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## 1. Background

This Integrated Thematic Care Pathway (ITCP) is written for the purpose of guiding End-of-Life care management for Home Nursing Foundation's (HNF) homecare clients.

Of the 2601 clients who were discharged from HNF in Financial Year 2021/2022, 997 (38%) were discharged because of death. Of these, 44% passed on within 6 months of enrolment; and 48% passed on at home. Out of these death discharges, 490 were receiving our Home Medical service.

All of this indicates that many of our clients would benefit from End-of-Life palliative care.

From a survey of clinical staff in HNF, many have identified lack of confidence in managing clients near End-of-Life as a gap and would require more guidance and training. In the survey to understand our Home Medical doctors' preference in Continuing Medical Education (CME) lessons topics, many had listed palliative medicine as their selected topics to attend. In addition, identification, and referral of client with palliative needs to appropriate resources/providers were delayed (Alisop, 2018).

All the above highlight the importance of palliative care competencies and level of practice in our clinical staff. This is in alignment with the HNF purpose statement of empowering clients to live with joy through quality care and all rounded support. For the purpose of adhering to HNF service in the community, this document is produced by the ITCP work group with the assistance of external subject experts and internal staff reviewers.

## 2. Definition and Scope

***This ITCP shall be deployed to all clients under HNF's homecare services (Home Nursing, Home Medical and Home Therapy) identified to require End-of-Life palliative care. The ITCP will end when the client is discharged from our service.***

***Advanced Care Planning (ACP)*** – Voluntary process of discussion between the client and their care providers/caregivers with the purpose of clarifying the client's wishes and care preference for future care should they become unable to make decision and/or communicate their wishes to others.

***Advance Medical Directive (AMD)*** – Advance Medical Directive is a legal document that the client signs in advance to inform the doctor attending (in the event client is terminally ill and unconscious) that client does not want any extraordinary life-sustaining treatment to be used to prolong your life. Decision to sign the directive is voluntary.

***Allied Health Professional (AHP)*** – Allied Health Professionals comprise diverse groups of healthcare professionals providing a wide range of health service. They include clinical psychologists, dietitians, occupational therapists, physiotherapists, speech therapists, MSW and others. Within the scope of this pathway, HNF's AHPs are Occupational Therapists (OTs), Physiotherapists (PTs), Speech Therapists (ST) and Medical Social Workers (MSWs).

***Certification of cause of death (CCOD)*** – A legal document whereby a registered medical doctor certifies the cause of death of a deceased. All deaths suspected of being due to unnatural causes should not be certified by our Home Medical doctors and should instead be referred to the police.

***Clinical staff*** – All client facing healthcare and allied health professionals that manage biopsychosocial care.

***Culture*** – Shaped by historical, economic, social, political, and geographical events and guides the client's values, beliefs, and behaviour. It defines who the client is within the context of society, and influences the interpretation of suffering, illness, and death. Culture affects how a client navigates within the healthcare system during illness and at the end-of-life.

***DIL*** – 'Dangerously Ill List' is a medically-verified status where the client's death is deemed imminent.

***End-of-life Care*** – Refers to care of clients identified by HNF clinical staff that requires palliative care. This includes clients with a prognostication of one year or less, and meets the criteria as delineated in Section 5.1 and 5.2.

***FICA*** – An assessment tool for grief management. The FICA tool is based on four domains of spiritual assessment: the presence of Faith, belief, or meaning; the Importance of spirituality on a client's life and the influence that belief system or values has on the person's health care decision making; the client's spiritual Community; and interventions to Address spiritual needs.

**HM** – Home Medical Services where visits are conducted by Doctors.

**HN** – Home Nursing Services where visits are conducted by Nurses.

**HT** – Home Therapy Services where visits are conducted by Therapists.

**LPA** – Lasting Power of Attorney is a legal document which allows a person who is at least 21 years of age ('donor'), to voluntarily appoint one or more persons ('donee(s)') to make decisions and act on his/her behalf if he/she loses mental capacity one day. A donee can be appointed to act in the two broad areas of personal welfare and property & affairs matters.

**MDR** – Multidisciplinary Round is a model of care where all Nurses, Therapists and MSWs allocated to a certain geographical area come together to discuss cases and plan client care as a team. Case discussions are led by a doctor.

**MSW** – Medical Social Workers.

**Palliative Care** – Multidisciplinary and holistic care, aims at improving the quality of life of clients and their families facing the problems associated with serious life-threatening illness, through the prevention and relief of suffering by means of early identification, assessment and management of pain and symptom controls, and other issue relating to physical, psychosocial and spiritual/cultural. Palliative Care is indicated for clients near the end-of-life.

**Preferred Plan of Care (PPC)** – A voluntary process of discussion between the client and their care providers/caregivers for clients who are likely to pass away within 12 months. Issues that will normally be discussed include preferences for life-sustaining treatment such as ventilation, CPR, and other treatments. The discussion would also probably explore the client's preferences for place of care, for example, home, hospice, or hospital.

