OPERATIONAL GUIDELINES

PALLIATIVE CARE AT HEALTH AND WELLNESS CENTRES

NATIONAL HEALTH MISSION
राष्ट्रीय स्वास्थ्य मिशन

Ministry of Health & Family Welfare
Government of India

Operational Guidelines for Palliative Care at Health and Wellness Centers

Background and Rationale:

- The Government of India (GoI) launched the National Program for Palliative Care (NPPC) in 2012. Ever since then Government of India has been earmarking funds under NRHM flexi pool[1] for initiating and scaling up palliative care services in various states depending on the Program Implementation Plan submitted by each state. The NPPC strategy is in line with 2014 World Health Assembly Resolution for achieving universal access to palliative care as part of Universal Health Coverage[2] (UHC). As per WHO, Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

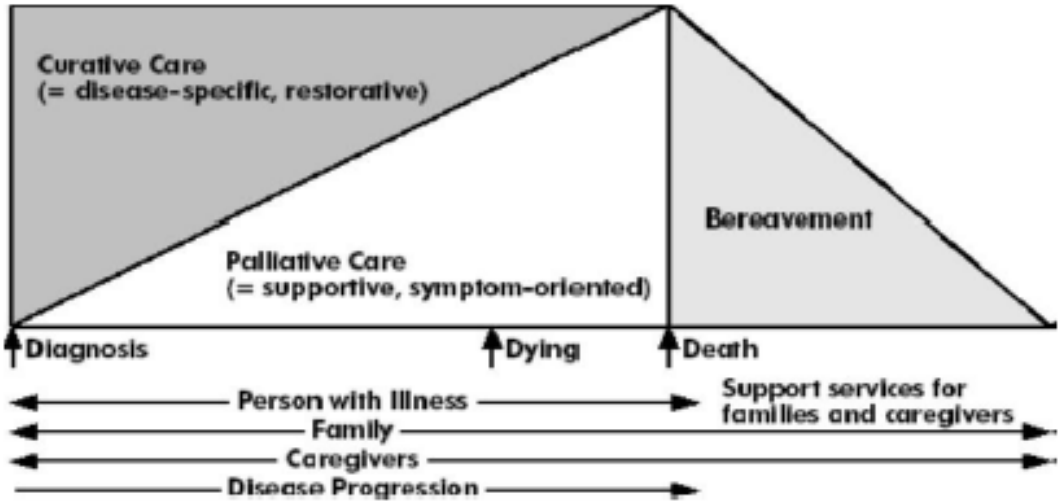
- Palliative care is required for patients with a wide range of life-limiting health problems. The majority of adults in need of palliative care have chronic diseases such as cardiovascular diseases (38.5%), cancer (34%), chronic respiratory diseases (10.3%), AIDS (5.7%) and diabetes (4.6%). Patients with many other conditions may require palliative care, including kidney failure, chronic liver disease, rheumatoid arthritis, neurological disease, dementia, congenital anomalies and drug-resistant tuberculosis.

- As per WHO estimates each year, an estimated 40 million people need palliative care, 78% of whom live in low – and middle-income countries. Worldwide, only about 14% of people who need palliative care currently receive it[3].

- Palliative Care, when indicated, is fundamental to improving the quality of life, well – being, comfort and human dignity for individuals. It is the responsibility of health system and health care professionals to alleviate pain and suffering, whether physical, psychosocial or spiritual, irrespective of whether the disease or condition can be cured.

- If cure is not possible, palliative care provides essential care resulting in pain relief, control of symptoms, and the minimising of suffering. Figure below illustrates a "continuum of care" for cancer, HIV/AIDS, and other life-limiting diseases:

[1]http://dghs.gov.in/content/1351_3_NationalProgramforPalliativeCare.aspx
[2]http://www.thewhpca.org/images/resources/publications – reports/Universal_health_coverage_report_final_2014.pdf
[3]https://www.who.int/news-room/fact-sheets/detail/palliative-care



- Global Burden of Disease (GBD) 2016 reports 9,795,344 deaths in India. Accordingly, the total need for palliative care both before and at the end of life was estimated to be **75,24,633 (7.5 million).** Around 2.7% of the total need is among children i.e. under 15 years of age, the rest 97.3% is the need among adults, i.e. above 15 years age.

- The principles of palliative care need to be applied starting from the time of diagnosis in chronic ailments like cancer. This is commonly referred to as supportive care and needs to be incorporated into disease specific treatment programmes. As the disease progresses and the curative treatment decreases, the role of palliative care increases. At the end of life, palliative care is provided as terminal care extending as bereavement counselling and support for grieving family after the patient's death.

