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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.

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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.

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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.

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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.

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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.

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

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

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

(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.:

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

(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.

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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 3rd 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.

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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/done/assumed health proxy are agreeable to receive care from the EoLMDT, the ITCP shall be activated.
5	1st 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.

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6	Review assessment/ICP	Refer to section 5.3. Prognostic screen should be conducted at least once every six monthly along with a comprehensive assessment. If positive, clinical staff should consider referring for enrolment to this pathway. In any case, during any clinical encounter, if limited prognosis is suspected, clinical staff should apply the Prognostic Screen and refer accordingly.
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	Bereavement support shall be rendered by the MSW where indicated (see section 5.3). 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.

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'

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- 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

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(e) Specific Clinical indicators for the following conditions.

Chronic Obstructive Pulmonary Disease (COPD) At least two of the indicators below: • Severe disease (i.e., FEV1 <30% predicted) • Recurrent hospital admissions (at least 3 in the last 12 months due to COPD) • Fulfils long term oxygen therapy criteria • MRC grade 4/5 – shortness of breath after 100 meters on level ground or confined to house • Signs and symptoms of right heart failure • Combination of other factors i.e., anorexia, multi-resistant organisms • More than 6 weeks of systemic steroids for COPD in preceding 6 months	**Heart Disease** At least two of the indicators below: • NYHA stage 3 or 4 – shortness of breath at rest on minimal exertion • Repeated hospital admissions with heart failure symptoms • Difficult physical or psychological symptoms despite optimal tolerated therapy • "NO" to the surprise question
Renal Disease Stage 4 or 5 chronic kidney disease whose condition is deteriorating with at least 2 of the indicators below: • "NO" to the surprise question • Clients choosing for "no dialysis", discontinuing dialysis, or not opting for dialysis if their transplant has failed • Difficult physical symptoms or psychological symptoms despite optimal tolerated renal replacement therapy • Symptomatic heart failure	**General Neurological Diseases** • Progressive deterioration in physical and/or cognitive function despite optimal therapy • Symptoms which are complex and too difficult to control • Dysphagia leading to recurrent aspiration pneumonia, sepsis, breathlessness, or respiratory failure • Speech problems – increasing difficulty in communications and progressive dysphasia
Frailty/Dementia Clients presenting with multiple co-morbidities, significant impairment to daily living and: • Deteriorating functional score i.e., Modified Barthel Index • Combination of at least 3 of the following	

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- 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.

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- 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

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	• Further interventions to maintain symptom control and quality of life have been planned, *AND* • Caregiver situation is relatively stable and new issues are apparent.
Unstable	An urgent change in the plan of care or emergency treatment is required because • Client experiences a new problem that was not anticipated in the existing plan of care; *AND/OR* • Client experiences a rapid increase in the severity of a current problem; *AND/OR* • Caregiver circumstance changes suddenly impacting on client care.
Deteriorating	The care plan is addressing anticipated needs but requires periodic review because • Client's overall functional status is declining; *AND/OR* • Client experiences a gradual worsening of existing problem; *AND/OR* • Donee/assumed health proxy/caregiver experience gradual worsening distress that impacts on the client's care.
Terminal	Death is likely within days.
Bereavement	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

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- 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.

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- 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

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- 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)

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- 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".

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- 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)

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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. Prearrangement 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:

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- 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

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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 (PalC)
- Palliative Care in advanced non-cancer conditions (PalC)

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

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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.

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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

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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/backgrounder/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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9. Acknowledgements

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Pain Management Considerations in End-of-Life Homecare Clients

Definition

An unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage. (IASP,2020)

- A personal experience that is influenced to varying degrees by biological, psychological, and social factors.
- Pain and nociception are different phenomena. Pain cannot be inferred solely from activity in sensory neurons.
- Through their life experiences, individuals learn the concept of pain.
- A person's report of an experience as pain should be respected.
- Although pain usually serves an adaptive role, it may have adverse effects on function and social and psychological well-being.
- Verbal description is only one of several behaviours to express pain; inability to communicate does not negate the possibility that a human or a nonhuman animal experiences pain.

Classification & possible causes of pain (non-exhaustive) (Lee,2022; Pak, et al., 2020)

Classification	Description	Cause	Possible diagnoses
Nociceptive	Stimulation of nerve endings in skin and deep tissue because of noxious stimuli		
Visceral	• Poorly localized, deep squeezing/pressure sensations. • May be associated with nausea, vomiting, diaphoresis	Originating from internal organs via infiltration, distension or stretching of viscera	• Neoplasia – benign or malignant • Bowel: Gastritis/ Constipation/ Gastroenteritis/ Colitis/ IBS • Hepatobiliary system: Gallstones; HB sepsis • Genitourinary system: ARU; renal colic; UTI; pyelonephritis; ovarian cyst torsion etc • Ascites • Pleuritis • Acute myocardial syndrome •
Somatic	• Sharp • Aching • Usually worsen with movement	Originating from musculoskeletal	Skin injuries/ infection e.g. cellulitis; abscess;

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			contusion; pressure injuries • Bone and joints e.g. arthritis, vertebral compression fracture, hip fracture, bone metastasis • Muscles, tendons and ligaments e.g., frozen shoulders; muscle strain; trigger fingers

Classification	Description	Cause	Possible diagnoses
Neuropathic			
Allodynia (pain elicited by innocuous stimuli) or hyperalgesia	• Pins and needles, electric shock, burning pain, tingling, prickling, shooting	lesion or disease of the somatosensory nervous system	• Sciatica/ radiculopathy • Cervical myelopathy • Causes of peripheral neuropathy • Herpes zoster • Trigeminal neuralgia • Paraneoplastic syndrome/ malignant tumour infiltration of the nervous system
Psychosomatic			
• Multiple non-specific pain may be symptoms of anxiety or depression			

Assessment

- Review past medical history
- Review medication list
- Pain History (SOCRATES)
    - Site
    - Onset (acute, subacute, chronic or recurrent)
    - Character
    - Radiation
    - Associated symptoms
    - Time/duration
    - Exacerbating/relieving factors
    - Severity

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- Vital signs: Heart rate, temperature, respiration rate, oxygen saturation, blood pressure, pain score and characteristics
- Response to treatment
- Distress to client/caregiver

Pain scoring

Clinicians may utilise the numeric rating scale (0-10) (Breivik, 2008) or the Wong-Baker Faces Pain rating scale for clients who are able to self-rate their pain. For uncommunicative clients, clinicians may use the Pain Assessment in Advanced Dementia Scale (PAINAD) scoring system as below.

PAINAD (Warden, Hurley & Volicer, 2003)

Behaviour/points	**0**	**1**	**2**	**Interpretation of scores**
Breathing	Normal	Occasional laboured breathing or short periods of hyperventilation	Noisy laboured breathing, long periods of hyperventilation or Cheyne-Stokes respirations	0-3: mild pain 4-6: moderate pain 7-10: severe pain
Vocal expression: cries, moans, sighs, grunts, whimpering	None	Occasional moan/groan or low-level speech with negative quality	Repeated troubled calling out, loud moaning or groaning, crying	
Facial expression	Smiling or inexpressive	Sad, frightened, frown	Facial grimacing	
Body language	Relaxed	Tense, distressed pacing/fidgeting	Rigid, fists clenched, knees pulled up, pulling, pushing away, striking out	
Consolability	No need to console	Distracted or reassured by voice or touch	Unable to console, distract or reassure	

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Referrals

Referrals can be made to the following disciplines at any point of time:

Home Medical	• If cause of pain is uncertain and diagnosis is required • Treatment and management of underlying cause and symptoms especially for pharmacological interventions • Prognostication • PPC discussions • Complex communications (i.e., differing care goals amongst family members)
Home Nurse	• Any nursing care needs e.g., wounds, monitoring of chronic disease, education on medication use and adjustment, education on non-pharmacological treatment, i.e., use of oxygen, ACP/PPC discussions • Follow-up after initial treatment by the doctors • Care-giver training and support • Care coordination
Home Therapist	• Gentle exercises • Transcutaneous electrical nerve stimulation (TENS) • Breathing techniques • Legacy
Medical Social Worker	• Complex communication (e.g., differing care goals amongst family members, requiring psycho-emotional support, spiritual support) • If counselling is indicated and agreed to • Caregiver stress not relieved by support services already in-place • Financial support needed

Management

Non-pharmacological

- Positioning
- Avoidance of exacerbating factors
- Acupuncture/ Tuina
- TENS
- Heat/ cold compress
- Massage
- Breathing techniques

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- Use of orthotics and guards i.e., corset, knee guard
- Dressing and protection of wound
- Distraction and activities

(St. Marie, 2013; Everyone's experience of pain, 2022).

Pharmacological Treatment

This section outlines some of the principles and options in the pharmacological treatments of pain management in EOL clients. It is not exhaustive, and practitioners must exercise clinical judgement and practice holistic management of clients.

WHO Analgesic Ladder

Step 1	Mild pain	Non-opioid analgesics	Paracetamol NSAID: Ibuprofen, Naproxen, Diclofenac COX2 inhibitors: Etoricoxib and celecoxib	Consider adjuvants for neuropathic pain
Step 2	Mild-moderate pain	Weak opioids oral route	Codeine, tramadol (Weak opioid) Morphine, Pethidine (strong)	
Step 3	Severe-moderate pain	Parental potent opioids	Subcutaneous Morphine, fentanyl	
Step 4	Intractable pain	Invasive therapy	Escalate to pain specialist	

Analgesia prescription principles (Lee, 2022)

By the mouth	Try oral route first, avoid intramuscular
By the clock	Regular and prophylactic, always prescribe a breakthrough dose
By the ladder	Decide appropriate analgesic from the ladder, pain specialist may not follow the ladder
By the individual	• Titration needed according to individual response, • Assess for potential reversable/treatable causes of pain • Existing medical conditions such as chronic kidney disease

Starting opiates (Lee, 2022).

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Opioid naïve

- Start morphine 2.5mg 4-6 hourly
- Lower dose morphine Q8hourly (or lower) for
    - Renal (eGFR <30)
    - Hepatic dysfunction
    - Elderly
    - Client at risk of respiratory depression, e.g., chronic type II respiratory failure (like COPD, neuromuscular weakness)
- Always prescribe a breakthrough dose (1/6 or 1/10 of total daily dose)

Fentanyl

Two forms available: Injection, Transdermal

Transdermal Fentanyl patch:

- Consider controlled release opioid Fentanyl Patch ONLY when symptoms well controlled on regimen of immediate release opioid
- NOT suitable to start for symptomatic clients who still require titration of opioids/ analgesia
- Time to onset: 12 hrs
- Each patch last 72 hrs
- Peak serum concentration after initial application – 20-72 hrs

Application of transdermal Fentanyl patch

- Apply to intact, non-irritated, non-irradiated skin on flat surface i.e., chest, back, flank, upper arm
- Do not alter patch i.e., cutting - Avoid exposure to heat as may increase fentanyl absorption
- Always check for existing fentanyl patches on chest/deltoids/upper back on client, to avoid double application
- Always indicate and check when the patch is due for change

Breakthrough subcutaneous Fentanyl

- 1/10 of total daily Fentanyl dose PRN, up to q1-2H
- TD Fentanyl patch 25mcg/h = Total fentanyl 600mcg/DAY
- S/C Fentanyl breakthrough = 600 ÷ 10 = 60mcg prn
- S/C breakthrough can be given if require rapid titration of pain control

Please refer to page 9 of this Appendix for Sample of CD prescription

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Escalation criteria

- Escalate to EoLMDT doctor if cause of pain is unclear and/or requires medical attention i.e., pain crisis
- Refer to hospital if symptoms are not manageable despite best efforts, and clients or caregivers prefer care in an acute hospital
- Team may consider referrals to home-based hospice care or specialist care if pain is not optimally managed despite best efforts with pharmacological and non-pharmacological measures within HNF's scope
- Refer to an inpatient hospice if clients or caregivers cannot cope at home and client meets the admission criteria

Client/family education and training

Explain assessment and care plan	Important to explain diagnosis, prognosis, and treatment plans, as well as contingency plans during after-hours and indications for escalation
Nonpharmacological treatment	Positioning; avoidance of exacerbating factors; reinforce treatment by PT/OT
Use of medications	The 5 Rights; timing of pain killers with activities, transdermal applications, subcutaneous injections, side effects, what to do if overdose
Health and symptom monitoring	Appropriate vital signs and symptom monitoring
Self-care	Taking 5-10mins of caregiving break can be very useful (e.g., drinking a cup of tea, deep breathing exercises, pray or meditate, release tension with exercise, talk to a friend, practice gratitude, use aromatherapy) Seek help from professionals if unable to cope

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References

Breivik, H., Borchgrevink, P., Allen, S., Rosseland, L., Romundstad, L., Breivik Hals, E., Kvarstein, G., & Stubhaug, A. (2008). Assessment of pain. British Journal of Anaesthesia, 101(1), 17–24. https://doi.org/10.1093/bja/aen103

Chang, V. T. (2022, February 28). *Approach to symptom assessment in palliative care* (T. J. Smith & J. Given, Eds.). UpToDate. https://www.uptodate.com/contents/approach-to-symptom-assessment-in-alliativecare?search=constipation&source=search_result&selectedTitle=9~150&usage_typ=default&display_rank=9

International association for the study of pain (2020). Revised definition of pain. Retrieved from: https://www.iasp-pain.org/publications/iasp-news/iasp-announces-revised-definition-of-pain/#:~:text=The%20definition%20is%3A%20%E2%80%9CAn%20unpleasant,pain%20for%20further%20valuable%20context.