**Spirituality** – A dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices. This was further defined by the EAPC (European Association for Palliative Care) taskforce on Spiritual Care in Palliative Care in 2010 as:

Spirituality is the dynamic dimension of human life that relates to the way persons (individual and community) experience, express and/or seeks meaning, purpose and transcendence, and the way they connect to the moment, to self, to others, to nature, to the significant and/or the sacred.

### 3. Principles of Care

The Principles of Care sets out the system of belief and/or behaviour guiding our delivery of palliative care in a professional and caring manner as espoused in HNF Core Values.

#### 3.1 Collaboration

Collaboration allows the Care Team to achieve Integrated Care. End-of-Life Multidisciplinary Team (EoLMDT) comprises of doctors, nurses, AHPs and MSWs engaged in transdisciplinary practices. When required, care team shall also work closely with providers in specialist fields i.e., oncologist for coordinated care.

#### 3.2 Excellence

Good clinical quality is achieved through pursuit of Excellence. Assessment and interventions are holistic, and evidence based. Needs of care recipients are regularly reviewed and cover pertinent care domains such as the client's physical, spiritual, emotional, and social needs.

#### 3.3 Compassion

Compassionate approach delivers a person-centric care model. As palliative care may give rise to complex clinical situations that staff may require further support, there shall be avenue for expert deliberations to take place to resolve ethically challenging circumstances. Family and caregivers must also be supported in client's journey during the palliative phase and after the client has passed on, via grief and bereavement support.

#### 3.4 Empowerment

Care recipients are empowered to make informed decisions and have their preferences respected. Staff are given continuous education to support clinical decision-making. End-of-Life care pathway with clear guidelines is made accessible to staff.

## 4. Objectives and Indicators

### 4.1 Objectives

To provide a clear guidance to all HNF clinical staff so that the target population in the ITCP shall experience “good death” when the time comes, and the caregivers shall feel supported.

A “good death” is contentious, generally, core elements for a “good death” include pain and symptoms control, clarity in decision-making, feeling of closure, sense of personhood, being prepared, and the perception of contribution. It should be noted that other factors such as culture, financial issues, religion, disease, age, and life circumstances were found to shape the concept across groups (Krikorian et al, 2019).

### 4.2 Indicators

#### 4.2.1 Process indicators:

- (a) **PPC rates: % of clients with PPC conducted within 3 months after enrolment into EOL program in a given year. i.e.**

$$\frac{\text{Number of clients with PPC documented and filed within 3 months of enrolment within a given year}}{\text{Number of clients enrolled in the EOL program within a given year}}$$

- (b) **Prognostic screening to be done for all clients: % of clients with prognostication estimated at first assessment.**

$$\frac{\text{Number of patients with prognostic screen at first assessment within a given year}}{\text{Number of clients enrolled in the Home Medical/Nursing/Therapy service within a given year}}$$

- (c) **Self-rated and/or Clinician rated pain score is administered at initial assessment and every subsequent assessment as per Appendix 1.**

#### 4.2.2 Outcome indicators

- (a) **Percentage of clients with improved ZBI score, i.e.:**

$$\frac{\text{Number of clients with lower ZBI score 3 months after enrolment into the program}}{\text{Number of clients enrolled into the programme within a given year with at least 2 ZBI scores}}$$

- (b) **If the death of client is aligned to family member’s definition of good death.**

- The question of “Do you feel your loved one has passed on peacefully without pain or suffering?” upon client’s passing as part of the post humous feedback, as a percentage of all caregivers interviewed for post-humous feedback.

### 4.3 Monitoring and Evaluation

To ensure quality assurance and measure the effectiveness of the care pathway, process and outcomes indicators shall be monitored and evaluated accordingly to the table below:

Table 1: Methodology of indicators monitoring and evaluation.

Measures	Tool	Frequency	Standard	Target
PPC rates	PPC filing into AIC system	Within 3 months of enrolment onto the care pathway	50%	All clients enrolled onto the care pathway
Prognostic screening	Random IHCS audit of progress notes	Upon enrolment into Home Medical / Home Nursing/ Home Therapy services	90%	All clients enrolled in HM/HN/ HT
Improvement of ZBI score	IHCS ZBI form	Upon enrolment onto the care pathway and 3 month and 6 monthly thereafter	Baseline trending	All clients enrolled onto the care pathway
Good death questions (section 4.2.2b)	Random (i.e., every 3 <sup>rd</sup> death-discharge) pick of client for post humous survey	1 month after the death	Baseline trending	Random pick of clients enrolled onto the care pathway
Pain score	Random audit of progress notes	Administered at initial assessment and every subsequent assessment	100%	All clients enrolled onto the care pathway

Data analysis is to be conducted annually by Operations and Special Projects department. Results will be submitted to Chief Executive Officer (CEO)/Clinical and Continuous Education Committee (CCEC) annually.