- The provision of palliative care needs the active support of family, members of which serve as primary care-givers, community volunteers and the health system. The HWC at SHC and PHC levels need to work in close collaboration with frontline workers to identify those in need of palliative care, mobilize and sensitize volunteers and community level collectives – such as Village Health Sanitation and Nutrition Committees (VHSNC), Mahila Arogya Samities (MAS), Resident Welfare Association (RWA) etc.

- The provision of palliative care at home and community level is also required as part of the continuum of care for those individuals with terminal illnesses, hospitalised at secondary and tertiary care facilities including under PMJAY, so as to reduce patient hardship and costs associated with repeated admissions.

- Palliative care can be delivered in a variety of ways including hospice care, in-patient care, outpatient care and home-based care. Home based palliative care services take care to the doorstep of the patient. This is where people are most comfortable at the end of their lives, surrounded by their loved ones. It is also well suited to conditions in India where a family member is usually available and willing to nurse the sick person. It provides care givers with the backup and support needed to plan care and to prepare for what lies ahead during the course of a long and potentially life-threatening illness at home. It also helps to develop a system of strong social support in general.

- Educating and supporting them would not only enhance care and quality of life of patients but also contribute to longevity. Comprehensive care and support packages can be developed, to maintain the continuity of care at home by family members and relatives. Through education on nursing, infection control, care of bed-ridden patients and end-of-life care, they can be empowered to care for patients in a manner customized to their individual circumstances and resources

- These operational guidelines are intended for State and District Program Managers and service providers to strengthen Palliative care services within the comprehensive primary health care package provided through Health and Wellness Center. Other companion documents include training manuals and standard treatment guidelines that would be updated and disseminated on a periodic basis. The addition of palliative care as part of comprehensive primary health care represents the inclusion of a new sub-population group into the activities of the HWC. This requires orientation, sensitization and learning from experiences with implementation across states

Service Delivery Framework:

Individual/Family/Community level:

- As part of the population enumeration and empanelment process, ASHAs will identify bed-ridden patients and others needing palliative care.

- Such individuals would be visited by the Multi-Purpose Worker (MPW)/Community Health Officer (CHO) for a further assessment using the Palliative Care Screening tool [*Annexure 1]*

- MPWs, ASHAs, Community volunteers and family to be trained in 'Communication skill'

- ASHAs and volunteers would undertake periodic, home visits to the patients and support to the patient and family members. Families will be assisted with routine home care, simple nursing skills and accessing various service as needed including mobilization of local resources.
- ASHA is expected to play the following role in providing palliative care:
  - ✓ Create awareness about palliative care, First level Screening of patient/families for potential palliative care needs
  - ✓ Identify and refer patients to the Community Health Officer (CHO) as required
  - ✓ Identify community volunteers for palliative care
  - ✓ Work with MPW to deliver basic patient management services
  - ✓ Provide general support to the families/patients
  - ✓ Escort the patient/family during initial visits to ensure better liaison between beneficiary and service providers
  - ✓ ASHA will continue to visit the beneficiaries identified by her for Palliative care services.
- ASHA and MPW will utilize meetings of the Jan Arogya Samiti/Village Health Nutrition and Sanitation Committee/Mahila Arogya Samiti (VHSNC/MAS) to raise awareness about the needs of palliative care patients, and mobilize individual and community level support, including accessing assistance available through other Government programmes.
- The CHO will undertake social and behaviour change communication effort in general community and specific groups (teachers, panchayat members, NGOs, youth groups and women self-help groups) inorder to recruit volunteers for palliative care services in her/his HWC coverage area.
- ASHA and MPW will identify a group of volunteers in her service area. Volunteers could be drawn from Youth Groups, Mahila Mandals, Co-operatives, Non-Governmental Organizations, etc. A social behaviour change communication training of such volunteers could be undertaken by the CHO /Staff nurse or Medical Officer at HWC – SHC or PHC/UPHC. Willing volunteers shall also be trained

in simple nursing skills. The list of trained volunteers to be displayed prominent locations in the HWC area including the health facility, schools, anganwadis, ration shops, panchayat office etc to enhance the credibility and pride in the volunteer. Certificates shall be given to the volunteers for providing home based palliative care.

- A simple format for the same for the documentation of Palliative Care Services is provided for ASHA [*Annexure 2*]. She will submit the same at the Sub Centre as part of her monthly report.

- The MPW would be trained to assess symptoms and undertake basic nursing tasks like dressing of the foulsmelling wound, bladder catheter change etc. She should also be able to communicate compassionately with the patient and family, answering all their queries with knowledge, patience and understanding.

    - Caregivers (family) can also be equipped to perform simple nursing tasks.

    - ANM/MPW to refer those needing a more thorough assessment to the CHO.

    - CHO to conduct home visit and assess the patient/family [*Annexure 3*].