Lee C.S. (2022, June 2022). HNF CME Session 1 - Updates on Palliative Care for Frail Elders for Home-visiting Doctors [Video]. YouTube. https://www.youtube.com/watch?v=46C2bZT9-xQ

Pak, D., Yong, J., & Shah, K. (2020). Interventional Management of Chronic Visceral Pain Syndromes. Elsevier Gezondheidszorg.

Pain management in palliative care | Information for professionals. (2022, July 21). Marie Curie. https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/symptom-control/pain-control

St Marie B. *Pain management in clients receiving palliative care*. Oncol Nurse Advis. 2013 May-Jun;2013:e1-e6. PMID: 26893953; PMCID: PMC4755508. Retrieved https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4755508/

Warden, V., Hurley, A. C., & Volicer, L. (2003). Development and Psychometric Evaluation of the Pain Assessment in Advanced Dementia (PAINAD) Scale. Journal of the American Medical Directors Association, 4(1), 9–15. https://doi.org/10.1097/01.jam.0000043422.31640.f7

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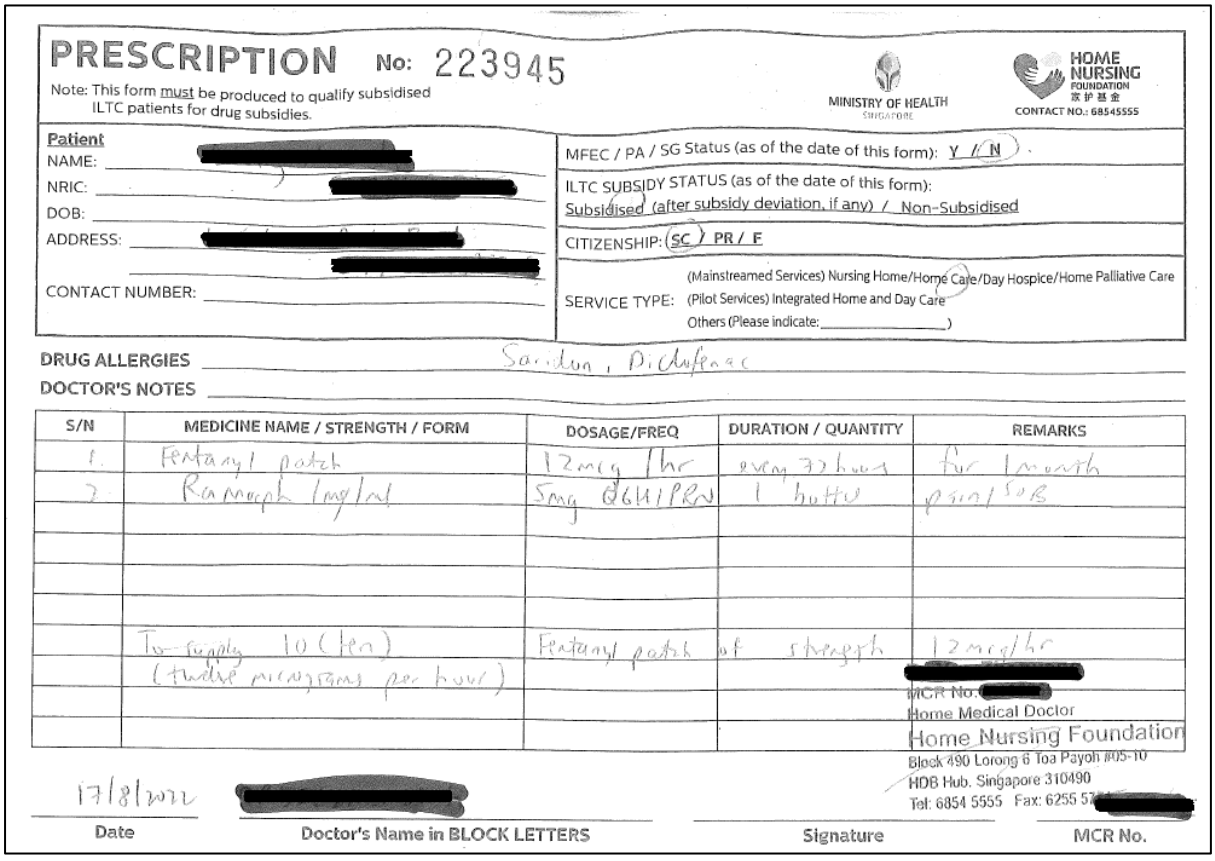
Samples of CD prescription



PRESCRIPTION No: 223945

Note: This form must be produced to qualify subsidised ILTC patients for drug subsidies.

MINISTRY OF HEALTH SINGAPORE

HOME NURSING FOUNDATION 家护基金 CONTACT NO.: 68545555

Patient
NAME: [redacted]
NRIC: [redacted]
DOB:
ADDRESS: [redacted]
CONTACT NUMBER:

MFEC / PA / SG Status (as of the date of this form): Y / N

ILTC SUBSIDY STATUS (as of the date of this form):
Subsidised (after subsidy deviation, if any) / Non-Subsidised

CITIZENSHIP: SC / PR / F

SERVICE TYPE: (Mainstreamed Services) Nursing Home/Home Care/Day Hospice/Home Palliative Care
(Pilot Services) Integrated Home and Day Care
Others (Please indicate: _____)

DRUG ALLERGIES: Sandoz, Diclofenac

DOCTOR'S NOTES:

S/N	MEDICINE NAME / STRENGTH / FORM	DOSAGE/FREQ	DURATION / QUANTITY	REMARKS
1	Fentanyl patch	12mcg 1hr	every 72 hours	for 1 month
2	Ramipril 1mg/ml	5mg Q6H PRN	1 bottle	pain/SOB
	To supply 10 (ten) (twelve micrograms per hour)	Fentanyl patch	of strength	12mcg/hr

[redacted]
MCR No: [redacted]
Home Medical Doctor
Home Nursing Foundation
Block 490 Lorong 6 Toa Payoh #05-10
HDB Hub, Singapore 310490
Tel: 6854 5555 Fax: 6255 57[redacted]

17/8/2022 [redacted]

Date | Doctor's Name in BLOCK LETTERS | Signature | MCR No.

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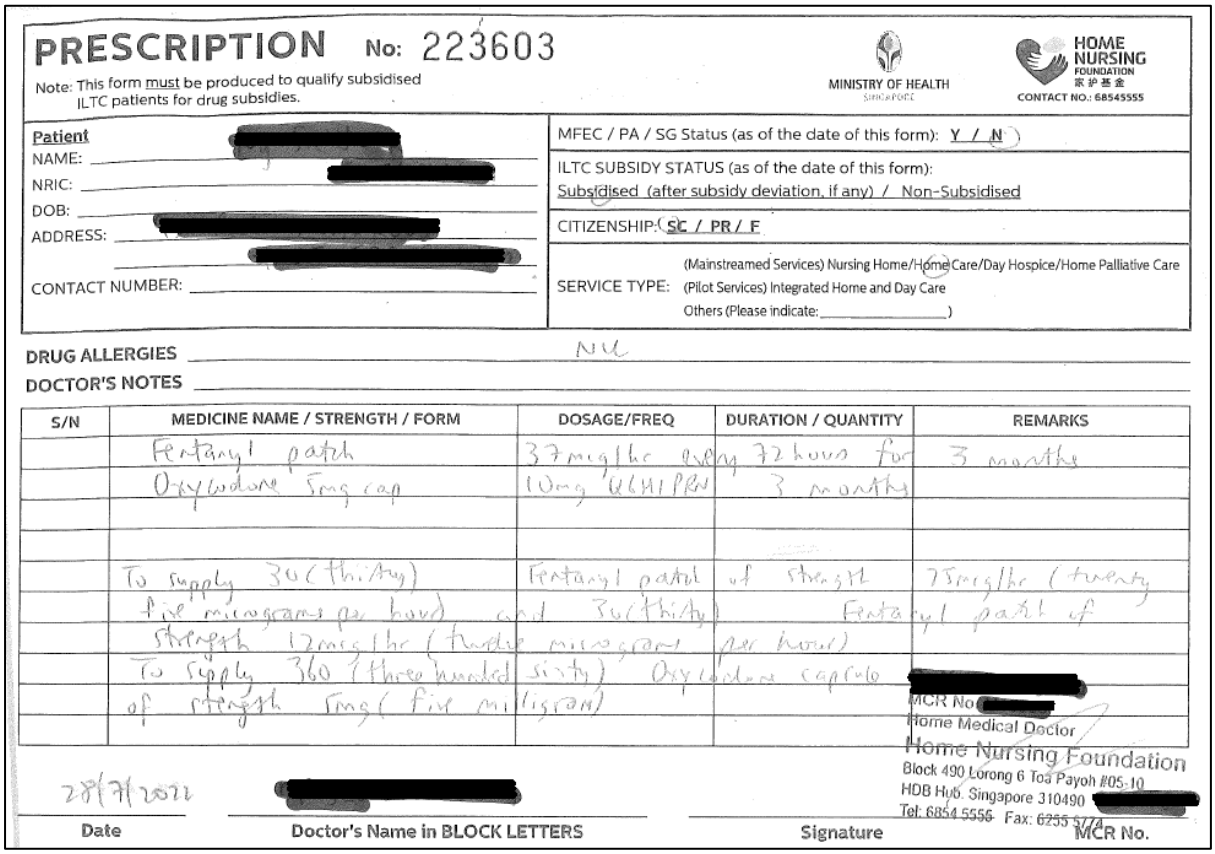
Samples of CD prescription



PRESCRIPTION No: 223603

Note: This form must be produced to qualify subsidised ILTC patients for drug subsidies.

MINISTRY OF HEALTH SINGAPORE

HOME NURSING FOUNDATION 家护基金 CONTACT NO.: 68545555

Patient
NAME: [redacted]
NRIC: [redacted]
DOB: [redacted]
ADDRESS: [redacted]
CONTACT NUMBER: [redacted]

MFEC / PA / SG Status (as of the date of this form): Y / N

ILTC SUBSIDY STATUS (as of the date of this form):
Subsidised (after subsidy deviation, if any) / Non-Subsidised

CITIZENSHIP: SC / PR / F

SERVICE TYPE: (Mainstreamed Services) Nursing Home/Home Care/Day Hospice/Home Palliative Care
(Pilot Services) Integrated Home and Day Care
Others (Please indicate: _____)

DRUG ALLERGIES: NIL

DOCTOR'S NOTES:

S/N	MEDICINE NAME / STRENGTH / FORM	DOSAGE/FREQ	DURATION / QUANTITY	REMARKS
	Fentanyl patch	37mcg/hr every 72 hours for	3 months	
	Oxycodone 5mg cap	10mg Q6H PRN	3 months	
	To supply 30 (thirty)	Fentanyl patch of strength		75mcg/hr (twenty
	five micrograms per hour) and 30 (thirty)		Fentanyl patch of	
	strength 12mcg/hr (twelve micrograms	per hour)		
	To supply 360 (three hundred	sixty) Oxycodone capsule		
	of strength 5mg (five milligram)			

MCR No. [redacted]
Home Medical Doctor
Home Nursing Foundation
Block 490 Lorong 6 Toa Payoh #05-10
HDB Hub. Singapore 310490
Tel: 6854 5556 Fax: 6255 5774

28/7/2022 [redacted]

Date | Doctor's Name in BLOCK LETTERS | Signature | MCR No.