Progress notes audit will be performed by the Medical Advisor and Advanced Practice Nurse on an annual basis.

## 5. Pathway Application

Clinical staff shall initiate care pathway for identified clients, i.e., ‘Positive Prognostic Screen’, after the initial discussion with clients/donee/assumed health proxy and/or after discussion with the multidisciplinary team.

Criteria for enrolment into “ITCP for Clients Near End-of-Life” are:

- Positive Prognostic Screen confirmed by Home Medical physician either through a visit or during a Multi-disciplinary Review Meeting.
- Client and family agrees to the EoLMDT care approach.

Kindly refer to Annex A for the overview of the care pathway.

### 5.1 Situation in HNF Service Delivery where Pathway Applies

Table 2: Situations and brief summary of the reactions to the situation

1	Outreach/ publicity	Only for clients referred to clinical programmes.
2	Receiving referral	Referrals for HM/HN/HT services will be received via Agency for Integrated Care’s (AIC) Integrated Referral Management System (IRMS) and will undergo triage by HM/HN/HT service owners.
3	First comprehensive assessment	Primary clinical staff governing HM/HN/HT will continue the usual comprehensive assessment format with an addition of Prognostic Screening.
4	Individualised Care Plan (ICP)	If Prognostic Screening indicates a limited prognosis, and the client/donee/assumed health proxy are agreeable to receive care from the EoLMDT, the ITCP shall be activated.
5	1 <sup>st</sup> or subsequent care encounters	Refer to section 5.3.  If a HM doctor has not assessed the client, this is the visit where the Prognostic Screening is confirmed by the doctor. In situation where the doctor disagrees with the Nurse or AHP, the client may be discharged from the ITCP and revert to existing care arrangements.

6	Review assessment/ICP	<p>Refer to section 5.3.</p> <p>Prognostic screen should be conducted at least once every six months along with a comprehensive assessment. If positive, clinical staff should consider referring for enrolment to this pathway.</p> <p>In any case, during any clinical encounter, if limited prognosis is suspected, clinical staff should apply the Prognostic Screen and refer accordingly.</p>
7	Care plan execution	Refer to section 5.3.
8	Transition to other healthcare institutions (transitory)	The EoLMDT shall communicate with the appropriate healthcare institutional team regarding the client's care plan and inform them of the client's PPC and Donee/Assumed Health Proxy (if any).
9	Non-death Discharge, i.e., transfer to other healthcare providers	A memo will be written and given to the next service provider regarding care so far and PPC.
10	Death discharge	<p>Bereavement support shall be rendered by the MSW where indicated (see section 5.3).</p> <p>For clients enrolled into this pathway, MSW will provide bereavement support for those at risk of complicated grief. HNF strives to coordinate for the signing of CCOD.</p>

## 5.2 Prognostic Screening

- (a)** The screening for clients with limited prognosis is to be done for all new admissions and at every review.
- (b)** Assess for three triggers that suggest clients are nearing end-of-life, i.e., 'Positive Prognostic Screen'

- Asking the surprise question “Would you be surprised if this client were to die in the next 12 months?”
- Any general indicators of decline-deterioration, increasing need or choice for no further active care?
- Any specific clinical indicators related to certain conditions, i.e., organ failure, frailty?

Any one of the above can be an indication of nearness to the end-of-life. If the prognostic screening was initially conducted by HN or HT, a HM doctor is required to confirm the prognostication either at the next Home Medical visit, or during a MDR if the doctor in attendance is satisfied with the HN/HT’s prognostic assessment.

**(c) The Surprise Question (SQ)**

This is a subjective indicator of limited prognosis based on a clinician’s experience and intuition. It is widely used and is reasonable in estimating prognosis (White et al, 2017).

**(d) General indicators for decline and increasing needs**

- Functional and/or general physical decline (i.e., Barthel score), limited self-care, in bed or chair 50% of the day and increasing dependence in most activities of daily living (ADL)
- Advanced disease – unstable, deteriorating complex system burden
- Decreasing response to treatments, decreasing reversibility
- Choice of no further active treatment
- Unintended weight loss of >10% in the past 6 months
- Repeated unplanned/crisis admissions
- Serious falls
- Serum albumin <25d/l

(e) Specific Clinical indicators for the following conditions.