Health and Wellness Centre – Sub Centre Level:

- **Home-Based Palliative care Services:** The Palliative Care team comprising of CHO, MPW, ASHA and Volunteers should conduct Home-Based palliative Care Services to those in need of 'home-care'. Although the visit is need based, the team shall endeavour to have a fixed schedule for visits to different patients to assure continued care

    ✓ Home Based care must be ably supported by a home visits by health care professionals trained in palliative care and by linkages to day-care centres and or hospices to manage situations that are difficult to handle at home.

    ✓ The CHO will be provided a 'palliative-care kit' ***(Annexure 4)*** containing necessary drugs and consumables.

    ✓ Home-care should also be provided to those patients seeking exclusive AYUSH treatment. The CHO and ASHA Facilitator shall be trained in basic physiotherapy to educate patients and caregivers.

- ✓ The details of home-based care are annexed at *Annexure 5*
- ✓ CHO shall have a list of such hospices and trained palliative care physicians in the neighbourhood and up to the district with all contact details. The same shall be provided to the CHO by the District Program Officer. The CHO shall publicise it for the benefit of the people in the area
- ✓ The services of the Yoga trainer shall be co
- ✓ opted in ensuring holistic care of the patient.
- ✓ The services of the ICTC counsellor at the PHC-HWC wherever available shall be made available at regular intervals for supportive supervision of the palliative care team at the Sub Centre – HWC and counselling of the patient and his/her family.

- **End-of-Life care:** The Palliative Care team should provide 'out-of-hours' care to those experiencing the final days of their life (End-of-life-care). Each death has to be duly reported to the HWC – PHC/UPHC. Bereavement support would also be provided after the death of the patient. VHSNC/JAS/MAS/RWA shall play a key role in bereavement support

Drugs and Consumables: The Drugs and consumables such as catheters, , air cushion etc should be made available at the HWC-SHC level. The CHO shall refer patients with high pain score (pain score of 6 and above) to the PHC-HWC for pain management.

The Medical Officer at the PHC-HWC with requisite training in Pain and Palliative Care shall treat the patients including prescription and dispensing of Oral Morphine. Oral Morphine shall be stocked and dispensed at the PHC-HWC as per The Narcotics Drugs and Psychotropic Substances Rules

This is a mechanism for ensuring that patients are able to receive opioids that they need. It will have to be backed by proper scrutiny and record keeping to ensure that the opioids are used properly.

Social support -VHSNC/JAS/MAS/RWA will ensure availability of benefits from various governments and nongovernmental programs/ schemes to the eligible patients/ caregivers.

- The CHO should take the leadership in creating Patient Support Groups and Care givers Support Groups with community volunteers. It is recommended that the group should be convened once in a month and the meeting shall be presided by the CHO.

Health and Wellness Centre – Primary Health Centre/Urban Primary Health Centre level:

Each PHC would provide primary palliative care. The PHC/UPHC Medical Officer would provide required leadership in implementing and coordinating the services in her/his sector area. The following are the services available at this level:

- *OPD:* Palliative care OPD should be conducted at least once in a week. The PHC/UPHC MO will be trained in basic palliative care skills like patient assessment, patient management, counselling services and pain management. The training shall be as peer the National Program Palliative Care guidelines already shared with the states. The trained PHC/UPHC MO can prescribe appropriate drugs, including Oral Morphine. Oral Morphine can be prescribed up to 4 weeks. Separate case sheet and patient card shall be maintained for palliative care patients.

- *Home Care and End of life care:* The PHC/UPHC Medical Officer should facilitate provision of palliative care services for those who need it, on a routine or emergency basis as required.

- *Drugs and Consumables:* Essential drugs including narcotic drugs like oral morphine should be made available at the PHC/UPHC level, while ensuring only minimum essential is stocked and prescribed. The district level authority should monitor the prescription and stocks at regular intervals.

- IEC/BCC/Training: Necessary sensitization session should be carried out under the leadership of MO for caregivers, general public, representatives from PRI/Urban Local Bodies (ULB), students etc. The IEC/BCC sessions are platforms to generate volunteers and impart basic patient management and communication skills to volunteers, caregivers etc.

- Referral: Those requiring secondary level of palliative care should be referred to appropriate higher centres. The first referral unit shall be CHC/UCHC/Taluk Hospital

- Monitoring: Medical Officer should incorporate palliative care activities in routine monitoring activities that he/she undertakes.

Community Health Centre /Taluk Hospitals/Urban Community Health Centre level:

- First Referral unit: The CHC/UCHC/ Taluk Hospital will be the first referral unit for patients from PHCs/UPHCs and below.
- Out Patient (OP) services: A dedicated palliative care OP will be conducted at least once in a week for walk-in patients and those referred from PHCs/UPHCs.
- In Patient (IP) services: At least 5 beds to be prioritised for palliative care patients. However, no needy patient should be denied IP services
- Continuum of Care must be ensured. – at the hospital, at higher level centre like District hospital and at home too as per the need of the patient
- Referral to District Hospitals would be facilitated, if needed.
- Supervision of activities at PHCs/UPHCs.