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Seizure Management Considerations in End-of-life Homecare Clients

Definition

Seizures can be challenging to identify in end-of-life (EoL) care clients who often have episodic changes of consciousness. In the homecare setting, seizure episodes are often not witnessed by professionals and reporting is largely based on the caregiver. Presentation in elderly clients is often different from healthier adults as well, adding to the challenges of early identification (Grönheit et. al,2018).

Status epilepticus is broadly defined as a prolonged seizure or multiple seizures with incomplete return to baseline. It is a neurological emergency defined as a single unremitting seizure of more than five mins or two or more seizures between which there is incomplete recovery of consciousness.

Signs/Presentation

Signs and symptoms can range from mild to severe and vary depending on the type of seizure. Seizure signs and symptoms may include:

- Temporary confusion
- Blank staring
- Uncontrollable jerking movements of arms and legs
- Loss of consciousness or awareness
- Cognitive or emotional symptoms

Possible causes

- Brain metastasis or primary brain tumour
- Hypoglycaemia, hyponatraemia, uraemia
- Hepatic encephalopathy
- Hypoxic encephalopathy, hypercarbia
- Stroke, scar epilepsy
- Infection
- Medication

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Assessment

- Measure and review vital signs (if charted by caregiver)
- Obtain detailed history on reported signs and symptoms
- Try to identify underlying cause and treat reversible causes if consistent with goals of care
- Review medications and consider pharmacological options
- Consider prognosis (for doctors)

Referrals

Home Medical	• If cause of seizure is uncertain and diagnosis is required • Treatment and management of underlying cause and symptoms especially for pharmacological interventions • Prognostication • PPC discussions • Complex communications (e.g., differing care goals amongst family members)
Home Nursing	• Any nursing care needs e.g., wounds, monitoring of chronic disease, education on medication use and adjustment, education on non-pharmacological treatment i.e., use of oxygen, ACP/PPC discussions • Follow-up after initial treatment by the doctors • Caregiver training and support • Care coordination
Medical Social Worker	• Complex communication (e.g., differing care goals amongst family members, requiring psycho-emotional support, spiritual support) • If counselling is indicated and agreed to • Caregiver stress not relieved by support services already in-place • Financial support needed

Management

First aid:

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1. Turn client to lateral position (preferably left)
2. Ensure safe environment – move anything away that is sharp or hard that could cause injury.
3. Give supplement oxygen (if available)
4. Time the seizure — or estimate the time if you do not have a watch or phone.
5. Do not try to hold the client down.
6. Do not put anything in the client's mouth.

Non-pharmacological

Client/caregiver education:

1. Rendering first aid (refer to first aid instructions)
2. Educate on administering rectal diazepam
3. Prevention of certain cause of seizures i.e.,
    a. Ensuring sufficient sleep/rest
    b. Prevent common infections whenever possible
4. Consider asking family to record (video or notes) future episodes (Seneviratne et al., 2012)

Pharmacological management

This section outlines some of the principles and options in the pharmacological treatments of seizures and status epilepticus in EoL clients. It is not exhaustive, and practitioners must exercise clinical judgement and practice holistic management of clients.

Status epilepticus

	Medication	***Stat/starting dose***	***Maintenance dose***	***Common side effects***
1st line	Diazepam	PR 10mg stat, may repeat in 5 mins	PR 20mg ON	Drowsiness, lethargy
2nd line	Midazolam	Not for use within HNF scope of practice		
3rd line	Phenobabitone			

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Anti-epileptic drugs (AEDs) for maintenance

Medication	***Starting dose***	***Maintenance dose***	***Common side effects***
Levetiracetam	PO 750-1000mg/day in 2 divided doses	1000-3000mg/day in 2 divided doses, dose adjust in renal failure	Drowsiness, headaches, dizziness
Phenytoin	PO 200-300mg/day	200-400mg/day in single or divided doses (check serum level)	Drowsiness, headaches, dizziness, constipation
Valproic acid	PO 250-500mg/day in divided doses	1000-2000mg/day in 2-3 divided doses, dose adjust in liver failure (check serum level)	

- If imminently dying, there is no role for Anti-epileptic drugs (AED)
- If consistent with prognosis and goals of care, start AED if no contraindications and AED naïve.
- If already on AED, consider increasing AED dose if possibly subtherapeutic +/- reloading

Escalation

- For first occurrence, advise to send to Emergency Department (ED) to fully investigate cause unless client is actively dying, and family has opted for client to pass on at home.
- Consider ED if seizures persist despite 2 doses of rectal diazepam or client requires alternative routes of administering AEDs.

Caregiver training/education

1. Charting of seizures
2. First aid (see above in management)
3. Insertion of enema in status epilepticus
4. Chronic illness management and managing underlying causes

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5. Self-care

    a. Taking 5-10mins of caregiving break can be very useful (e.g., drinking a cup of tea, deep breathing exercises, pray or meditate, release tension with exercise, talk to a friend, practice gratitude, use aromatherapy)
    b. Seek help from professionals if unable to cope

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References

Beniczky, S. A., Fogarasi, A., Neufeld, M., Andersen, N. B., Wolf, P., van Emde Boas, W., & Beniczky, S. (2012). Seizure semiology inferred from clinical descriptions and from video recordings. How accurate are they?. *Epilepsy & behavior : E&B*, *24*(2), 213–215. https://doi.org/10.1016/j.yebeh.2012.03.036

Grönheit, W., Popkirov, S., Wehner, T., Schlegel, U., & Wellmer, J. (2018). Practical Management of Epileptic Seizures and Status Epilepticus in Adult Palliative Care Patients. *Frontiers in neurology*, *9*, 595. https://doi.org/10.3389/fneur.2018.00595

Lee C.S. (2022, June 2022). HNF CME Session 1 - Updates on Palliative Care for Frail Elders for Home-visiting Doctors [Video]. YouTube. https://www.youtube.com/watch?v=46C2bZT9-xQ

Seneviratne, U., Rajendran, D., Brusco, M., & Phan, T. G. (2012). How good are we at diagnosing seizures based on semiology?. *Epilepsia*, *53*(4), e63–e66. https://doi.org/10.1111/j.1528-1167.2011.03382.x

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Agitation Management Considerations in End-of-Life Homecare Clients

Definition

Clients can become agitated towards the end of their life. There are different causes, and it can often be recognised by irritability, restlessness, fidgeting and changes to a client's behaviour. Agitation can be distressing for the client, their caregivers, family, or friends. It can be linked to emotional, physical, or spiritual distress, but there are interventions to manage the behaviour and support the caregivers and family (Terminal Agitation at the End of Life, Information for Professionals, 2022b).

Terminal agitation means agitation that occurs in the last few days of life. It may be difficult to discern whether symptoms are due to delirium or having terminal agitation and anxiety. For practical purposes, if a client has been treated for delirium and is still agitated and distressed, the addition of a benzodiazepine such as lorazepam may be helpful.

Signs of agitation

Agitation can come on suddenly or gradually, and often it comes and goes. Signs and symptoms of terminal agitation can include:

- Distressed behaviour e.g., crying, being inconsolable
- Confusion
- Repeated calling, moaning, shouting, or screaming
- Hallucinations
- Drowsiness
- Trying to get out of bed or wandering
- Being sleepy during the day but active at night
- Being unable to concentrate or relax, or getting easily distracted
- Rambling conversation or switching topics often
- Angry and aggressive behaviour
- Facial cues, like frowning, grimacing, and looking less peaceful
- Fidgeting, including repeatedly picking at clothes or bed sheets

Possible causes of agitation

Agitation can be a sign that the client is in the last days of life, but it can also occur in earlier stages of their illness. Terminal agitation happens to people who are in the advanced stages of their illness. Agitation can be caused by medications the client is on, their condition, or psychological factors. Below are some causes for the clinician's consideration. It is not exhaustive, and the clinician should exercise their own judgement in the assessment.

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Reversible causes	**Irreversible**
Medications e.g., opioids or corticosteroids	Brain tumour including metastases
Uncontrolled pain or discomfort	Organ failure
Urinary retention	Pre-existing mental disorders
Constipation	
Nausea	
Low oxygen	
Reversible	
Altered blood levels including urea and creatinine, calcium, sodium, glucose	
Infection or sepsis	
Emotional or spiritual distress	
Substance withdrawal e.g., nicotine/alcohol	

Assessment

When trying to diagnose the cause of a client's agitation, it's important to perform a detailed history about the client, including if anything new has happened e.g., starting a new medication, not sleeping well, etc.

Below are some questions that the clinician can get information to help ascertain cause

1. Onset and duration of the agitated behaviour
    a. Was it sudden or gradual
    b. When did it start, how long does it last
    c. is there a pattern to it e.g., always happens after certain activity or at a certain time
2. What is the behaviour and how is it different from the normal?
3. Are there any changes to their treatment, medications, routines, environment.
4. Review medical notes and charts-Could the client have a physical/ medical cause for agitation (more example available below in Causes of agitation)
5. Unmet psychosocial needs

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Management

Treat any reversible causes first. Refer to the list above. Once the treatable courses have been addressed, and non-pharmacological interventions have also been done, consider pharmacological interventions.

Referrals

Home Medical	For diagnosis and management of agitation
Home Nursing	For care-giver training, any nursing needs that need to be addressed
Home Therapy	If assessed to be potentially helpful; gentle mobilization/turning
Medical Social Worker (MSW)	Psycho-social support/ spiritual support/grief

Non-pharmacological management and caregiver training

Social & environmental interventions	• Consider 'Social Psychology' (consider Kitwood's Enriched Model for dementia care) i.e., elder's agitation could be a reaction to social contacts • Soft lighting • soft and calming music • Watch their favourites shows • Aromatherapy • Avoid sudden changes in environment/routine
Psychological interventions	• Consider unmet emotional needs e.g., need for companionship, i.e., loneliness; need to have autonomy (i.e., helplessness) and boredom • Relaxation through gentle massage, light mobilization exercises as tolerated • Encourage family to take turns to accompany client e.g., holding their hands, talking, praying with them, reading to them • Engage a spiritual leader for prayers or counselling

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	• Inform family and caregivers of the end-of-life status and explain terminal agitation, it can help them be more client and empathetic to the client's mood and behaviours and prepare themselves. MSW may be engaged to support next of kin/care-givers as well • Assure family that they can approach
Physical	• See pharmacological interventions • Attending to comfort needs e.g., oral toilet, moistening mouth, sips of water, pain management, ambient temperature
Spiritual	• Engage a spiritual leader/chaplain for prayers • Readings of scriptures/ singing songs/ stimuli that inspire faith • Finding meaning and purpose in life and in death

Pharmacological management

This section outlines some of the principles and options in the pharmacological treatments of agitated behaviours in EoL clients. It is not exhaustive, and practitioners must exercise clinical judgement and practice holistic management of clients.

When reversible causes have been treated and agitation persists despite non-pharmacological measures, medication can be used to manage the client. The aim should be to maintain comfort and dignity. The following medications can be used to calm and help the client sleep.

