist	Intact
☐ Skin	☐	☐	☐
☐ Mucosa	☐	☐	

Color ☐ Pink ☐ Red ☐ Pale ☐ Rash ☐ Wound (Please complete wound care clinical pathway)

Comment:

Chest & Respiratory

Appearance ☐ Normal ☐ Kyphosis ☐ Scoliosis ☐ Kyphoscoliosis
☐ Drain tube ☐ Scars ☐ Wounds

Comment:

Chest Investigations ☐ None

Comments

☐ CXR Date _____
☐ CT Pulmonary Angiogram Date _____
☐ Ventilation-Perfusion Scan Date _____
☐ Other Date _____

Abdomen

Appearance
☐ Normal ☐ Distended ☐ Scars ☐ Wound ☐ Stoma ☐ Other _____

Bowel Movement: ☐ Normal ☐ Abnormal **Bowel Sounds:** ☐ Active ☐ Nil ☐ Hyperactive

Bowel Habit: ☐ Daily ☐ Other _____

*Colostomy/Ileostomy: ☐ N.A. ☐ Active ☐ Inactive Product: ☐ Other:

Comment:

Gastrointestinal *** Indicates high nutritional risk**

Appetite: ☐ Good ☐ Fair ☐ Poor* Comment: _____

***Enteral Nutrition:** ☐ NGT ☐ PEG tube Frequency: _____ Amount: _____

Nutritional status: ☐ Good ☐ Fair ☐ Poor*

Nausea ☐ Yes ☐ No

Vomiting ☐ Yes ☐ No

Comment:

Renal

Voiding
☐ Normal ☐ Indwelling Catheter ☐ Suprapubic ☐ Urosheath ☐ Incontinent
☐ Dysuria ☐ Yes ☐ No **Urine Color** ☐ Normal ☐ Abnormal
☐ Haematuria ☐ Yes ☐ No **Urine Clarity** ☐ Clear ☐ Cloudy
☐ Frequency ☐ Yes ☐ No

Comment:

Musculoskeletal

☐ Normal Movement ☐ Impaired Mobility ☐ Bedridden ☐ Wheelchair bound

Requires Assistant with ADLS ☐ No ☐ Yes **Gait / Balance**

Requires Assistant with Movement ☐ No ☐ Yes ☐ NA ☐ Steady ☐ Unsteady

Upper Limbs:

☐ Normal Power	☐ Rt Limb	☐ Lt Limb
☐ Mild Weakness	☐ Rt Limb	☐ Lt Limb
☐ Severe Weakness	☐ Rt Limb	☐ Lt Limb
☐ No movement	☐ Rt limb	☐ Lt Limb

Lower Limbs:

☐ Normal Power	☐ Rt Limb	☐ Lt Limb
☐ Mild Weakness	☐ Rt Limb	☐ Lt Limb
☐ Severe Weakness	☐ Rt Limb	☐ Lt Limb
☐ No movement	☐ Rt Limb	☐ Lt Limb

Wound:

Wound History:					
Type Of Wound					
☐ Pressur Ulcer ☐ Surgical ☐ Diabetic ☐ Other					
Factors Influencing Wound Healing					
☐ Diabetes ☐ Immobility ☐ Tissue Perfusion ☐ Incontinence ☐ Malnutrition ☐ Infection ☐ Blood Related ☐ Immunocompromised ☐ Other					
Potential Risk					
☐ Infection ☐ Poor Healing ☐ Others					
Measurable Goals (By Review Date)					
☐ Free from signs of infection ☐ Increase in area granulating tissue ☐ Free from skin excoriation ☐ Free from necrosis					
Wound Assessment					
Wound Number	1	2	3	4	5
Analgesia pre dressing:	No	No	No	No	No
Wound Base: Necrotic	%	%	%	%	%
Stough (yellow)	%	%	%	%	%
Granulation (red)	%	%	%	%	%
Epithelialisation (pink)	%	%	%	%	%
Other:	%	%	%	%	%
Exudate Volume:					
Exudate Type:					
Offensive Odour:					
Surrounding Skin:					
Measurement: Length	cm	cm	cm	cm	cm
Width	cm	cm	cm	cm	cm
Depth	cm	cm	cm	cm	cm
Undermining					
Dressing Plan					
Location of wound					
Dressing Frequency					
Clean / Irrigate with:					
Periwound Skin Care:					
Primary Dressing					
Secondary Dressing					
Secure with:					
Pressure Ulcer Stage					