District Hospital/Sub-Divisional Hospital level:

- Outpatient Services:
  - ✓ Patients coming for OPD consultations should undergo clinical assessment by a trained and competent doctor. The assessment should be geared at formulating a treatment / intervention plan and receive a prescription accordingly.
  - ✓ All patients (and their attendants), assessed by the trained doctor, should receive counselling / psychosocial interventions / psycho-education, as per the clinical needs. For this purpose, it may be necessary to involve a trained medical social worker / counsellor / psychologist from one of the existing National Health Program. The ICTC counsellor at the PHC shall be trained and deputed to extend this support wherever available.
- Inpatient Treatment Services:

  Patients, who require in-patient management, should be admitted and all efforts must be made to provide treatment for an adequate length of time. During the in-patient stay, following services should be made available to the patient:

- ✓ Assessment by the doctor(s): At least once per day during the morning rounds.
- ✓ Availability of nursing care: round the clock.
- ✓ Availability of emergency care (on call doctor): round the clock.
- ✓ Psychosocial and spiritual interventions – including counselling (ICTC counsellor could be co-opted for the care). Services of physiotherapist, yoga trainer and relevant people to address spiritual concerns of the patient should also be co-opted in the care
- ✓ Medicines: For management of symptoms/associated conditions.
- ✓ Food/Diet.
- ✓ Facility to meet visitors during the specified visiting hours.
- ✓ Recreation facilities: newspapers, television (if available), indoor games.

The in-patient treatment period should be used to formulate the plans for home – based palliative care and the same must be discussed with the patient and care – givers. All admitted patients should be provided with a discharge summary with detailed plan for further care and follow-up from the OPD.

Health Promotion including the use of IEC for Behaviour Change Communication:

- Collaborate with NGOs to act as technical advisory agencies for the process of community awareness, mobilisation and empowerment in the field of palliative care programs.
- Empower the palliative trained staff to orient and educate care-givers/family members in providing home-based care.
- Empower Community Based Organizations and families in continued care for the patient through structured care & support educational activities.
- Ensure involvement of the Local Self Government Institutions/PRIs through sensitisation workshops for the members.
- Sensitize healthcare professionals in private and public-private health facilities.
- Conduct awareness/sensitization programs for regulatory and administrative nodal

officers. Professional organisations like Indian Association of Palliative care and NGOs could be co-opted for this.

- Ensure active support from the media.

Human Resources: Mapping of providers to Services for Palliative Care

Considering the varied dimensions of palliative care, a package of essential services will be made available at each level of care. Volunteers will play a very important role at each stage, especially in provision of social and spiritual care. Other team members can also provide psycho-social-spiritual care based on their capacity or training. For those in psychological distress not manageable by primary palliative care interventions, will be referred to a clinical psychologist or Psychiatrist available in District Hospital. The package of essential palliative care services provided at various levels will be as summarized in table below:

Sl.No.	Palliative Care Provider	Components of essential service package
1	JAS/VHSNC/MAS/RWA	• Awareness for Palliative care and the importance of volunteers for Psycho-social-economic-spiritual support • Help families with routine home care • Help in accessing various service as needed including mobilization of local resources • Bereavement support
2	ASHA	• Identifying patients/families for palliative care needs • Help families with routine home care • Help in accessing various service as needed • Networking to assure community support • Referral services • Encourage VHSNC/JAS/MAS/RWA to provide bereavement support

Sl.No.	Palliative Care Provider	Components of essential service package
3	MPW/ANM	• Assessment of patient/families by home visits • Perform basic nursing procedures • Supporting – caregivers/ ASHA/Volunteers • Compassionate communication and Counselling • Provide basic medications as per instructions from Staff Nurse/MO • Referral services • Bereavement support
4	Staff Nurse/CHO (H&WC(SHC)/PHC/ CHC)	• Detailed assessment of patient/families by home visits • Perform basic nursing procedures • Training of the caregivers/ ASHA/Volunteers/ ANM. • Dispense medication as per the prescription of MO to palliative care patients excluding Narcotic Drugs. • Conduct weekly outpatient clinics in H&WC or PHC/UPHC • Referral & Linkage services for complex cases • Data management for entire H&WC /PHC / CHC – rural and urban • IEC activities • Compassionate communication and Counselling