Medication	Dosage	Contraindications	Side effects
Anti-depressant	Depends on the choice of antidepressant. Useful for persons with longer lead to work	Variable	Variable
Haloperidol	0.5mg-1.5mg PO stat followed by prn 2-hourly Maximum dose is 8mg in 24 hours PO or SC	Severe toxic CNS depression, comatose states, Parkinson's disease, basal ganglia lesions, thyrotoxicosis, significant cardiac disorders (e.g.,	Extrapyramidal syndrome, CNS depression, anticholinergic effects

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		acute MI, uncompensated heart failure, arrhythmias, clinically significant bradycardia, 2nd or 3rd degree heart block, uncorrected hypokalaemia).	
Olanzapine (Antipsychotic)	2.5mg PO/SL or SC stat followed by prn 2-hourly. Maximum dose 10mg in 24 hours	Use with caution in patients with cardiac abnormalities and / or seizures	
Midazolam (Benzodiazepine)	S/C 2.5-10mg stat followed by intermittent S/C doses of 2.5mg@4hourly/prn	Acute narrow-angle glaucoma, severe respiratory failure/depression, CNS depression	CNS depression, hypotension, paradoxical reactions (e.g., hyperactive, or aggressive behaviour)
Lorazepam (Benzodiazepine)	S/L 0.5mg Q4hourly/prn to a maximum of 10mg per day	Narrow angle glaucoma	Drowsiness, weakness
Diazepam (Benzodiazepine)	PR diazepam 10mg/prn	Respiratory depression	Drowsiness

Escalation

- Escalate to EoLMDT doctor if cause of agitated is unclear and/or requires medical attention
- Refer to hospital if symptoms are not manageable despite best efforts, and clients or caregivers prefer care in an acute hospital
- EoLMDT may consider referrals to home-based hospice care or specialist care if agitated behaviour is not optimally managed despite best efforts with pharmacological and non-pharmacological measures within HNF's scope
- Refer to an inpatient hospice if clients or caregivers cannot cope at home and client meets the admission criteria

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Caregiver education

1. Refer to non-pharmacological interventions
2. Self-care
    a. Agitated behaviours can be very distressing and overwhelming to caregivers
    b. Taking 5-10mins of caregiving break can be very useful (e.g., drinking a cup of tea, deep breathing exercises, pray or meditate, release tension with exercise, talk to a friend, practice gratitude, use aromatherapy)
    c. Seek help from professionals if unable to cope

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References

Cheshire and Merseyside Palliative & End of Life Care Network Audit. (n.d.). Docslib. https://docslib.org/doc/9639003/cheshire-and-merseyside-palliative-end-of-life-care-network-audit

Haloperidol: Indication, Dosage, Side Effect, Precaution | MIMS Singapore. (n.d.). https://www.mims.com/singapore/drug/info/haloperidol?mtype=generic

Max, W., Rachell, Campbell., Nandini, V., Stephen, W. & Jo, Wells. Oxford Handbook of palliative care. 3rd edition. Oxford Medical Book.

Midazolam: Indication, Dosage, Side Effect, Precaution | MIMS Malaysia. (n.d.). https://www.mims.com/malaysia/drug/info/midazolam/

Overview | Care of dying adults in the last days of life | Guidance | NICE. (2015, December 16). https://www.nice.org.uk/guidance/ng31

Overview | Care of dying adults in the last days of life | Guidance | NICE. (2015, December 16). https://www.nice.org.uk/guidance/ng31

Terminal agitation at the end of life | Information for professionals. (2022, July 6). Marie Curie. https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/symptom-control/agitation

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Constipation Management Considerations in End-of-Life Homecare Clients

Definition

Constipation is a common complaint in older adults. According to the Rome IV criteria, functional constipation is defined as any two of the following features: straining, lumpy hard stools, sensation of incomplete evacuation, use of digital manoeuvres, sensation of anorectal obstruction or blockage with 25 percent of bowel movements and decrease in stool frequency (less than three bowel movements per week).

Common causes of constipation in a homecare client:

- Reduction in physical activity
- Slow transit
    - Polypharmacy
    - Underlying conditions e.g., Parkinson's disease, spinal injuries
- Insufficient water or fibre

Assessment

History taking

1. Onset & duration
2. Nature of bowel movement
    a. Type of stool using Bristol stool chart (refer to page 5)
    b. Amount
    c. Frequency over the last two weeks
3. Review of medication list, especially if new onset of symptoms correlates with new medications being started. (Refer to page 6 for list of medications which are associated with constipation)
4. Review of chronic disease and functional status (this list is not exhaustive)
    a. Neurological diseases e.g. Parkinson's, spinal cord injury, multiple sclerosis
    b. Endocrine disorders e.g. Hypothyroidism, Diabetes mellitus
    c. Others, etc slow colonic transit, myotonic dystrophy, immobility, haemorrhoids
5. Diet history
    a. Changes in dietary patterns
    b. Fluid intake and fiber intake

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Physical examination

- Abdominal examination including digital rectal examination if not contraindicated.
    - If stool is present, consistency and colour should be noted
- Check for anal fissures and/or haemorrhoids

Red flags

- Fresh blood in or with stools/positive faecal occult blood test
- Obstructive symptoms e.g., vomiting, inability to pass gas, severe bloating, severe abdominal cramps
- Acute onset of constipation
- Severe persistent constipation that is unresponsive to treatment
- Weight loss ≥4.5kg
- Change in stool calibre
- Family history of colon cancer or inflammatory bowel disease should be specifically noted as these will indicate the need for more extensive evaluation

Referrals

Home Medical	• Red flags as stated in above • If cause of simple constipation is uncertain and diagnosis is required i.e., suspected intestinal obstruction • Treatment and management of underlying cause and symptoms • Prognostication/ PPC discussion if newly identified as EOL, condition has changed from stable to unstable/critical/terminal • Complex communications (i.e., differing care goals amongst family members)
Home Nursing	• Any nursing care needs e.g., education on medication use such as suppository insertion, non-pharmacological treatment i.e., potting advises, diet and fluid advise • Follow-up after initial treatment by the doctors • Care-giver training and support • Care coordination needs
Home Therapy	• Gentle exercises

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Medical Social Worker	• Complex communication (i.e., differing care goals amongst family members, requiring psycho-emotional support, spiritual support) • If counselling is indicated and agreed to • Caregiver stress not relieved by support services already in-place • Financial support needed

Management

Non-pharmacological management

- Regular potting especially after mealtimes
- Encourage sufficient fluid, if not contraindicated i.e., heart failure on fluid restriction
- Encourage fibre
- intake as tolerated, or, if not contraindicated i.e., dragon fruit, papaya, banana, sweet potato, pumpkin.
- Encourage mobility and/or ROM exercises to promote gut movement

Pharmacological management

Medication	**Dosage for titration**	**Onset of action**	**Side effects**
Osmotic agents- usually for hard stools			
Lactulose	10-20mls OM/BD/TDS	24 to 48 hours	Abdominal bloating, flatulence
Centa enema	Once every 3 days	15-60 minutes	Megacolon
Stimulant laxatives – slow colonic transit, decreased ability to push			
Bisacodyl (Only use if faecal loading in rectum)	10 mg suppository per rectum 1 time per day	15 to 60 minutes	Rectal irritation, megacolon
	10mg PO OM	6-10 hours	Gastric irritation
Senna	15mg (2tabs) ON/ BD	6 to 12 hours	Melanosis coli, megacolon

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Bowel clearance regime

For severe constipation, the EoLMDT may consider the following combination for bowel clearance

1. Daily supp Dulcolax x 3 days, till cleared.
2. Manual evacuation for severely loaded rectum (according to individual institutional guidelines, policies, and competencies)
3. Prevent subsequent occurrence of severe constipation by ensuring baseline laxatives prescribed and caregivers taught how to adjust according to client response after clearance done

The EoLMDT notes that there are instances where constipation occurs higher up the gastrointestinal tract, i.e., not in the rectum. A digital rectal examination will reveal ballooning, and empty rectum. In such cases, suppository Dulcolax has limited effect. A high fleet is recommended (if the institution has trained healthcare professionals to perform, please follow institution policy and guidelines).

Escalation

- See red flags and referrals above. Clients may require urgent home medical review/ be directed to the emergency department or referred to another appropriate service provider if HNF team is unable to manage at home despite best efforts
- Refer to an inpatient hospice if clients or caregivers cannot cope at home and client meets the admission criteria

Caregiver education

Skills	**Knowledge**
Maintaining output charting	Identifying signs and symptoms of constipation
Insertion of enemas and suppositories	Bristol stool chart
Non-pharmacological methods of encouraging bowel movement e.g., gentle movement and massage	Non-pharmacological methods of encouraging bowel movement e.g., potting after meals, diet fluid
	Use of and adjustment of oral laxatives

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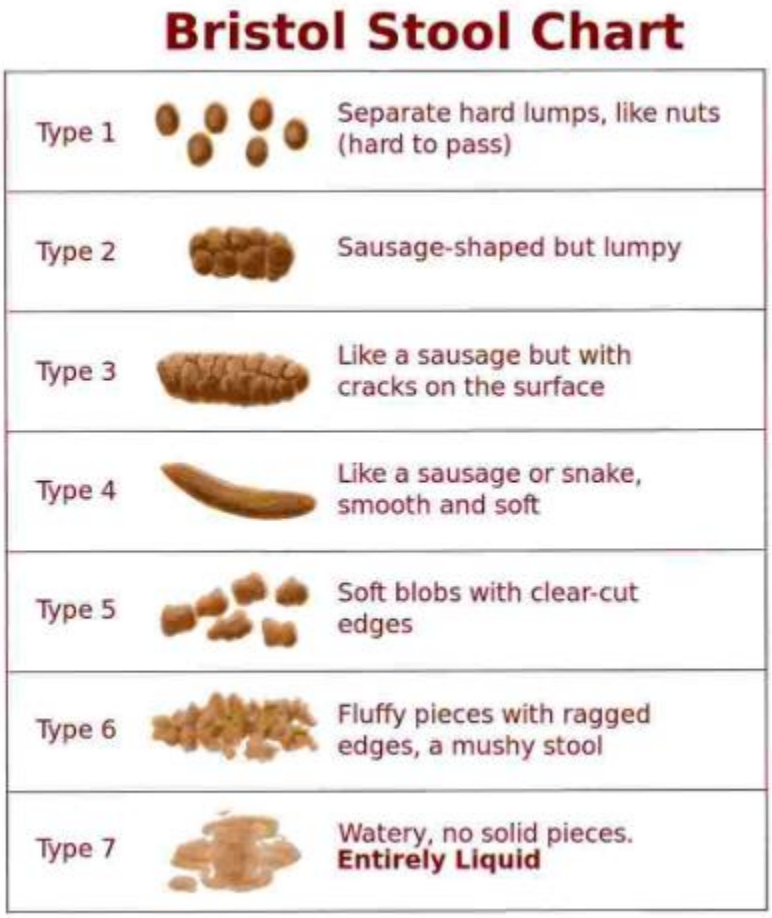
Bristol Stool Chart



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Drugs associated with constipation

Analgesics
Anticholinergics
Antihistamines
Antispasmodics
Antidepressants
Antipsychotics
Cation-containing agents
Iron supplements
Aluminum (antacids, sucralfate)
Barium
Neurally active agents
Opiates
Antihypertensives
Ganglionic blockers
Vinca alkaloids
Calcium channel blockers
5HT3 antagonists

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References

Bruera, E. (2021, December 17). *Overview of managing common non-pain symptoms in palliative care (T. J Smith & J. Givens, Eds.).* UpToDate. https://www.uptodate.com/contents/overview-of-managingcommonnonpainsymptomsinpalliativecare?search=nutrition%20and%20hydration%20in%20palliative%20care&source=search_result&selectedTitle=1~150&usage_type=default&display_rank=1

Chang, V. T. (2022, February 28). *Approach to symptom assessment in palliative care (T. J. Smith & J. Given, Eds.).* UpToDate. https://www.uptodate.com/contents/approach- to-symptom-assessment-in-palliativecare?search=constipation&source=search_result&selectedTitle=9~150&usage_type=default&display_rank=9

Rao, S. S. (2022, July 28). *Constipation in the older adult (N. J. Talley & S. Grover, Eds.).* UpToDate. https://www.uptodate.com/contents/constipation-in-the-older-adult?search=constipation&source=search_result&selectedTitle=3~150&usage_type=default&display_rank=3

Wald, A. (2022, June 3). *Management of chronic constipation in adults (N. J. Talley & S. Grover, Eds.).* UpToDate. https://www.uptodate.com/contents/management-of-chronic-*constipation-in-adults?search=constipation&source=search_result&selectedTitle=1~150&usage_type=default&display_rank=1*

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Dyspnoea Management Considerations in End-of-Life Homecare Clients

Definition and presentation

Subjective uncomfortable experience that can be described as difficulty with air movement, increased effort and can be distressing. Client may report their symptoms as, not being able to breathe fully, needing to breathe more or faster, feel like suffocating. The experience derives from interactions among multiple physiological, psychological, social, and environmental factors, and may induce secondary physiological and behavioural responses.