Type of Surgery/Procedure Done:				
Type of drain/catheter inserted: ☐ Pleurx ☐ Pigtail ☐ Jackson Pratts ☐ other:				
Location: ☐ Chest ☐ Abdomen ☐ other:Specify:				
Type of Drainage: ☐ Free Drainage ☐ Vaccum ☐ other:Specify:				
Potential/Actual Risk				
Drain site infection				
Seroma Formation				
Dislodgement of drain tube				
Measurable Goals (By Review Date)				
Drain site will remain free from infection				
Drainage system will remain patent with vacuum intact				
Drain tube will be removed if less than 30mls drainage in last 24 hours				
Drain remains insitu and drainage done as per doctor's order				
Patient Assessment				
Vital signs remain within normal limits				
Patient's pain under control with regular analgesia				
Performing arm exercises as required				
Drain Tube and Site Assessment				
Dressing dry and Intact:		Nature of drainage:		
Presence of drain site infection:		Drainage amount last 24hrs:		
Presence of leakage		Drain tube removed:		
Follow Up Care		**Psychological Needs**		
Other service required:		Support Needs:		
Breast Care Clinic Appointment:		Patient care maintained:		
Review dates:		Caregiver coping:		
Patient/Caregiver Education				
Patient understands importance of drain to be carried not dragged				
Actions to take if leaking or tube becomes dislodged				
Understands when suction is Off/On				
Taking analgesia regularly or as required				
Measuring and recording drainage as required				
Report increase of temperature, change in color and amount of drainage				
Discharge education post removal of draintube				
Self drainage procedure				

Medication profile:

Medications Profile	Drug Allergy: ☐ Yes :specify			☐ No	
Prescriber	**Drug Name**	**Quantity**	**Frequency**	**Route**	**Expiry Date**
Over the counter, Natural and/or Herbal Medications					
Potential Contraindication, Drug Reaction and Interaction					
Category	**Medication**	**Action Done**			
Reason for Medication Review:	60 days summary	**Next Review:**			
The above medication has been reviewed and checked for potential contraindication, drug reaction and interactions according to DPP: Medication Record 01020303/017/33					
Admission History	☐ Readmission History(include ER presentation)				

APPENDIX 4

Social Worker Initial Assessment

Initial Assessment Template

Social work

- Name: ……..
- Age: Gender:
- Date of Visit… /……. /…….
- Location of Visit:
- Persons Present:
- Current Advance Directives: ☐ **Yes** ☐ **No**

SOCIAL WORKER INITIAL ASSESSMENT

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

☐ Yes ☐ No, If not, Specify ……..

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

☐ Yes ☐ No, If not, Specify ……..

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

☐ Yes ☐ No, If not, Specify ……..

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

☐ Yes ☐ No, If not, Specify ……..

Housing and Social Support Environment Review:

- What is your housing situation today?
  Answer: ……
- Do you have any problems with your housing? (e.g., mold, inadequate heat, bug infestation)

  ☐ **Yes** ☐ No If not, Specify ……..

- Do you have any problems with your housing?

  ☐ **Yes** ☐ No If not, Specify ……..

- Are you worried that in the next few months, you may not have stable housing?

  ☐ **Yes** ☐ No If not, Specify ……..

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

  1) How often do they visit?
     Answer ……..
  2) How is your relationship with them?
     Answer ……..
  3) Do they help you with anything?
     ☐ **Yes** ☐ No, If not, Specify ……..
  4) Do you ever have to care for someone else?
     ☐ **Yes** ☐ No, If not, Specify ……..
  5) Do you socialize much outside of your home?
     ☐ **Yes** ☐ No, If not, Specify ……..
  6) Are you involved with any community groups?
     ☐ **Yes** ☐ No, If not, Specify ……..
  7) Do you often feel as though you lack companionship?
     ☐ **Yes** ☐ No, If not, Specify ……..
  8) Aside from the people you mentioned
     ☐ **Yes** ☐ No, If not, Specify ……..

9) Doing what (……), how often (……..)
10) Home Attendant Agency Name (……)
11) Hours per week (……)
12) How long has your current HA / HHA worked with you? (……..)
13) Do you feel you need help with anything inside or outside the home?