Sl.No.	Palliative Care Provider	Components of essential service package
5	Medical officer (PHC/ CHC – rural and urban)	• Detailed assessment of patient/families by home visits or Outpatient basis • Perform basic procedures [Ryle's Tube Insertion, Urinary Catheter Insertion, Ascites Tapping, Complex wound dressing, Colostomy Care, Tracheostomy Care etc.] • Training of the caregivers/ ASHA/Volunteers/ ANM/ Staff Nurse. • Prescribe medication to palliative care patients including Essential Narcotic Drugs. • Conduct weekly outpatient clinics in HWC &/ or PHC/UPHC • Manage palliative care patients referred to PHC/UPHC • Referral & Linkage services for complex cases • Supervision of all palliative care activities under his/her unit. • Compassionate communication and Counselling
6	Staff Nurse (District Hospital)	• Primary management of complex cases • Inpatient management of cases • Training of all sub-district level healthcare functionaries in palliative care. • Compassionate communication and Counselling
7	Medical officer (District Hospital)	• Management of complex cases • Inpatient management of cases • Training of all sub-district level healthcare functionaries in palliative care. • Compassionate communication and Counselling
8	Specialized Palliative Care Centres (Including Medical Colleges)	• Specialized Palliative Care Services • Inpatient care • Research & Training • Policy & Advocacy

Capacity Building plan

Training of entire healthcare team and infrastructure would enable incorporation of palliative care at all levels of health care delivery so as to meet the demand. Since the Comprehensive Primary Health Care mainly focuses on the primary and secondary levels of care givers, with active engagement of the community, more stress is to be given to the training programmes for various categories of health care providers at the basic and mid-levels and community volunteers.

A cascade model of training is to be imparted where National, State and District trainers are trained in Elderly and Palliative care in a combined package. ASHA requires 6 days of training and MPW-F, Community Health Officer and Staff Nurse requires5days of training at block level. Medical Officer will need training for a period of 4 days in a tertiary care setting

The State Program Officer shall plan and implement a training schedule for all the above as per the training guidelines and train materials provided. The services of reputed Palliative Care Organisations in the county may be harnessed for efficient delivery of quality training.Additional training material for various categories of healthcare personnel are available at https://dghs.gov.on/content/1351_3_NationalProgramforPalliativeCare.aspx.

Referral & Treatment

The Primary Health Care provides for a three-tiered system with bi-directional referral system. The existing system will be leveraged for providing palliative care services. The referrals will be accompanied by a referral slip, providing in brief key problem identified, plan of treatment and reasons for referral. The usual sequence of events are as below

- Volunteers/ ASHA will identify the patient/family in need of palliative care based on the Community Based Assessment Checklist (CBAC)
- MPW along with ASHA would assess the patient/family using assessment form and identify those in need of urgent medical and/or nursing attention (in pain, with bed-sores, unable to swallow, need a catheter, etc) – based on the above assessment scores. Home visits to be undertaken to build rapport, make first hand assessment, take medical history as well as intervene where possible.

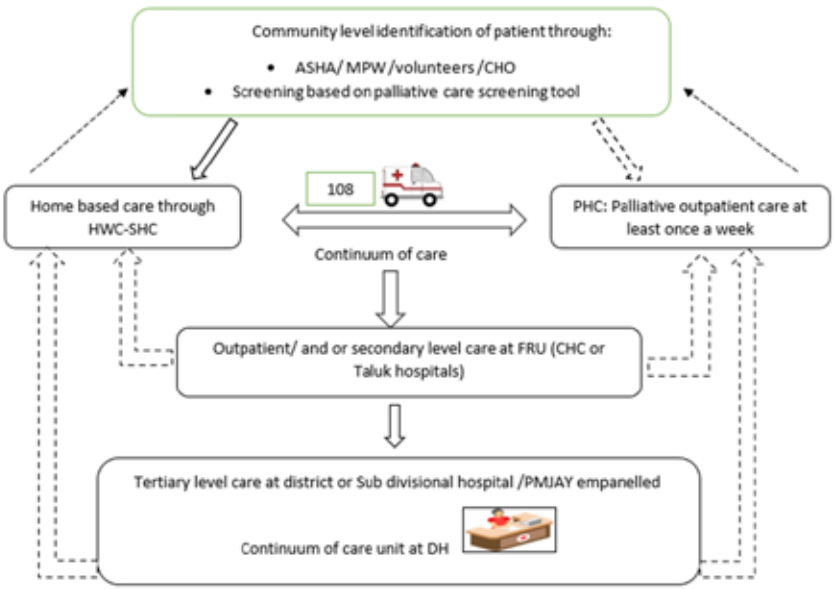
- The ANM/MPW would be trained to assess symptoms and undertake nursing tasks. She should also be able to communicate compassionately with the patient and family, answering all their queries with knowledge, patience and understanding.
- Caregivers (family) can also be equipped by her to perform simple nursing tasks.
- ANM/MPW to refer those needing a more detailed assessment through CHO to Medical officer in PHC/UPHC
- Community Health Officer/Staff Nurse to conduct home visit and assess the patient/family.
- Patient referred to Medical Officer at the PHC who would in turn seek guidance of District Level Palliative Care Physician for prompt assessment and treatment by means of teleconsultation services
- The Medical Officer in the PHC-HWC could refer the patient to suitable higher centre [District Hospital / Palliative Care Centre] for specialized management including inpatient care of variable duration as per Standard Operating Protocol of continuum of care .
- For packages\services covered under the PMJAY – eligible patient will have the choice to opt to go to any PMJAY public/ private empanelled hospital. No referral shall be necessary for this.
- The patients will have access to their Electronic Health Record (EHR) when EHR is implemented. In case a PMJAY eligible patient opts to access PMJAY benefits and if such patient has been provided services from a public health facility, the available records for that patient may be provided to concerned PMJAY hospital on request, upon verification of such request being authenticated with the consent of the patient concerned. Until EHR becomes operational paper based discharged summary with details of symptoms, treatment, progress and follow up should be provided.
- Service provider at the higher centre would provide feedback to MO about the planned care of the patient for further dissemination.