<p><b>Chronic Obstructive Pulmonary Disease (COPD)</b></p> <p>At least two of the indicators below:</p> <ul style="list-style-type: none"> <li>• Severe disease (i.e., FEV1 &lt;30% predicted)</li> <li>• Recurrent hospital admissions (at least 3 in the last 12 months due to COPD)</li> <li>• Fulfils long term oxygen therapy criteria</li> <li>• MRC grade 4/5 – shortness of breath after 100 meters on level ground or confined to house</li> <li>• Signs and symptoms of right heart failure</li> <li>• Combination of other factors i.e., anorexia, multi-resistant organisms</li> <li>• More than 6 weeks of systemic steroids for COPD in preceding 6 months</li> </ul>	<p><b>Heart Disease</b></p> <p>At least two of the indicators below:</p> <ul style="list-style-type: none"> <li>• NYHA stage 3 or 4 – shortness of breath at rest on minimal exertion</li> <li>• Repeated hospital admissions with heart failure symptoms</li> <li>• Difficult physical or psychological symptoms despite optimal tolerated therapy</li> <li>• “NO” to the surprise question</li> </ul>
<p><b>Renal Disease</b></p> <p>Stage 4 or 5 chronic kidney disease whose condition is deteriorating with at least 2 of the indicators below:</p> <ul style="list-style-type: none"> <li>• “NO” to the surprise question</li> <li>• Clients choosing for “no dialysis”, discontinuing dialysis, or not opting for dialysis if their transplant has failed</li> <li>• Difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy</li> <li>• Symptomatic heart failure</li> </ul>	<p><b>General Neurological Diseases</b></p> <ul style="list-style-type: none"> <li>• Progressive deterioration in physical and/or cognitive function despite optimal therapy</li> <li>• Symptoms which are complex and too difficult to control</li> <li>• Dysphagia leading to recurrent aspiration pneumonia, sepsis, breathlessness, or respiratory failure</li> <li>• Speech problems – increasing difficulty in communications and progressive dysphasia</li> </ul>
<p><b>Frailty/Dementia</b></p> <p>Clients presenting with multiple co-morbidities, significant impairment to daily living and:</p> <ul style="list-style-type: none"> <li>• Deteriorating functional score i.e., Modified Barthel Index</li> <li>• Combination of at least 3 of the following</li> </ul>	

- Weakness
- Slow walking speed
- Significant weight loss
- Exhaustion
- Low physical activity
- Depression

#### Late-stage dementia

- Functional Assessment Staging Test (FAST) score 7C and above
- (a) Plus, any of the following
  - Weight loss
  - UTI
  - Severe pressure sores- stage 3 or 4
  - Recurrent fever
  - Reduced oral intake
  - Aspiration pneumonia

### 5.3 Initiate Discussion with Clients and their Donee/Assumed Health Proxy about the ITCP Enrolment

#### (a) Who to initiate

- The clinician who made the positive prognostic screen should initiate the discussion of enrolment into the ITCP, before the client is officially enrolled into the pathway.

#### (b) Who to discuss with

- All clients who have decision making ability with regards to their own care not severely affected by depression
- Family members who are donees, or if LPA is not done, assumed Health Proxy for clients who are incapable of making such decisions

#### (c) When to initiate discussion

- When there is a positive Prognostic Screen and is sufficient rapport between the Team and the clients are established
- When the client/donee/assumed health proxy are ready to talk about prognosis and care plan

#### (d) What to discuss on

Obtain consent from client/donee/assumed health proxy regarding referral to the EoLMDT. This may mean discontinued care from the previously assigned primary care doctor or nurse.

- Address Ideas, Concerns, and Expectations at the juncture where limited prognosis is suspected.
- To explore if client/donee/assumed health proxy are open to discussing PPC. If client/donee/assumed health proxy is not ready, this shall be revisited within the next 3 months or whenever client's condition changes. If client/donee/assumed health proxy is ready, the clinician in attendance shall activate in-house resources designated to conduct PPC.
- To consider if they would like to make LPA under Mental Capacity Act 2010 and AMD under AMD Act 1996. If client/donee/assumed health proxy is ready, the EoLMDT shall be informed to effect this.

**(e) How to document the discussion**

- The prognostic screen and the communication about the transfer of care shall be documented in the progress notes and the enrolment tagged on HNF's clinical system.

**5.4 Enrolment into the ITCP for Clients Near End-of-Life**

5.4.1 Once a HM doctor has confirmed the Positive Prognostic Screen, and the client/donee/assumed health proxy has agreed to receive care from the EoLMDT, client's care shall be transferred to a palliative competent clinical team i.e., HNF's EoLMDT.

5.4.2 The Prognostic Screen and the communication about the transfer of care shall be documented in the progress notes and the enrolment tagged on HNF's clinical system.

**5.5 Reaction Framework after Enrolment into the Pathway**

This section describes the different situation and how clinical staff shall react to it after the enrolment into the pathway.

**5.5.1 Prognostication and Phase Categorisation**

Doctors of the EoLMDT are to conduct a visit to confirm the prognostication and categorise the clients into the phases. Phase definition shall follow that of Palliative Care Outcomes Collaboration (2014).