Current Home Equipment Review:

Commode:

☐ **Yes** ☐ No, If not, Specify ……..

Hospital Bed:

☐ **Yes** ☐ No, If not, Specify ……..

Cane:

☐ **Yes** ☐ No, If not, Specify ……..

Walker:

☐ **Yes** ☐ No, If not, Specify ……..

Wheelchair:

☐ **Yes** ☐ No, If not, Specify ……..

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

☐ **Yes** ☐ No, If not, Specify ……..

Transportation Needs Review:

How often do you get out of your home?

☐ Yes ☐ No, If not, Specify ……..

Do you need anyone to help you get out of your home?

☐ Yes ☐ No, If not, Specify ……..

Do you need any assistive devices when you are out of your home?

☐ Yes ☐ No, If not, Specify ……..

What mode of transportation do you use? (……)

Public transportation, Driving, Some other arrangement

Do you have any difficulty using public transportation or driving?

☐ Yes ☐ No, If not, Specify …….

Do you use any transportation services?

☐ Yes ☐ No, If not, Specify …….

In the last 12 months, has lack of transportation kept you from medical appointments or from getting the things needed for your daily life?

☐ Yes ☐ No, If not, Specify …….

Do you feel you need any additional transportation services?

☐ Yes ☐ No, If not, Specify …….

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

- Do you have any problems paying utility bills? (……..)
- In the last 12 months, has the electric, gas, oil or water companies threatened to cut off the supply to your home? (……..)
- Do you have any problems affording food? (……..)
- In the last 12 months, did you ever worry the food would run out before you had money to pay for more? (……..)
- 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? (……..)
- Do you or have you ever received food stamps or SNAP?

  ☐ Yes ☐ No, If not, Specify …….
- Do you have any problems affording the cost of your medications?

☐ Yes ☐ No If not, Specify ……..

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

☐ Yes ☐ No If not, Specify ……..

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

☐ Yes ☐ No If not, Specify ……..

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

☐ Yes ☐ No If not, Specify ……..

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 ……

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

1) Emergency Contact:
2) Address:
3) Mobile Phone:
4) Work Phone:
5) Relationship:

Extended Emergency Contact Information:

1) Emergency Contact:
2) Address:
3) Mobile Phone:
4) Work Phone:

Relationship: TIME SPENT Completing Assessment:

i. Start time:
ii. End time:
iii. Total time:

Living arrangement: (Yes /No)

1) Lives alone.

☐ Yes ☐ No

2) Lives with family. If so, specify:

☐ Yes ☐ No If not, Specify ……..

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

☐ Yes ☐ No If not, Specify ……..

4) Apartment building – walkup

☐ Yes ☐ No If not, Specify ……..

5) Apartment building – elevator

☐ Yes ☐ No

6) Private house

☐ Yes ☐ No

APPENDIX 5

Weekly Check-in

Weekly Check-in Template:

Community Health Worker

Visit Date (…… / ……./……)

Present during visit: (……..)

Interval Changes

1) General health status/ problems in the past week (……..)

2) Is the patient able to take all their medications as prescribed?
   ☐ Yes ☐ No If not, Specify ……..

3) What problems do they have taking their medications as prescribed?
   (……)

4) Hospitalization / ED / office visits since last contact?
   ☐ Yes ☐ No If not, Specify ……..

5) Upcoming doctor visits / therapies / procedures? χ No χ Yes:
   ☐ Yes ☐ No If not, Specify ……..

6) Status of outstanding referrals / durable medical equipment orders?
   (……)

Edmonton Symptom Assessment System: (revised version) (ESAS-R) -English – Arabic

Edmonton Symptom Assessment System shall be completed for in-patient at initial assessment and every week

Functional Status:

☐ Complete Palliative Performance Scale

Community Health Worker Initial Assessment Template

Goals of Care/Advance Care Planning:

Goals of care discussed today?

"Planning My Way" reviewed

☐ **Yes** ☐ **No**

Health Care Proxy discussed

☐ **Yes** ☐ **No**

DNR/DNI discussed

☐ **Yes** ☐ **No**

MOLST discussed

☐ **Yes** ☐ **No**

End of Life Wishes

☐ **Yes** ☐ **No**

Other: (……..)

Caregiver Support:

1. Supportive counseling
2. Disease education
3. Medication education
4. Community resource referrals