Possible Causes

Cardiovascular	Advanced heart failure (stage 3,4,5), poor effort tolerance
Respiratory	COPD, asthma, chest infection
Metabolic	End stage renal failure
Pain	Refer to pain management protocol
Neuropsychological	Anxiety

Assessment

- Onset, duration
- Vital signs (see * below to score dyspnoea for non-communicative clients)
- Associated symptoms e.g.
    - Secretions
    - Fatigue
    - Decline in physical and cognitive condition
    - Generalised oedema
- Response to treatment
- Distress to client/ caregivers

***Non-verbal cues of dyspnoea-RESPIRATORY DISTRESS OBSERVATION SCALE (RDOS)**

Variable	**0 points**	**1 point**	**2 points**	**Total**
Heart rate per minute	Baseline to +5	Baseline +6-10 beats	Baseline >+10bpm	
Respiratory rate per minute	Baseline to +3 breaths	Baseline +4-6 breaths	Baseline +>6 breaths	
Restlessness	none	Occasional slight movements	Frequent movement	
Accessory muscle use	None	Slight rise	Pronounced rise	

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Grunting at end-expiration	None		Present	
Nasal flaring	None		Present	
Look of fear	none		The upper iris is visible, the teeth are visible, the teeth are not parted, there are lines in the forehead, the eyebrows are flat, the eyebrows are raised, there are no wrinkles in the nose	

Referrals

Referrals can be made to the following disciplines at any point of time

Home Medical	• If cause is uncertain for full assessment and diagnosis for underlying cause to dyspnoea • Treatment and management of underlying cause and symptoms • ACP/PPC discussions • Complex communications (e.g., differing care goals amongst family members) • If symptoms are not manageable despite best efforts, may initiate hospice referrals/ referrals to specialists
Home Nursing	• Any nursing care needs e.g., wounds, monitoring of chronic disease, education on medication use and adjustment, ACP/PPC discussions • Care-giver training and support i.e., medication use and monitoring of vitals, patch applications • Care coordination
Home Therapy	• Chest therapy • Breathing techniques • Endurance training/ energy conservation • Swallowing assessment (if needed)
Medical Social Worker	• Complex communication (e.g., differing care goals amongst family members, requiring psycho-emotional support, spiritual support)

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	• Caregiver stress not relieved by support services already in-place • Likely to have complicated grief • Financial support needed

Management

Non-Pharmacological	
Oxygen	Provide relief of dyspnoea who are hypoxemic at rest & during minimal activity
Fan to the face	Provide subjective relief of dyspnoea
Anxiety reduction training (non-pharmacological)	• Deep breathing exercise • Refer MSW for emotional support and counselling
Physical rehabilitation	Respiratory and cardiovascular rehabilitation
Energy conservation	Timing activities with medications and energy levels of the day Breaking up tasks into smaller and shorter steps

Pharmacological		
Factors to consider • Consider the underlying causes to the dyspnoea and treat the underlying cause • The degree to which they interfere with overall function and well-being • Compromised hepatic and renal function • Potential adverse effects of the drug therapy	Pain and breathless sensation 1. Morphine	• Mist morphine 2.5-5mg 4-6hourly (Mild to moderate dyspnoea) • Fentanyl
	Anxiety & Insomnia	• Alprazolam 0.25-0.5mg TDS/prn and/or

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	1. Short Acting benzodiazepines e.g. (midazolam, lorazepam)	• Lorazepam 0.5-1mg ON prn

Escalation

- Escalate to EoLMDT doctor if cause of dyspnoea is unclear and/or requires medical attention
- Team may consider referrals to hospice care or specialist care if dyspnoea is not optimally managed despite best efforts with pharmacological and non-pharmacological measures within HNF's scope

Client/family education

Side effects of medications	For opioids i.e., application of Fentanyl patch
	For Sleeping pills
	For Antidepressants
Non-pharmacological interventions	As mentioned above e.g., fan to the face, pacing activities to conserve energy, reducing anxiety through deep breathing
Secretion management	Refer secretion management protocol
Caregiver self-care	• Dyspnoea can be very distressing and overwhelming to caregivers • Taking 5-10mins of caregiving break can be very useful (e.g., drinking a cup of tea, deep breathing exercises, pray or meditate, release tension with exercise, talk to a friend, practice gratitude, use aromatherapy) • Seek help from professionals if unable to cope

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References

Aw C.H. (2022). HNF CME Session 2- Updates on Palliative Care for Frail Elders for Home-visiting Doctors [Video]. YouTube. https://www.youtube.com/?v=0rtQMzF8rGY

Bruera, E. (2021, December 17). Overview of managing common non-pain symptoms in palliative care (T. J Smith & J. Givens, Eds.). UpToDate. https://www.uptodate.com/contents/overview-of-managingcommonnonpainsymptomsinpalliativecare?search=nutrition%20and%20hydration%20in%20palliative%20care&source=search_result&selectedTitle=1~150&usage_type=default&display_rank=1

Campbell, M. L. (2008b). Psychometric testing of a respiratory distress observation scale. Journal of Palliative Care Medicine, 11(1), 48.

Chang, V. T. (2022, February 28). Approach to symptom assessment in palliative care (T. J. Smith & J. Given, Eds.). UpToDate. https://www.uptodate.com/contents/approach-to-symptom-assessment-in-palliativecare?search=constipation&source=search_result&selectedTitle=9~150&usage_type=default&display_rank=9

Chiam Z.Y. (2022). HNF CME Session 3- Updates on Palliative Care for Frail Elders for Home-visiting Doctors[Video]. YouTube. https://www.youtube.com/watch?v=-iaQS41hNoc&t=12s

Dudgeon, D. (2021, October 6). Assessment and management of dyspnea in palliative care (E. Bruera & J. Givens, Eds.). UpToDate. https://www.uptodate.com/contents/assessment-and-management-ofdyspneainpalliativecare?search=dyspnoea%20in%20pallative%20care&source=search_result&selectedTitle=1~150&usage_type=default&display_rank=1

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Nutrition and Hydration Considerations in End-of-Life Homecare Clients

Introduction

Fluid and nutritional deficits in end-of-life patients are frequently multifactorial in aetiology. The dying process is usually characterized by decreased oral intake, decreased perception of thirst and hunger. There may be progressive accumulation of medications (including opioids) and their metabolites, which can cause or exacerbate symptoms of fatigue, dizziness, myoclonus, sedation, and hallucinations which impair fluid intake. These result in total body water depletion and decrease in renal function. In general, patients who go without nutrition or hydration in the context of a terminal illness only live for a short time (around 1-2 weeks) (Danis, 2022).

Home Nursing Foundation's View

Medically assisted nutrition and hydration should be considered as medical interventions rather than basic provisions of comfort. It is thus important to, first; **(1) explore and understand** the views and preferences of the client and loves ones, **(2) determine the goals of care** with the client and their loved ones before discussing stopping nutrition and hydration. Clinical teams should be prepared to engage in **shared decision-making** that accommodates their decision-making preferences, for example, conducting a preferred plan of care conversation (PPC) with patient (if still able to), or with family members for those patients who can no longer do so.

In line with current evidence, HNF **does not** advocate for artificial nutrition e.g., via nasogastric tube, or intravenously, for clients in the active dying phase as studies indicate that artificial nutrition has no effect on prolonging life or improving functional status in the setting of many advanced illnesses at their terminal stages (Good et al., 2014).

General approaches (Danis, 2022; ANA Center for Ethics and Human Rights, 2017).

Explore and Understand

- Conduct PPC early even if the patient is in stable phase so that the clinical team and family are both aware of care goals and can practice shared decision-making
- Help client/ next-of-kin to understand that artificial nutrition and hydration is a medical treatment that is often not indicated when the client is dying and will not improve the patient's condition
- Family should be reassured that it is ethical to withhold and withdraw artificial hydration.
- Many symptoms such as thirst, dry mouth, and fatigue are not specific for hydration status, and hydration is not likely to be of any benefit.
- Iatrogenic overhydration can lead to pain and dyspnoea from fluid retention.
- Giving a realistic estimate of the time until death can prepare loved ones to handle the ensuing time

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Referrals

Home Medical	• Insufficient nutrition/hydration is acute, cause is unclear and/or requires medical attention e.g., suspected underlying infection • Explore oral supplemental milk to aid in achieving some level of nutrition for clients in the stable/unstable phase at end-of-life. • Monitor drug dosages, particularly pain medications, because dehydration may be accompanied by reduced consciousness and reduced drug elimination • Informing of prognosis
Home Nursing	• PPC discussion • Any nursing care needs e.g., caregiver education on safe feeding, wound care, monitoring of chronic disease, education on medication use and adjustment, • PPC discussions • Follow-up after review by the doctors • Care coordination
Speech Therapist	For institutions that have a speech therapist service, it may be beneficial for assessing need for altered diet consistency. For clients at unstable, deteriorating and/or terminal stages, the clinical team should assess if patient would benefit
Dietician	For institutions that have a speech therapist service, it may be beneficial for assessing need for nutritional supplements, i.e., Ensure/Glucerna, Diaben, Nepro, Resource, etc For clients at unstable, deteriorating and/or terminal stages, the clinical team should assess if patient would benefit.
Medical Social Worker	• Complex communication (i.e., differing care goals amongst family members, requiring psycho-emotional support, spiritual support) • If counselling is indicated and agreed to • Caregiver stress not relieved by support services already in-place • Financial support needed

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Escalation

- Escalate to EoLMDT doctor cause of insufficient nutrition/hydration is unclear and/or requires medical attention e.g., suspected underlying infection
- Refer to hospital if symptoms are not manageable despite best efforts, and clients or caregivers prefer care in an acute hospital
- Team may consider referrals to home-based hospice care or specialist care if pain is not optimally managed despite best efforts with pharmacological and non-pharmacological measures within HNF's scope
- Refer to an inpatient hospice if clients or caregivers cannot cope at home and client meets the admission criteria

Caregiver education

1. Continue or encourage oral intake if it is compatible with the overall goals of care and comfort.
   - Proper positioning
   - Slow small spoon feeding as tolerated (pleasure feeding)
   - Selecting food that has appropriate temperature, taste, and consistency (using thickeners as needed)
   - Offering foods with strong flavours
   - Varying the size and frequency of the meals
   - Avoiding distractions while eating
   - Regular sips of water

2. Engage the family in providing good oral care
   - Alleviates symptoms of dry mouth and thirst
   - Regular oral cleaning
   - Giving ice chips
   - Use of moisturising mouth gels/lip balm

3. Self-care
   - Taking 5-10mins of caregiving break can be very useful (i.e., drinking a cup of tea, deep breathing exercises, pray or meditate, release tension with exercise, talk to a friend, practice gratitude, use aromatherapy)
   - Seek help from professionals if unable to cope

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References

ANA Center for Ethics and Human Rights (2017). Position Statement: Nutrition and Hydration at the End of Life. https://www.nursingworld.org/~4af0ed/globalassets/docs/ana/ethics/ps_nutrition-and-hydration-at-the-end-of-life_2017june7.pdf

Bruera, E. (2021, December 17). Overview of managing common non-pain symptoms in palliative care (T. J Smith & J. Givens, Eds.). UpToDate. https://www.uptodate.com/contents/overview-of-managingcommonnonpainsymptomsinpalliativecare?search=nutrition%20and%20hydration%20in%20palliative%20care&source=search_result&selectedTitle=1~150&usage_type=default&display_rank=1

Good, P., Richard, R., Syrmis, W., Jenkins-Marsh, S., & Stephens, J. (2014). Medically assisted nutrition for adult palliative care patients. Cochrane Database of Systematic Reviews. https://doi.org/10.1002/14651858.cd006274.pub3

Marion Danis (2022) Stopping nutrition and hydration at the end of life. UpToDate. Retrieved July 26, 2022, from https://www.uptodate.com/contents/stopping-nutrition-and-hydration-at-the-end-oflife?search=Stopping%20nutrition%20and%20hydration%20at%20the%20end%20of%20life&source=search_result&selectedTitle=1~150&usage_type=default&display_rank=1

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Secretion Management Considerations in End-of-Life Homecare Clients

Respiratory secretions impact negatively on patients anywhere on the end-of-life journey. It can be secretions from infections or death rattle, manifesting as noisy breathing and causing distress to caregivers and family.