Table 3: Phase definition adopted from PCOC (Phase Definition, 2014)

Phase	Description
Stable	Client's problems and symptoms are adequately controlled by established care plan and

	<ul style="list-style-type: none"> <li>• Further interventions to maintain symptom control and quality of life have been planned, <i>AND</i></li> <li>• Caregiver situation is relatively stable and new issues are apparent.</li> </ul>
<b>Unstable</b>	<p>An urgent change in the plan of care or emergency treatment is required because</p> <ul style="list-style-type: none"> <li>• Client experiences a new problem that was not anticipated in the existing plan of care; <i>AND/OR</i></li> <li>• Client experiences a rapid increase in the severity of a current problem; <i>AND/OR</i></li> <li>• Caregiver circumstance changes suddenly impacting on client care.</li> </ul>
<b>Deteriorating</b>	<p>The care plan is addressing anticipated needs but requires periodic review because</p> <ul style="list-style-type: none"> <li>• Client's overall functional status is declining; <i>AND/OR</i></li> <li>• Client experiences a gradual worsening of existing problem; <i>AND/OR</i></li> <li>• Donee/assumed health proxy/caregiver experience gradual worsening distress that impacts on the client's care.</li> </ul>
<b>Terminal</b>	Death is likely within days.
<b>Bereavement</b>	Client has passed on and bereavement support is provided to caregivers and documented.

Periodic reviews are to be conducted at every review either by the EoLMDT doctor or nurse, and changes in client's phases shall be highlighted to the team through clinical notes documentation and/or case presentation at EoL MDRs.

### 5.5.2 Care activities for different phases

#### (a) Stable phase

Defined as the phase where client's symptoms and issues are well managed with the established care plan. In this phase:

- Doctors/Advanced Practice Nurse (APN) shall introduce and lead the PPC conversation with nurses/MSWs participating/facilitating

- The Doctors shall collaboratively develop an individualised care plan for each client if not already done. The care plan shall include:
  - Prognostication
  - Stability assessment
  - Management plans for any distressing symptoms
  - Rationalise specialist appointments
  - Prioritise chronic disease management
  - Prescription and/or deprescription of medication
  - Informing family members of changes in health status
  - Equipment prescription (e.g., oxygen concentrator/ suction machine)
  - Timely review (3 monthly/prn)
  
- The Nurses shall
  - Collaboratively participate in the care planning process
  - Implement, and follow up on the client's symptoms
  - Highlight changes in client's condition in a timely manner and/or discussed at MDRs to review the care plan, if necessary.
  - Consider non-pharmacological interventions under the care plan and prescribe equipment such as hospital bed/air mattress/ dressing materials) if necessary. Nursing review should occur minimally every 2 monthly in this stable phase.
  
- The Therapists shall
  - Assess and prescribe activities suitable for symptom control in a timely manner.
  - Activities can include chest therapy, mobilization, and positioning
  - Speech therapy if indicated
  - OT may prescribe cognitive engagement activities, if indicated.
  - Therapist will highlight acute or potential health risk and update the EoL MDT in a timely manner.
  
- Caregiver education/training shall be carried out by the nurses and, if applicable, therapists. Caregiver training may include (but not limited to):
  - General care and symptoms management
  - Maintenance or mitigation of functional decline
  - Use of assistive devices if prescribed
  
- Psychosocial needs
  - Nurses shall assess the psychosocial needs of clients and family members alike. Cases identified to possess high social emotional needs shall be escalated to MSW.
  - MSW shall provide counselling, discuss LPA/Deputyship application when client/family members had expressed needs of it.

- For clients/families that are identified to have high stress or poor coping, MSW shall prepare family on illness trajectory (coping strategies). Interventions may include referral for required services (including activation of volunteers) Identify potential risk for complicated grief/FICA
- MSW shall discuss ancillary or financial support such as financial assistance, acquisition of medical devices, meals on wheels, if client is assessed to require it.

### **(b) Unstable phase**

Defined as the phase where there is an urgent change in care plan and if emergency treatment is required due to a new problem not in the initial care plan, rapid increase in severity of a current problem or if caregiving circumstance changes suddenly with impact on client's care. In this phase:

- If PPC was not initiated previously, the doctor/APN shall introduce and lead the PPC conversation. Nurses/MSW may facilitate/participate or continue the discussion.
- If PPC had already been discussed and developed and this is a new phase, the doctor shall lead the review of PPC with nurses participating and/or facilitating.
- The Doctors shall collaboratively develop an individualised care plan for each client if not already done. If care plan had already been drafted it shall be reviewed when the phase changed to "unstable". The care plan shall include the following:
  - Management plans for any distressing symptoms
  - Rationalise specialist appointments and reduce whenever possible.
  - Review prognostication and update family members on the new prognosis.
  - Review the prioritisation of chronic disease in the care plan.
  - Prescription and/or deprescription of medication.
  - When applicable, doctors shall inform family members of DIL.
  - Equipment prescription (e.g., oxygen concentrator/ suction machine)
  - Care plan should be reviewed monthly/prn
- The Nurses shall
  - Collaboratively participate in the care planning process, implement, and follow up on the client.
  - Symptoms are monitored by nurses and changes in client's condition should be highlighted to the doctors in a timely manner and/or discussed at MDRs to review the care plan, if necessary.
  - Consider non-pharmacological interventions under the care plan and prescribe equipment such as hospital bed/air mattress/ dressing materials) if necessary.
  - Nursing review should occur minimally every 2-weekly/PRN and education for NOK on contingency plans in case of demise beyond office hours.
  - Provide caregiver training as necessary