- The loop between the primary care medical provider and the specialist must be closed. This can be achieved when the specialists at district facility or higher are able to communicate to the medical officer of the adequacy of treatment, any change in treatment plans, and further referral action through teleconsultation Services.
- In order to expand access to services, and reach remote populations, Mobile Medical Units would enable an expansion of service delivery and serve the role of enabling the provision of care and serving to establish Continuum of care.
- ASHA/Community Volunteer/MPW/ CHO shall ensure consistent follow up care both at home and also in the HWC using SHS tool for monitoring the functionality is advised over time.

Monitoring and Supervision

Reporting will be done by using format prescribed by Central Division to report physical and financial progress made under the different components of the program by the state and the district at regular intervals. In addition to this, the State Program/Nodal program officer or the Co-ordinator of the program in the State Palliative Care Cell will visit the districts regularly for monitoring.

Referral Pathway for patients in need of Palliative care



Annexure 1: Suggested Palliative Care Screening Tool for Community Health Officer/ Staff Nurse/Medical Officer

Name of ASHA	Village Part
Name of ANM	Sub Centre
PHC	Date
Name	Dependent (financially): Yes / No
Number of earning members in the household: Number of children (under the age of 18 years):	Any Identifier (Aadhar Card, UID, Voter ID)
Age _____	RSBY beneficiary: (Y/ N)
Sex	Telephone/ Mobile No.
Address :	Undergoing treatment from:
Date of diagnosis Diagnosis:	

	Screening Items	**Points**
1	Nature of serious health related suffering including diagnosis (India SHS screening tool – see below)	2
2	Functional status score, according to ECOG/WHO performance status score • Normal & Asymptomatic • Symptomatic, able to do Normal Work as pre-diseased • Symptomatic, able to do activities of Daily life without assistance • Needs assistance with ADL, Limited Mobility • Bed ridden, Totally dependent on others for ADL	 0 1 2 3 4
3	Presence of one or more serious comorbid diseases also associated with poor prognosis (eg, moderate-severe COPD or CHF, dementia, AIDS, end stage renal failure, end stage liver cirrhosis)	1
4	Presence of palliative care problems	
	• Symptoms uncontrolled by standard approaches**	1
	• Moderate to severe distress in patient or family, related to cancer diagnosis or therapy	1
	• Patient/family concerns about course of disease and decision making	1
	• Patient/family requests palliative care consult	1
	Total score (0-13)	
Cut off of 4 or more will be considered for referral for palliative care services		