Common causes

Cardiovascular	Heart failure with fluid overload
Respiratory	COPD, chest infection, asthma, bronchiectasis
Neurological	Causes of neurological dysphagia: Parkinson's, stroke, advance dementia; 'death rattle'
General	Patients on tracheostomy, poor oral hygiene, atelectasis, poor cough reflex

Assessment Checklist

- Assess onset, duration
- Characteristics of secretions (thick/thin/ colour)
- Associated factors
    - more secretions post feed, in the evening/morning, etc
    - fever/hypothermia/ increased drowsiness/lethargy (may indicate infective process)
    - generalised oedema
    - position when secretions most audible
- Response to previous treatment
- Distress to patient/ caregivers
- Consult/refer EoLMDT doctor if cause is uncertain for full assessment and diagnosis for underlying cause to secretions

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Referrals

Home Medical	• If cause of secretions is uncertain and diagnosis is required • Treatment and management of underlying cause and symptoms especially for pharmacological interventions • Prognostication • PPC discussions • Complex communications (i.e., differing care goals amongst family members)
Home Nursing	• Any nursing care needs e.g., need for oral suction; monitoring of chronic disease, education on medication use and adjustment, education on non-pharmacological treatment PPC discussions • Follow-up after initial treatment by the doctors • Caregiver training and support • Care coordination
Home Therapy	• Respiratory or Cardiac rehabilitation • Postural drainage • Chest Physiotherapy • Breathing techniques • Swallowing assessment (if needed) and rehabilitation
Medical Social Worker	• Complex communication (e.g., differing care goals amongst family members, requiring psycho-emotional support, spiritual support) • If counselling is indicated and agreed to • Caregiver stress not relieved by support services already in-place • Financial support needed

Management

Non-pharmacological

- Nurse the client on their side, reposition to other side every 3-4 hours. Side lying position allows secretions to be drained out from the mouth.
- Elevate the head of the bed slightly, retain a position of comfort
- Provide frequent mouth care (every 1-2 hours).

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- **Deep suctioning should be avoided** as it can be very irritating and distressing, only use gentle suctioning within oral cavity.
- Postural Drainage/Chest Physiotherapy (CPT): CPT loosens secretions and facilitates cough or suctioning.
- Discontinuation or reduction of enteral feedings after discussion with donee/assumed health proxy and EoLMDT

Pharmacological

- Refer to EoLMDT doctor to diagnose & treat underlying cause (refer to possible differentials)
- EoLMDT Nurses may initiate non-pharmacological treatments first while awaiting physician input

Common medications used to treat secretions in palliative care:

Medications	**Dosage**	**Side effects**	**Contraindications**
Terminal/ deteriorating phase e.g. death rattle			
Atropine 1% ophthalmic solution (reduce saliva and respiratory secretion)	1-2 drops sublingually stat, then every 2-4 hours	Constipation, dry mouth, confusion, closed angle glaucoma	Acute angle glaucoma
Buscopan (reduce saliva and respiratory secretion)	S/C 20mg TDS/prn	Constipation, dry mouth, confusion, closed angle glaucoma	Acute angle glaucoma
In any other spectrum of palliative care phase e.g. stable/unstable/deteriorating			
Acetylcysteine (Flumucil) (For thick copious, viscous secretions, making secretions easier for expectorating)	PO 600mg Om/BD	Increased coughing (as acetylcysteine breaks up the mucous in your airways)	
Bromhexine (For thick copious, viscous secretions, making secretions easier for expectorating)	PO 8mg TDS/prn	Same as above	

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Escalation

- Escalate to EoLMDT doctor if cause of secretions is unclear and/or requires medical attention
- Team may consider referrals to home-based hospice care or specialist care if secretions is not optimally managed despite best efforts with pharmacological and non-pharmacological measures within HNF's scope
- Refer to hospital only if symptoms are not manageable despite best efforts, and clients or caregivers prefer care in an acute hospital
- Refer to an impatient hospice if clients or caregivers cannot cope at home and client meet the admission criteria

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The patient is actively dying and has respiratory secretions

GENERAL APPROACH

Initial assessment
Refer EoLMDT to determine differentials and treat underlying cause

Home nurses may start non-pharmacological care stated below.
Non-pharmacological client care (led by nurse):

- Nurse the person on their side, reposition to other side every 3-4 hours.
- Elevate the head of the bed slightly, retaining a position of comfort
- Provide frequent mouth care (every 1-2 hours).
- Use background music or a fan to diffuse the sound
- If suctioning is needed, only use gentle oral suctioning
- Explain to caregivers and family how & why noisy secretions develop. Emphasising it is a normal part of dying process.
- Give reassurance that the noise & secretions are not distressing for the patient

Refer HT/MSW if indicated

Are the secretions still problematic

YES

Continue with General care as above and activate home medical team to review need for add on trial of medications below:

1. Atropine 1% ophthalmic solution, 1-2 drops sublingually stat, then every 2-4 hours and/OR
2. s/c Buscopan 20mg TDS/prn

Has it been effective?

YES

Maintain the general approach

- Repeat subcutaneous dose in 4-6 hours as needed
- If ongoing doses of medication are required, consider a continuous subcutaneous infusion of either

NO

Maintain General approach as above and review periodically

Has it been effective?

NO

- Provide ongoing support to family, reiterating the noise is a part of the dying process and not distressing for the patient
- Continue with the general approach (as outlined above)
- An alternate drug or dose may be used but is unlikely to relieve the noise
- Address the grief and bereavement needs of

References

Bickel, K. and Arnold, R. Death rattle and oral secretions. Fast Facts and Concepts #109. June, 2015. Retrieved from https://www.mypcnow.org/blank-wz9l3

Bromhexine: Indication, Dosage, Side Effect, Precaution | MIMS Malaysia. (n.d.). https://www.mims.com/malaysia/drug/info/bromhexine

Bruera, E. (2021, December 17). Overview of managing common non-pain symptoms in palliative care (T. J Smith & J. Givens, Eds.). UpToDate. https://www.uptodate.com/contents/overview-of-managingcommonnonpainsymptomsinpalliativecare?search=nutrition%20and%20hydration%20in%20palliative%20care&source=search_result&selectedTitle=1~150&usage_type=default&display_rank=1

Chang, V. T. (2022, February 28). Approach to symptom assessment in palliative care (T. J. Smith & J. Given, Eds.). UpToDate. https://www.uptodate.com/contents/approach-to-symptom-assessment-in-palliativecare?search=constipation&source=search_result&selectedTitle=9~150&usage_type=default&display_rank=9

Chiam Z.Y (2022). HNF CME Session 3- Updates on Palliative Care for Frail Elders for Home-visiting Doctors[Video]. Youtube. https://www.youtube.com/watch?v=-iaQS41hNoc&t=12s

Management-of-Respiratory-Secretions-in-the-Terminal-Phase-May-2016.pdf (emrpcc.org.au).

Martinez, H. & Berry, P. (Eds). (2015). Core curriculum for the hospice and palliative registered nurse. (4th ed.). Dubuque, IA: Kendall Hunt Clary, P., and Lawson, P. Pharmacologic pearls for end-of-life care. American Family Physician. 2009 Jun 15;79(12): 1059-1065

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Management of Grief Considerations in End-of-Life Homecare Clients

Purpose
To provide guidelines on managing grief.

Scope
This document applies to EoLMDT working with persons experiencing loss and high grief.

Definition of Issue
Grief is a normal reaction to loss and should be given time and space for the person to express emotions.

Anticipatory Grief refers to a feeling of grief occurring before an impending loss. Anticipatory grief might be better understood as grieving the loss of experiences, possibilities, or an imagined future together, rather than loss of a person.

There is higher risk for Complicated Grief when the grief is of a persistent nature with no signs of abatement three months after passing on of the loved ones, and the symptoms are severe enough to cause problems and stop them from functioning well in their lives.

A. FOR NURSES, DOCTORS AND THERAPIST COLLEAGUES:

Detection, Screening and Assessment
As part of early intervention, screening for high grief is important in identifying caregivers at risk of complicated grief. Home Care Team to screen cases using the following scale:

- Screen for high grief using the 6-items scale adapted from Marwit–Meuser Caregiver Grief Inventory (refer Appendix 8a).

Inter-disciplinary Activation and Referral
- 21 points or more indicates high grief and shall be referred to MSW.

Useful Communication and Actions
- Be open to different grieving experiences.
- Offer the space to talk.
- Acknowledge the difficult times caregiver is going through.
- Adopt active listening to seek out content and embedded feelings that may come with the message.
- Propose to involve MSW to support their coping.

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B. FOR MEDICAL SOCIAL WORKER COLLEAGUES:

Social Work Assessment

- Upon knowledge of the referral, establish contact with the caregiver experiencing high grief as soon as practicable or within 2 working days (from the day of acknowledgement).

- Perform Brief Grief Questionnaire (BGQ) (Appendix 8b) for screening complicated Grief.

- Use the Social Report format (refer Appendix 8c) to document details of the family situation, including FICA spiritual assessment to identify spiritual distress, learn about spiritual resources, and to invite caregiver to share what gives them meaning and purpose.

Interventions

- For BGQ score less than 4, provide grief counselling towards restoration and completion of mourning tasks (refer Appendix 8d).

- For BGQ score 4 or more, in addition to above, provide weekly check-in on caregiver's coping.

- Where self-harm tendencies are present, put in place safety plans (refer suicide management SOP).

- Intervene according to needs presented at different phases of the EoL trajectory:

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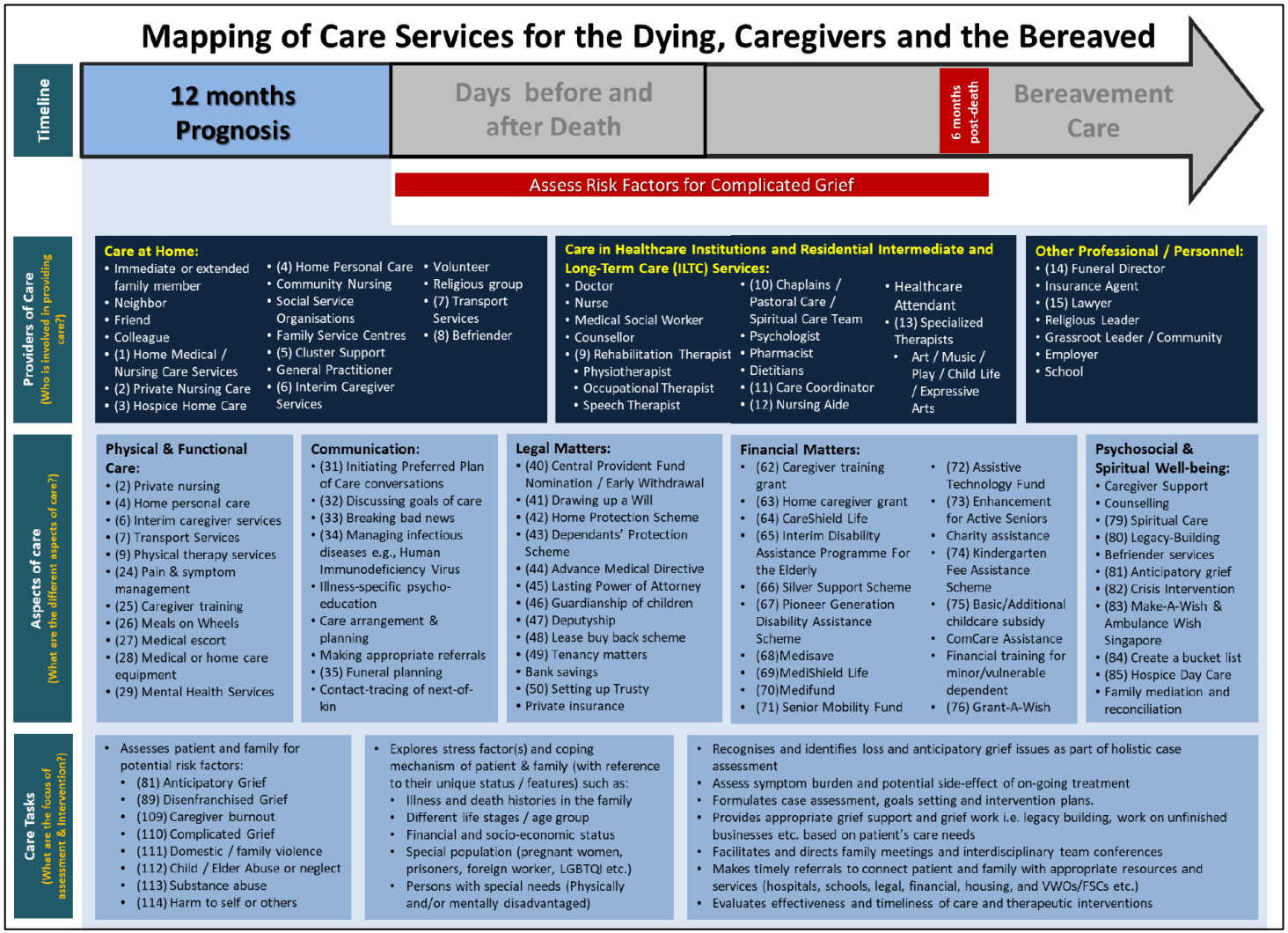

Figure 1: Developed by the Grief and Bereavement Community of Practice: <u>Interventions at 12-month prognosis</u>

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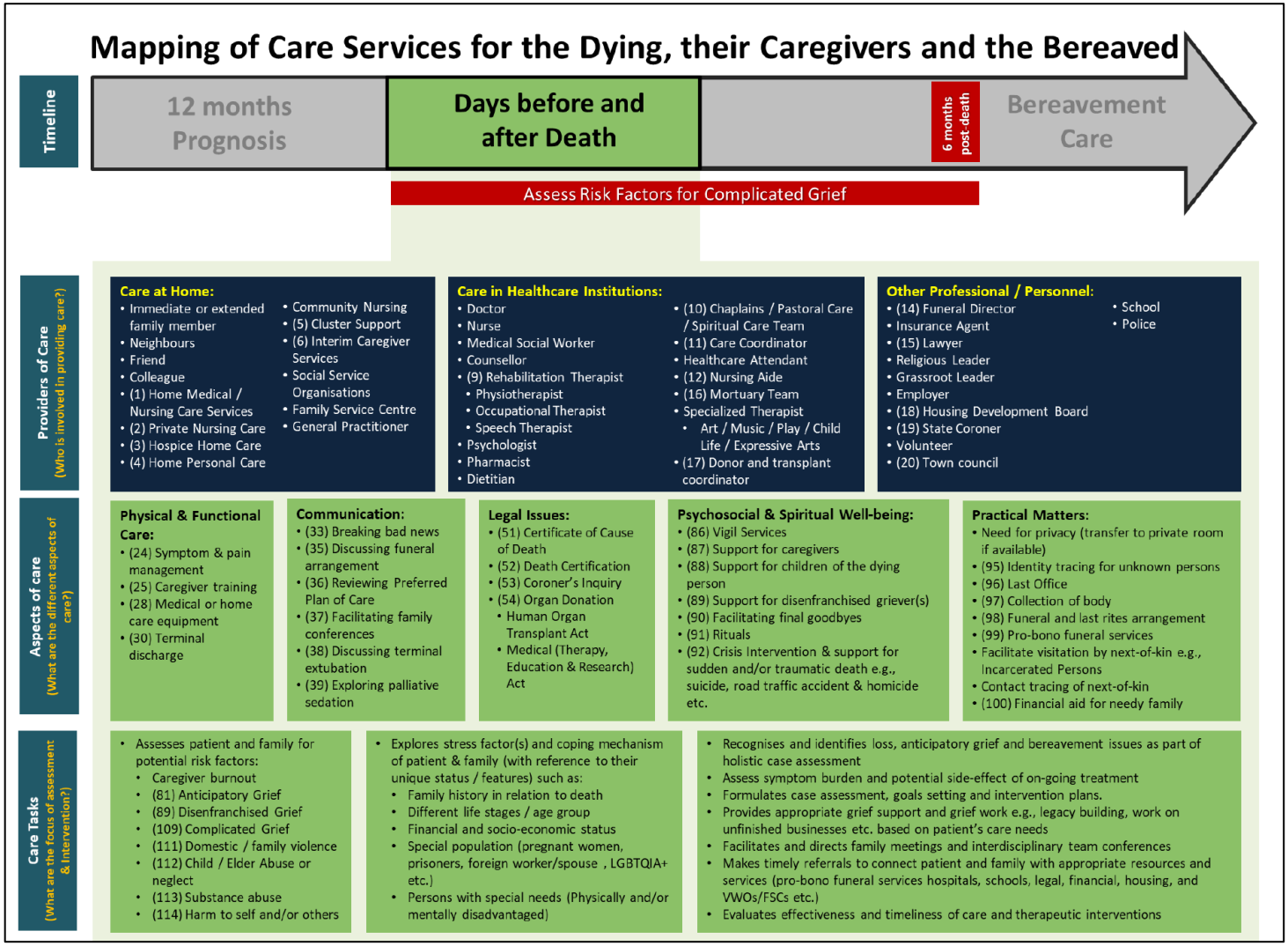

Figure 2: Developed by the Grief and Bereavement Community of Practice: <u>Interventions at days before and after death</u>

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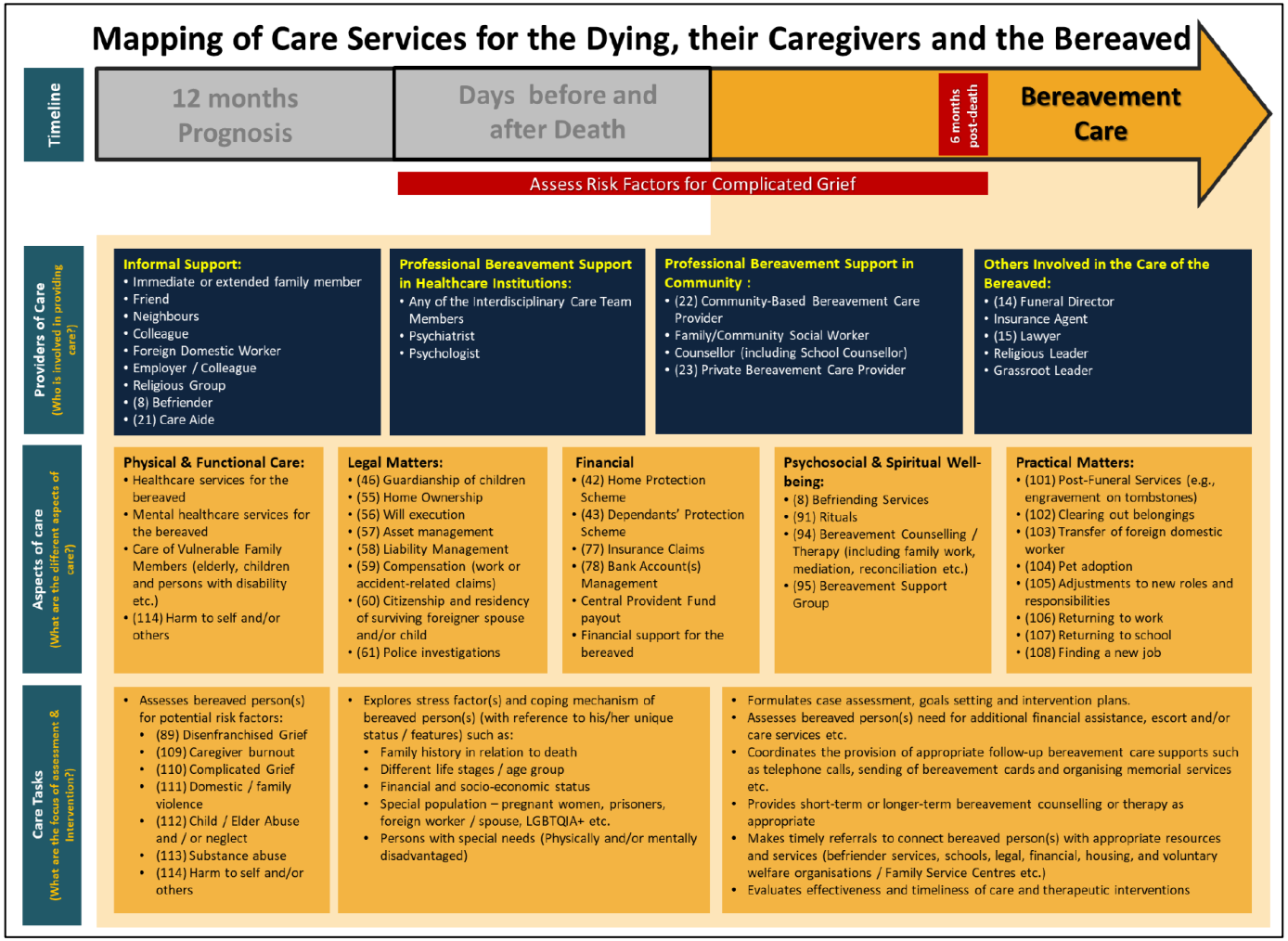

Figure 3: Developed by the Grief and Bereavement Community of Practice: <u>Interventions for bereavement care</u>

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- For high profile (media and multi health-social agencies involvement) and high-risk cases, flag out to EOL multidisciplinary team and HOD

- Case assessment and intervention should be communicated with the EoLMDT and recorded in patient's notes.

Escalation and External Referrals

- Escalation to mental health specialist to be facilitated in the following situations:
    a. The person experiencing loss has immediate self-harm or suicide tendency that could not be contained/managed in the community (refer suicide management SOP).
    b. The person is not able to benefit from counselling due to severe mood disorder i.e,. depression or anxiety.

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Appendix 7.2.8a

6-items scale adapted from Marwit–Meuser Caregiver Grief Inventory

Instructions: This inventory is designed to measure the grief experience of current family caregivers of persons living
with a progressive illness. Read each statement carefully, then decide how much you agree or disagree with what is said.

Circle a number 1-5 to the right using the answer key below (For example 5 = Strongly Agree). It is important that you respond to all items so that the scores are accurate.

Patient Name : _____

NRIC : _____

Caregiver Name: _____

ANSWER KEY **1 = Strongly Disagree** // 2 = Disagree // 3 = Somewhat Agree // 4 = Agree // **5 = Strongly Agree**						
1	I miss so many of the activities we used to share.	1	2	3	4	5
2	This situation is totally unacceptable in my heart.	1	2	3	4	5
3	I'm angry at the disease for robbing me of so much.	1	2	3	4	5
4	I long for what was, what we had and shared in the past.	1	2	3	4	5
5	I feel powerless.	1	2	3	4	5
6	I can't contain my sadness about all that's happening.	1	2	3	4	5

Adapted from 6-item Scale for Caregiver Grief

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Appendix 8b

Brief Grief Questionnaire*

1. How much are you having trouble accepting the death of _____?

Not at all..... 0 Somewhat.....1 A lot..... 2

2. How much does your grief still interfere with your life?

Not at all..... 0 Somewhat.....1 A lot..... 2

3. How much are you having images or thoughts of _____ when s/he died or other thoughts about the death that really bother you?