- The Therapists shall
  - Assess and prescribe activities suitable for symptom control such as chest therapy, mobilisation and positioning, speech therapy if indicated.
  - Continue to provide therapy sessions with focus on caregiver's education and training
  - Highlight acute or potential health risk and update the EoLMDT timely
  
- Psychosocial needs
  - Nurses shall assess the psychosocial needs of clients and family members alike. Cases identified to possess high social emotional needs shall be escalated to MSWs
  - MSWs shall provide counselling, discuss LPA/Deputyship application when client/family members had expressed needs of it
  - MSW shall discuss ancillary or financial support such as financial assistance, acquisition of medical devices, meals on wheels, if client is assessed to require it
  - MSW shall assess and identify complicated grief using the FICA tools

### **(c) Deteriorating phase**

Defined as the phase where client overall functional status is declining, there's a worsening of existing problem or caregivers experience worsening distress that impacts on the client's care. In this phase:

- If PPC was not drafted and discussed, doctor shall re-explore the PPC conversation with client/family. If PPC had already been discussed and developed, and this is a new phase, the EoLMDT shall review the PPC.
  
- EoLMDT shall develop the individualised care plan for each client, if it has been done previously, it shall be reviewed when the phase changed to "deteriorating".
  
- The Doctors shall
  - Ensure the care plan include management plans for any distressing symptoms
  - Review prognostication and update family members on the new prognosis
  - Inform DIL
  - Identify reversible conditions and manage accordingly
  - Prepare CCOD memo for standby
  - Rationalise specialist appointments and reduce whenever possible
  - Review prescription and/or deprescription of medication
  - Look into equipment prescription (e.g., oxygen concentrator)

- The Nurses shall
  - Implement care plan and monitor symptoms.
  - Communicate changes in client's condition to the doctors and/or discussed at MDRs to review the care plan, if necessary.
  - Monitor for changes in prognostic status and inform the EoLMDT
  - Consider non-pharmacological interventions under the care plan
  - Look into prescribing consummables (i.e., wound care consummables/supplements)
  - Review/assess clients minimally every week/when necessary (if agreeable with family).
  - Reinforce caregiver training
  - Discuss contingency plans with client/donee/assumed health proxy in case of demise beyond office hours
  - Assess family's psychosocial needs and escalate to EoLMDT or MSW if needed
- The Therapists
  - Therapists have no active role during this phase unless specified by EoLMDT
- Psychosocial needs
  - MSW shall assess family's psychosocial needs
  - Interventions may include referral for required services (including activation of volunteers)
  - MSW shall review FICA
  - MSW shall assess for caregiver grief
  - MSW shall facilitate PPC review and conversations on court deputyship
  - MSW shall provide bereavement education and support
  - MSW shall provide counselling if indicated and support mediation work with family if required
  - MSW shall highlight acute or potential health risk and update the EoLMDT timely

#### **(d) Terminal phase**

Defined as the phase where client's demise is in a few days. In this phase:

- If PPC was not drafted and discussed, it is highly recommended to start the process of PPC discussion
- If PPC had already been discussed and this is a new phase, the EoLMDT shall review the PPC
- EoLMDT shall develop the individualised care plan for each client, if it has been done previously, it shall be reviewed when the phase changes to "terminal".

- The Doctor shall:
  - Ensure care plan includes management plans for any distressing symptoms.
  - Review prognostication and update family members on the new prognosis.
  - Inform family members of imminent death and educate on signs and symptoms of imminent death as well as death
  - Prepare CCOD memo for standby
  - Prescribe and/or deprescribe medication
  - Inform family members of imminent death
  - Assess for possible complicated grief and trigger MSW timely
  - Observe for behavioural and mental wellbeing, involve MSW if necessary
  - Perform PRN review
  
- The Nurse shall:
  - Implement and monitor the progress of distressing symptoms according to care protocol set out by EoLMDT doctor
  - Update family on new prognosis and treatment plan if DIL status was informed over phone by doctor
  - Inform family of imminent death and provide emotional support to family
  - Education on signs and symptoms of imminent death as well as death
  - Education on CCOD process and remind family to standby CCOD memo if available
  - Review PPC and reiterate to family not to call 995/999 when patient passes on
  - Assess for possible complicated grief and trigger MSW timely
  - Observe for behavioural and mental wellbeing, involve MSW if necessary
  - Perform PRN review
  
- Psychosocial needs
  - See nursing role as above as well
  - MSW shall review FICA/PPC
  - MSW shall offer emotional support and counselling
  - MSW shall provide bereavement education and support

### **(e) Deceased**

The client has passed on at this stage. The role of the EoLMDT is supportive in nature.