** To be assessed by a trained Medical Officer

<table>
<tr><th colspan="4"><u>NCG – SHS Tool for Field Testing</u></th></tr>
<tr><th>Domains of Health-related Suffering</th><th>Not at all
Score 0</th><th>A little
Score 1</th><th>A lot
Score 2</th></tr>
<tr><td>Associated with your health, do you suffer physically? With pain/ breathing difficulty/ vomiting/ constipation/ weakness / feeding/loose motion/ bleeding/ itching/ wounds /difficulty with senses (see, hear, smell, touch, taste) / difficulty moving/ other issues</td><td></td><td></td><td></td></tr>
<tr><td>Associated with your health, do you suffer emotionally? Feeling sad/ unloved / worried/ angry/ lonely/ difficulty sleeping/ confused/ poor memory / other issues</td><td></td><td></td><td></td></tr>
<tr><td>Associated with your health, do you suffer due to issues with family/ relationships/ friends/ community/ feeling isolated/ difficulty at work/ difficulty with hospital visits/ difficulty communicating/ other issues</td><td></td><td></td><td></td></tr>
<tr><td>Associated with your health, do you suffer due to feeling punished/ fearful/ shame / guilty / angry with God / no meaning to life/ disconnected/ other issues</td><td></td><td></td><td></td></tr>
<tr><td>Associated with your health, do you suffer due to lost job/ stopped studies/ stopped working/ loan / debt/ sold property/ sold assets / migrated out / other issues</td><td></td><td></td><td></td></tr>
<tr><td>Is there Presence of <u>Health-related Suffering</u>?</td><td>Total Score ≥ 2
<u>YES</u></td><td></td><td>Total Score < 2
<u>NO</u></td></tr>
<tr><td colspan="4">If <u>YES</u>: Is the health-related suffering <u>Serious</u>?
Has this suffering limited you from doing what you need to do, for ≥ 14 days over the last 30 days? e.g. self-care (feed, bathe, dress, walk, toilet); care for others; communicate; learn / think/perform duties; sleep / rest?</td></tr>
<tr><td colspan="3">☑ <u>YES.</u> (SHS)
1. Document as ‘Patient has screened positive for <u>Serious</u> Health-related Suffering on the case file, notify and activate further evaluation by the primary treating team
2. Ask the patient – Do you seek more help for your concerns?</td><td rowspan="2">☒ <u>NO.</u> (SHS)
The screening for SHS is continued at quarterly intervals.</td></tr>
<tr><td><u>YES, I seek help</u>
Activate further evaluation and care-pathways to respond to SHS[1]</td><td colspan="2"><u>NO, I do not seek more help</u>
Educate patient/family on how to seek additional support in case they feel the need for it and empower with the necessary information.</td></tr>
</table>

Annexure 2: Suggested format for documentation of Palliative Care Services

	Patients with palliative care needs					
Sr. No.	**Name**	**Age/Sex**	**Diagnosis**	**Functional Diagnosis***	**Screening score**	**Referral Yes/ No**
1						
2						
3						
4						
5						
	Home care visits					
Sr. No.	**Name**	**Age/Sex**	**Diagnosis**	**Functional Diagnosis***	**Accompanied by**	**Main interventions**
1						
2						
3						
	Sensitization/ IEC activities					
Sr. No.	**No. of beneficiaries**	**Venue**	**Resource person**		**Type of beneficiaries**	**Method used**
1						
2						
3						

* With respect to Activities of Daily Living(ADL) – Independent/ Minimal support required/ Bed ridden

Annexure 3: Home visit case sheet

(To be attached to screening form)

Name of the patient: _____Age: _____ Sex:_____

Education status: _____Marital status:_____

Date: _____

Type of visit: Routine /Emergency

Diagnosis:

ECOG performance status: 0 / 1 / 2 / 3 / 4;

General condition	Fairly good / Poor / Debilitated / Very weak / Drowsy / Unconscious/ Terminal state
Communication	Easy / Occasionally / Withdrawn /Non – communicative
Ambulation/ Activity	Normal activities / Limited activities (needs support) / Needs assistance for ADL/ Bed bound
Main concerns	
Sleep	Normal /Disturbed /Wakeful nights (reason)
Urination	Normal / Hesitancy/ Increased frequency / Incontinence / on catheter
Bowel	Normal /Diarrhoea / Constipation /Stoma
Malodour	Due to incontinence/ Infected ulcer
Appetite	Good / Fair / Poor / None

Present symptoms: (by patient / informant)

Pain	Sore mouth	Itching
Nausea	Swelling	Delirium
Vomiting	Ulcer/ Wound	Breathlessness
Swallowing difficulty	Bleeding	Tiredness
Heart burn	Lymphoedema	Drowsiness
Cough	Pressure sores	Others (List)
Constipation	*	

*Blank spaces for other symptoms

Most distressing symptoms:

Distress level:

Ongoing Medicines:

Mental Status: (tick appropriately)

Normal; Anxious; Sad/No Interest: Irritable: Withdrawn: Fearful: Body Image: Suicidal

Socio-economic issues:

Care Giver – Name_____; Age_____ Sex:_____ Relationship with the patient: _____

Contact No: _____

No of dependents:

Social Entitlements: Ration Card: Yes/No ; Aadhar Card: Yes/No; Old age pension: Yes/no; Widow pension – Yes/No; Disability Pension – Yes/No; Education support for children: yes/no

Etc (based on state specific entitlements); Bank Account – Yes/No;

Emotional concerns:

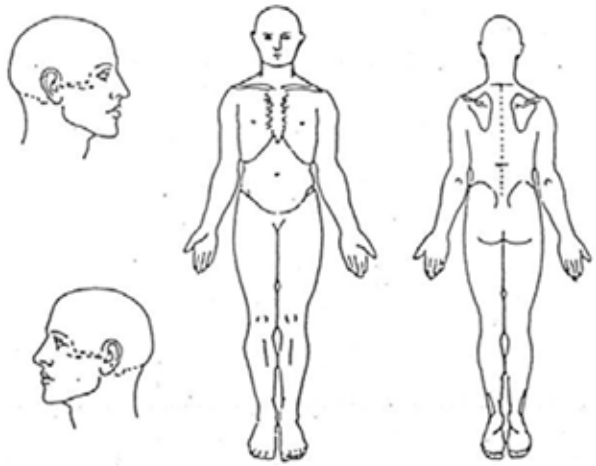
Spiritual concerns:

Pain Assessment:

Patient has no pain.