Not at all..... 0 Somewhat.....1 A lot..... 2

4. Are there things you used to do when _____ was alive that you don't feel comfortable doing anymore, or that you avoid? Like going somewhere you went with him/her, or doing things you used to enjoy together? Or avoiding looking at pictures or talking about _____? How much are you avoiding these things?

Not at all..... 0 Somewhat.....1 A lot..... 2

5. How much are you feeling cut off or distant from other people since _____

died, even people you used to be close to like family or friends?
Not at all..... 0 Somewhat.....1 A lot..... 2

A score of 4 or more suggests an individual may have complicated grief.
Refer the individual to Social Work Department.

** Developed by M. Katherine Shear MD and Susan Essock PhD.*

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Appendix 8c

SOCIAL REPORT

A. PATIENT CONTACT

Patient Profile

a. Name : _____
b. NRIC : _____
c. DOB : _____
d. Gender : _____
e. Address : _____
f. Housing Type : _____
g. Marital Status : _____

B. Primary Caregiver

a. Name : _____
b. Relationship to patient : _____
c. Contact : _____

C. Known Agencies Supporting Patient (delimit by comma for multiple agencies)

a. Agency Name : _____
b. Name of Contact Person : _____
c. Contact No. : _____
d. Contact Email. : _____
e. Service provision : _____

D. ASSESSMENT

Family Set Up (Write up or genogram)

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Physical & Cognitive Needs and Strengths

Psychological & Emotional Needs and Strengths

Social & Financial Needs and Strengths

Spiritual Needs and Strengths

F. Faith, Belief, Meaning: Determine whether or not the patient identifies with a particular belief system or spirituality at all.
I. Importance and Influence: Understand the importance of spirituality in the patient's life and the influence on healthcare decisions.
C. Community: Find out if the patient is part of a spiritual community, or if they rely on their community for support.
A. Address/Action in Care: Learn how to address spiritual issues with regards to caring for the patient.

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Risk Issues (eg abuse, self-harm, violence, neglect)

F. INTERVENTION AND RECOMMENDATION

Intervention

Recommendation

G. OTHERS/REMARKS

Reported by:

_____

Date:

_____

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Appendix 8d

Worden's Four Tasks of Mourning

- Task 1: To Accept the Reality of the Loss.
- Task 2: To Process the Pain of Grief.
- Task 3: To Adjust to a World Without the Deceased.
- Task 4: To Find an Enduring Connection With the Deceased in the Midst of Embarking on a New Life.

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References

American Psychiatric Association. (2022). Diagnostic and Statistical Manual of Mental Disorders, 4th Edition, Text Revision (DSM-IV-TR) (4th ed.).

Christina, P. (1996, updated 2022). FICA Spiritual History Assessment Tool. Retrieved from https://gwish.smhs.gwu.edu/programs/transforming-practice-health-settings/clinical-fica-tool

Grief and Bereavement Community of Practice (2020). Mapping of Care Services for the Dying, their Caregiver, and the Bereaved. Singapore Association of Social Workers (SASW) and Singapore Hospice Council (SHC).

Ito M, Nakajima S, Fujisawa D, Miyashita M, Kim Y, et al. (2012) Brief Measure for Screening Complicated Grief: Reliability and Discriminant Validity. PLoS ONE 7(2): e31209. doi:10.1371/journal.pone.0031209

Liew, T. M., Yap, P (2018). A Brief, 6-Item Scale for Caregiver Grief in Dementia**.** *Gerontologist*, 2020, Vol. 60, No. 1, e1–e10.

Margaret Stroebe, Henk Schut (1999) The Dual Process Model Of Coping With Bereavement: Rationale and Description, Death Studies, 23:3, 197-224.

Petruzzi, J. (2019). The Different Forms and Reactions of Grief and Bereavement.

Worden, J. W. (2009). Grief Counseling and Grief Therapy: A Handbook for the Mental Health Practitioner, Fourth Edition, Springer, N.Y.

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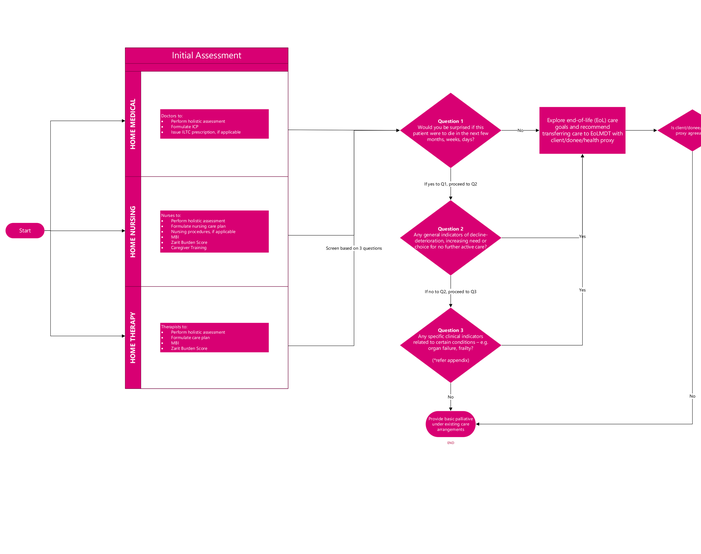
End-of-Life ITCP Flowchart

(Annex A)



	EoLMDT Doctors	EoLMDT Nurses	Medical Social Workers	Allied Health Professionals
STABLE	Visit Frequency – 3 monthly **Role:** • Prognostication and assess for category of viability • Introduce and lead PPC conversations • Assess and provide management plan for any distressing symptoms especially the need for pharmacotherapy • Identify reversible conditions and manage accordingly • Review priorities of chronic diseases • Rationalising TCAs • Medication reconciliation/de-prescribing • Consider referral to allied health professionals • Highlight acute or potential health risk • Timely review of the client	Visit Frequency – 2 monthly **Role:** • Participate in/facilitate PPC conversations • Monitor for changes in prognostic status, inform the EoLMDT Dr and the EoLMDT, if applicable • Perform triage of acute health and social care needs, escalate to EoLMDT Dr or MSW accordingly • Provide caregiver education and support on symptom management, general care • Implement and monitor the progress of distressing symptoms according to care protocol set out by EoLMDT Dr • Consider non-pharmacological interventions • Assist EoLMDT Dr in medication reconciliation • Highlight acute or potential health risk and update the EoLMDT timely • Place a copy of the medical summary in client's home • Timely review of the client	Visit Frequency self-depend on needs **Role:** • Assess family's psychosocial needs • Prepare family on dress trajection (coping strategies) • Interventions may include referral for required services (including activation of volunteers) • Identify potential risk for complicated grief/FCA • Facilitate PPC review • Facilitate conversations on LPA, court deputyship • Provide bereavement education and support • Provide counselling if indicated • Highlight acute or potential health risk and update the EoLMDT timely • Facilitate caregiver feedback on ITCP experience	Visit Frequency self-depend on needs **Role:** • Continue to provide therapy sessions as long as client is stable • Assess and prescribe activates suitable for symptom control – e.g. education and training, speech therapy, occupational therapy • OT to prescribe cognitive engagement activates, if applicable • Highlight acute or potential health risk and update the EoLMDT timely • Perform timely review of client
UNSTABLE	Visit Frequency – 1 monthly (or as necessary and PRN) **Role:** • Review prognosis and update family on new progress and treatment plan • May inform family of DIL • Review PPC • Assess and provide management plan for any distressing symptoms especially the need for pharmacotherapy • Identify reversible conditions and manage accordingly • Review priorities of chronic diseases • Medication reconciliation/de-prescribing • Consider referral to allied health professionals • Highlight acute or potential health risk • Timely review of the client	Visit Frequency – Weekly to Fortnightly **Role:** • Participate in/facilitate PPC review • Monitor for changes in prognostic status, inform the EoLMDT Dr and the EoLMDT, if applicable • Perform triage of acute health and social care needs, escalate to HNI Pal Dr or MSW accordingly • Provide caregiver education and support on symptom management, general care • Implement and monitor the progress of distressing symptoms according to care protocol set out by EoLMDT Dr • Consider non-pharmacological interventions • Assist EoLMDT Dr in medication reconciliation • Highlight acute or potential health risk • Educate NOK on contingency plans in case of demise beyond office hours • Update the medical summary if there are changes made • Timely review of the client	Visit Frequency self-depend on needs **Role:** • Assess family's psychosocial needs • Interventions may include referral for required services (including activation of volunteers) • Identify potential risk for complicated grief/FCA • Facilitate PPC review • Facilitate conversations on LPA, court deputyship • Provide bereavement education and support • Provide counselling if indicated • Highlight acute or potential health risk and update the EoLMDT timely	Visit Frequency self-depend on needs **Role:** • Continue to provide therapy sessions with focus on caregivers education and training • Assess and prescribe activates suitable for symptom control – e.g. education and training, occupational therapy, speech therapy • Highlight acute or potential health risk and update the EoLMDT timely • Perform timely review of client
DETERIORATING	Visit Frequency – 1 monthly (or as necessary and PRN) **Role:** • Review prognosis and update family on new progress and treatment plan • Inform family of DIL • Prepare CCOD memo for standby • Review PPC • If PPC was not drafted and discussed, doctors shall re-explore and lead the PPC conversation • Assess and provide management plan for any distressing symptoms especially the need for pharmacotherapy • Identify reversible conditions and manage accordingly • Assess for possible complicated grief and trigger MSW timely • Observe for behavioural and mental wellbeing, involve MSW if necessary • Consider referral to Allied Health Professionals • Timely review of the client	Visit Frequency – PRN **Role:** • Participate in/facilitate PPC review • Monitor for changes in prognostic status, inform the EoLMDT Dr and the EoLMDT, if applicable • Perform triage of acute health and social care needs, escalate to EoLMDT Dr or MSW accordingly • Provide caregiver education and support on symptom management, general care • Implement and monitor the progress of distressing symptoms according to care protocol set out by EoLMDT Dr • Consider non-pharmacological interventions • Assess for possible complicated grief and trigger MSW timely • Observe for behavioural and mental wellbeing, involve MSW if necessary • Educate NOK on contingency plans in case of demise beyond office hours • Update the medical summary if there are changes made • Timely review of the client	Visit Frequency self-depend on needs **Role:** • Assess family's psychosocial needs • Interventions may include referral for required services (including activation of volunteers) • Review FCA • Assess for caregiver grief • Facilitate PPC review • Facilitate conversations on court deputyship • Provide bereavement education and support • Provide counselling if indicated • Support mediation work with family if required • Highlight acute or potential health risk and update the EoLMDT timely	Therapists have no active role during this phase unless specified by EoLMDT
TERMINAL	PRN **Role:** • Review prognosis and update family on new progress and treatment plan • Review PPC and reiterate to family not to call 995/999 when patient demise • If PPC was not drafted and discussed, it is highly recommended to do so to maximise process • Inform family of imminent death • Education on signs and symptoms of imminent death as well as death • Education on CCOD process and prepare memo for standby • Assess and provide management plan for any distressing symptoms especially the need for pharmacotherapy • Assess for possible complicated grief and trigger MSW timely • Observe for behavioural and mental wellbeing, involve MSW if necessary • Timely review of the client	N.A **Role:** • Review prognosis and update family on new progress and treatment plan • 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 demise • Implement and monitor the progress of distressing symptoms according to care protocol set out by EoLMDT Dr • Assess for possible complicated grief and trigger MSW timely • Observe for behavioural and mental wellbeing, involve MSW if necessary • Timely review of the client	PRN **Role:** • Offer emotional support and counselling • Review FCA • Assess for caregiver grief • Facilitate PPC review • Provide bereavement education and support • Highlight acute or potential health risk and update the EoLMDT timely	Therapists have no active role during this phase unless specified by EoLMDT
DECEASED	PRN **Role:** • To sign CCOD (if possible) if demised during office hours and perform pronouncement • Offer last office visit support • Inform EoLMDT of demise	N.A **Role:** • Work with MSW in bereavement support	PRN **Role:** • Conduct bereavement support • Grief counselling and emotional support	Therapists have no active role during this phase unless specified by EoLMDT

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