The Doctor shall:

- Sign CCOD (if possible) if demised during office hours and provide emotional support
- Offer last office advice
- Inform EoLMDT of client's demise (if informed first by donee/assumed health proxy)

The Nurse shall:

- Offer last office advice
- Informs EoLMDT of demise (if informed first by donee/assumed health proxy)
- Work with MSW in bereavement support

The MSW shall:

- Conduct bereavement support
- Grief counselling and emotional support

### 5.5.3 Out of office support

As HNF does not operate on a 24-hour basis, clients and their donee/assumed health proxy shall be provided with resources to tap on for out of office support when they could not engage HNF's help. Staff shall communicate clearly that resources provided are not affiliated with HNF and fees will not be subsidised.

To facilitate 24-hours support, all clients enrolled into the ITCP for EoL Care should have a summary of medical diagnoses, medications list and a copy of the PPC. For clients who are acutely deteriorating, there should be a memo to describe the latest clinical deterioration and treatment plan, and the suspected Cause of Death if death were to take place after office hours.

#### (a) External after-hours medical and nursing services

- Private GPs known to the clients. Prerarrangement is necessary, using our medical memo.
- Dr Choo Wei Chieh's 24 Hour House Call Service.
- Casket Services
  - EoLMDT shall ask client/donee/assumed health proxy if they have any casket services in consideration before recommending to them.

### 5.5.4 Discharge & Bereavement

This care pathway for the client ends when

- The client's needs are beyond HNF's capabilities and more specialised palliative care is needed, i.e., requires home hospice, or in-patient hospices
- The client requires a different long term care service option i.e., nursing home.
- The client has passed on under HNF's care.

#### (a) Discharge/transfer to Hospice care

If client's condition is no longer adequately supported by HNF's resources, the client shall be discharged/transferred to Hospice care, the criteria include but is not limited to:

- Client meets the criteria to be enrolled into Hospice care
- Family's preference
- EoLMDT has assessed that client's needs cannot be adequately supported by HNF's resources (i.e., symptom management requires equipment/resources that is not available in HNF)

EoLMDT Doctors shall be responsible to raise the referral to the relevant Hospice providers.

### **(b) Death and Bereavement Support**

Support for the client under this care pathway shall not stop at the client's death. HNF shall continue to support family:

- EoLMDT Nurses shall perform a post humous assessment, by means of prescribed template via phone calls one month after the client's death.
- If there are signs of complicated grief or additional needs of the caregivers, the nurse shall highlight to MSW for further management.
- MSW shall assist family in grief management and escalate care to appropriate agencies if beyond the MSW's capacity, i.e., Grief Matters.

## **5.6 Staff Roles and Competency Required in Reaction Framework**

This section describes the overview of the roles and responsibilities of individuals in disciplines. The summary of the roles and responsibilities is delineated in Appendix A.

### **5.6.1 Doctors**

- (a) Doctors involved in the care pathway are expected to have at least one year experience in serving palliative clients under supervision.
- (b) Doctors' roles in the EoL care pathway
- To endorse PPC discussions
  - Prognostication including informing family of DIL
  - Phase categorisation
  - Prescription and pharmacological intervention
    - Medication reconciliation and de-prescribing
  - Review and prioritisation of medical conditions
  - Referral to AHPs
  - Provide CCOD memo (if necessary and possible)
  - Caregiver education on signs and symptoms to observe for terminal clients
  - Development of Individualised Care plan for clients
  - Rationalising specialist appointments
  - Ordering of laboratory testing
  - Facilitate the transfer of care to Hospice when necessary

### 5.6.2 Nurses

- (a) Nurses involved in the care pathway should have attended at least 2 courses in Palliative care as approved by HNF. Courses include:
- End-of-Life Nursing Education Consortium (ELNEC)
  - Geriatric Palliative Care in advanced dementia (PaIC)
  - Palliative Care in advanced non-cancer conditions (PaC)

All Nurses involved shall be trained in PPC facilitation.

- (b) Nurses' role in the care pathway includes but is not restricted to:
- Facilitate PPC conversation including documenting and uploading into AIC system
  - Monitor client's condition and escalate to doctors and/or EoLMDT as required
  - Perform triaging of acute health and social care needs
  - Assessment/identification of high psychosocial emotional care needs to escalate to MSW.
  - Caregiver training and support on symptom management and general care
  - Consider non-pharmacological interventions
  - Consider the need for equipment such as oxygen concentrator and suction machine
  - Assist in medication reconciliation
  - Ensure that there's one copy of medical summary in the client's house for their use when comanaged by other healthcare institutions
  - Caregiver education on after office hours supports and actions required in times of clients' demise

### 5.6.3 Medical Social Workers

- (a) MSWs involved in the pathway shall be trained in PPC facilitation and should have attended at least one palliative course as approved by HNF. All MSW in HNF will be included for Palliative support.