Effectiveness of present pain medicine: Good / Fair /Poor / not on any pain medication

Site	Intensity (0-10)	Duration	Type (Constant/ Intermittent)	Character (Aching/ Throbbing / Burning / Pricking/ Lanciating)	Cause*	Provoking/ Palliating factor
A						
B						
C						
D						



Systemic Examination:

Treatment advised (Pharmacological & Non-pharmacological):

Annexure 4 : Home Care Kit

For effective delivery of home-based palliative care services, the home care team will be provided a home care kit. The kit will be located in sub centre or Health & Wellness Centre. CHO will be responsible for maintain the home care kit. PHC will ensure an uninterrupted supply the contents of the kit. The contents of the kit will be procured from through existing state specific procedures. The funds for the same will be provided as part of NPCDCS budget. The suggested composition of home care kit would be as follows:

Supplies	Medicines
Equipment 1. Stethoscope 2. BP Apparatus 3. Light weight foldable stool 4. Torch 5. Thermometer 6. Tongue Depressors 7. Forceps 8. Glucometer	**Pain Control** 1. Paracetamol 2. Ibuprofen 3. Diclofenac 4. Tramadol 5. Dexamethasone (as adjuvant)
Supplies 1. Dressing Supplies 2. Cotton 3. Scissors 4. Gauze Pieces 5. Gauze bandages 6. Dressing Trays 7. Gloves 8. Micropore Tapes 9. Syringes and Needles 10. Condom Catheters 11. Urine Bags 12. Feeding Tubes 13. Foley's Catheter	**Wound Management** 1. Betadine Lotion and Ointment 2. Metrogyl Gel 3. Hydrogen Peroxide 4. Turpentine oil

Gastrointestinal Symptom Management 1. Domperidone 2. Bisacodyl 3. Loperamide 4. Oral Rehydration Salts 5. Ranitidine 6. Metoclopramide 7. Dicyclomine+ 8. Hyoscine Butyl Bromide	**Antibiotics and Antifungals** 1. Ciprofloxacin 2. Metronidazole 3. Amoxycillin 4. Fluconazole
Psychological Symptom Management 1. Lorazepam 2. Amitriptyline	**Nutritional Supplements** 1. Iron, Vitamin and Mineral Supplements **Other Miscellaneous** 2. Spirit 3. Lignocaine Gel 4. Ethamsylate 5. Deriphylline 6. Cough Preparations

Annexure 5: Home based care:

Advantages of home care

Home based palliative care has several additional advantages for the patient and family such as comfort, privacy, familiarity with surroundings, security, autonomy and a greater degree of independence. It is also cost effective and as it does not entail travelling to the hospital repeatedly for follow up visits and unnecessary investigations and treatments. Some additional advantages of home care include:

1. **Easy access to care:** The patient and family have access to advice and to all aspects of palliative care (physical, psychological, social and spiritual) at their doorstep.

2**. More effective caring**: Advice, training and additional support for the family is available so that they can become more effective in their role as care givers.

3. **Access to complementary services**: The home care team can facilitate liaison with complementary and supportive services when required. The patient and family do not have to go out seeking such support on their own. Patients receive one – on-one attention, this makes treatment more effective and build trust among the patient, care giver and home care team.

4. **Expert referrals for the patient**: The team can facilitate referral to other medical and nursing specialists involved in palliative care thereby ensuring the best possible care for the patient.

5. **Maintains confidentiality**: This is especially important for people with Cancer & HIV/AIDS who may otherwise be shunned by the community out of ignorance and due to misconceptions about the disease.

6. **Spreading awareness in the community**: Wherever appropriate, community platforms can be used to spread awareness about home based palliative care. It is often the case that when a family is nursing someone with cancer their friends and associates become more aware and are more willing to discuss issues around terminal care. The family member of the patient can become ambassadors for the cause.

7**. Mobilising local resources**: Local support groups and volunteers can be mobilized to support patients and care givers living in their catchment area. They would be more willing to do this not only because they may know or have personal ties with the people affected. It is much easier for neighbours to help each other than travel long distances to do so.

8. **Training opportunities**: Training in palliative care can be offered to medical professionals, para-medical professionals, community volunteers and caregivers in the area being covered by the home care team.

Requirements for effective home care work.

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