- (b) MSW's role in the care pathway includes but not limited to:
- Assessing family's psychosocial needs
  - Review FICA
  - Facilitate financial assessments for clients with financial constraints
  - Facilitate PPC conversations
  - Facilitate LPA/court deputyship management
  - Caregiver education on grief management
  - Counselling and referral to support groups when necessary
  - Support mediation work within family members when necessary
  - Referral to ancillary services (such as Home Personal Care, Meals on Wheels, Lion's befrienders)
  - Activate volunteers

### 5.6.4 Therapists

- (a) The involvement of Physio/Occupational and Speech Therapists shall be contingent on the client’s needs and conditions. All Therapists shall be involved in the care pathway.
- (b) The general role of therapist includes but not restricted to:
- Access and prescribe assistive and/or adaptive equipment
  - Access and prescribe activities suitable for symptom control
    - Aiming to improve comfort through movement, reduce rate of deterioration, and increase caregiver confidence as they care of clients
  - Highlight acute or potential health risk and update the EoLMDT timely
  - Caregiver training for general care

Table 4: Situations and roles of Physio/Occupational and Speech therapists

Therapist	Indication	Who is it for?
Physiotherapist	Secretion management/ respiratory management	Client who has lots of secretion and family ready to learn about positioning and chest physio.
	Maintenance or mitigation of functional decline	Caregivers who wish to learn exercises to reduce the rate of contractures, or slow down deterioration rate.  Clients who are still alert and wish to prolong current functional status, i.e., walking or transfer.
Occupational Therapist	Meaningful occupation and activities that enhances sense of well-being	Client whose cognition is intact, and possibly feeling regrets or wishing to work on legacy, increase sense of personhood and sense of purpose.
	Empower ADLs performance	Clients who require modification so they can be as independent as possible.
	Challenging behaviours at home	
Speech Therapist	Leisure feeding for wellbeing	For client and caregivers lacking the awareness of aspiration pneumonia risks.

Therapist	Indication	Who is it for?
	Lack of verbal communication	Clients who are cognitively intact, but unable to speak due to medical condition.

## 6. Documentation

Clinical documents shall follow prevailing policy within HNF. PPC forms should be uploaded into the National ACP IT System for continuity of care.

## 7. Annexures and Appendices

### 7.1 Annexures

Table 5: List of annexures and their descriptions

Annexures	Description
Annex A	End-of-Life ITCP Flowchart

### 7.2 Appendices

Table 6: List of appendices and their descriptions

Appendices	Description
Appendix 7.2.1	Pain Management Considerations in EoL Homecare Clients
Appendix 7.2.2	Seizure Management Considerations in EoL Homecare Clients
Appendix 7.2.3	Agitated Behaviour Management Considerations in EoL Homecare Clients
Appendix 7.2.4	Constipation Management Considerations in EoL Homecare Clients
Appendix 7.2.5	Dyspnoea Management Considerations in EoL Homecare Clients
Appendix 7.2.6	Nutrition and Hydration Management Considerations in EoL Homecare Clients
Appendix 7.2.7	Secretion Management Considerations in EoL Homecare Clients
Appendix 7.2.8	Grief Management Considerations in EoL Homecare Clients

## 8. References

- Allsop, M. J., Ziegler, L. E., Mulvey, M. R., Russell, S., Taylor, R., & Bennett, M. I. (2018). Duration and determinants of hospice-based specialist palliative care: A national retrospective cohort study. *Palliative Medicine*, 32(8), 1322–1333. <https://doi.org/10.1177/0269216318781417>
- Borneman, T., Ferrell, B., & Puchalski, C. M. (2010). Evaluation of the FICA Tool for Spiritual Assessment. *Journal of Pain and Symptom Management*, 40(2), 163–173. <https://doi.org/10.1016/j.jpainsymman.2009.12.019>
- Menon, S. (2017). *Advance decision-making in Singapore – Caring for Older People in an Ageing Society*. <https://www.bioethicscasebook.sg/background/advance-directives/>
- Ministry of Health. (2019). *Advance Medical Directive*. Ministry of Health. Retrieved August 18, 2022, from <https://www.moh.gov.sg/policies-and-legislation/advance-medical-directive>
- Ministry of Social and Family Development. (2020). *The Lasting Power of Attorney*. Government of Singapore. Retrieved August 18, 2022, from <https://www.msf.gov.sg/opg/Pages/The-LPA-The-Lasting-Power-of-Attorney.aspx>
- Palliative Care Outcomes Collaboration. (2014). *Phase Definitions*. Palliative Care Outcomes Collaboration. Retrieved 19 August 2022, from <https://documents.uow.edu.au/content/groups/public/@web/@chsd/@pcoc/documents/doc/uow222232.pdf>
- Salt & Light. (2021). *Called to nurse the terminally ill through "Trying times" brought on by COVID*. Assisi Hospice. Retrieved August 18, 2022, from <https://www.assisihospice.org.sg/news/called-to-nurse-the-terminally-ill-through-trying-times-brought-on-by-covid/>

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