

Draft

**Principles and Guidance for the
Last Days of Life: Te Ara Whakapiri
- The Path of Closeness and Unity**

April 2015

Palliative Care Council of New Zealand

The Palliative Care Council (“PCC”) was established in 2008 by Cancer Control New Zealand to provide independent and expert advice to the Minister of Health, and to report on New Zealand’s performance in providing palliative and end-of-life care.

This is achieved through independent advice on:

- a strategic approach to palliative and end-of-life care that supports and involves the sector
- initiatives to reduce inequalities in access to palliative and end-of-life care services
- how effectively initiatives have been implemented
- international directions and initiatives in palliative and end-of-life care.

The Palliative Care Council is currently part of, and supported by, Cancer Control New Zealand. The Council includes representatives from the New Zealand Branch of the Australian and New Zealand Society of Palliative Medicine, Hospice New Zealand, Hospital Palliative Care New Zealand, Palliative Care Nurses New Zealand, members nominated by the Royal New Zealand College of General Practitioners/New Zealand Rural General Practitioner Network, Nursing Council of New Zealand, Māori and consumers.

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This document is available from the Cancer Control New Zealand website:
www.cancercontrolnz.govt.nz

About this document

This document has been developed by the Last Days of Life Working Group in collaboration with the Last Days of Life Governance Group and the Palliative Care Council.

The guidance comprises four parts:

- Part 1: Overarching principles to guide the care of people in their last days of life
- Part 2: The components of care that represent the minimum level of expected service provision
- Part 3: Examples of approaches that could be used by services to document and provide care to people in their last days of life
- Part 4: Tools that have sufficient demonstrable and robust evidence which will provide practical guidance to health practitioners and services caring for people in their last days of life.

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Executive Summary

The *Principles and Guidance for the Last Days of Life: Te Ara Whakapiri - the Path of Closeness and Unity* represents the recommended approach to caring for all people in New Zealand across all sectors and settings who have a life-limiting illness and are in their last days of life.

The development of this guidance commenced in November 2013, as a result of the approach taken in the United Kingdom to phase out the use of the Liverpool Care Pathway for the Dying Patient (“LCP”) and replace it with individual care plans for people who are dying. Since 2006, the LCP has been implemented internationally including in over 350 services in New Zealand.

In developing this guidance, a Last Days of Life Working Group and Governance Group were established to identify an appropriate New Zealand approach to ensure quality care for people in their last days of life no matter where they are being cared for. This comprehensive process included an analysis of the findings of an independent review in the UK of the LCP compared with New Zealand findings; a stocktake across all health sectors and services to establish how care is being provided to people in their last days of life in New Zealand; a literature review to establish best practice and evidence; and a survey of family/whānau to gain the consumer perspective on the care of people in their last days of life.

As a result of this process, a principles based approach has been taken which has four parts:

- Part 1: Overarching principles to guide the care of people in their last days of life
- Part 2: Components of care that represent the minimum service delivery requirements
- Part 3: Examples of how services could document care provided to people in their last days of life
- Part 4: Tools and resources to provide practical guidance to services and health practitioners caring for people and their family/whānau in the last days of life.

The approach focuses on achieving principles of care which are based on Te Whare Tapa Whā, the four cornerstones of health enabling a holistic approach to care and addressing physical, family, psychological, and spiritual aspects which are important in the last days of life.

The overarching approach in the provision of care for people in their last days of life is the development of an individual plan of care, which addresses physical, social, cultural, and spiritual issues. The plan should be agreed, coordinated and delivered with compassion and take into account any wishes expressed in an advance care plan. The individual plan of care should be documented and undergo regular review.

Background

The Liverpool Care Pathway

The Liverpool Care Pathway for the Dying Patient (“LCP”) is an integrated pathway approach to care that was developed in the UK in the 1990s, which aimed to transfer best practice approaches used in hospices to other settings in relation to the care of people who are dying. The LCP provides guidance on caring for people who are dying including comfort measures, anticipatory prescribing of medications, discontinuation of interventions no longer necessary, psychological and spiritual care, and care of the family both before and after the person’s death. Support materials and guidance forms part of the LCP including template documents, training for staff and arrangements for auditing and evaluation.

The LCP was introduced in New Zealand in 2006 and included a cultural component appropriate to the New Zealand context. Implementation of the LCP was supported by a National LCP Office and over 350 health care services progressively implemented the LCP in New Zealand.

In June 2013, an independent review of the LCP identified a number of problems with the implementation of the LCP in the UK and recommended that it be replaced by individual care plans for each patient. As a result of the UK findings, in November 2013 the Ministry of Health commissioned the Palliative Care Council to initiate a programme of work to investigate an appropriate approach for the care of people in their last days of life in New Zealand.

The Last Days of Life Working Group

The Palliative Care Council appointed a Last Days of Life Governance Group in November 2013 to provide leadership in the development of an appropriate approach for New Zealand. As part of this process, a Last Days of Life Working Group was established. Representatives were appointed according to their skills and experience rather than representing particular organisations. The Working Group comprises individuals with expertise in palliative care medicine; palliative care nursing; aged residential care; gerontology; general practice; last days of life and LCP facilitators. There was also a consumer representative.

The Last Days of Life Working Group agreed a comprehensive programme of work to inform an appropriate approach for the New Zealand context. This process included analysing the UK review findings and their relevance to New Zealand, conducting a stocktake of services to establish how services were providing care to people in their last days of life in light of the UK review findings and recommendations, conducting a literature review to investigate best practice and evidence in relation to specific aspects of care for people in their last days of life, and completing a comprehensive survey of family/whānau to establish the consumer perspective.

Key stakeholders were identified at the initial stages of the project and were involved and consulted in a range of ways including via their participation on the Working Group, Governance Group, or PCC; through presentations to relevant groups; and via regular updates.

Care of people in their last days of life: New Zealand based approaches

A comparison of the UK review findings with New Zealand findings was conducted to establish any commonalities and differences in the implementation of the LCP. A

stocktake of the provision of care to people in their last days of life identified key aspects of care that required further consideration for New Zealand including:

Terminology: The need to clarify terminology used in the last days of life and in relation to death and dying

Evidenced based: including specific review of evidence regarding culturally appropriate care in the last days of life as well as dementia care

Diagnosis of dying: significant challenges have been highlighted regarding the timing of the diagnosis of dying and the need for both guidance around the diagnosis of dying and communication with family/whānau regarding the uncertainties associated with caring for people who are in their last days of life

Workforce issues: access to an appropriate workforce after hours in terms of decision-making and treatment for people who are dying

Nutrition and hydration: guidance around appropriate approaches to nutrition and hydration in the last days of life

Symptom and pain management: guidance around symptom management

Documentation: guidance with the documentation of the person's care which is robust enough for data collection and auditing requirements, but that does not take a 'tick box' approach to care

Education and training: the need for improved consistency and access to appropriate education and training about caring for people in their last days of life

Leadership: the need for a dedicated team or person to support and coordinate the introduction and implementation of any last days of life model of care

Quality indicators and data collection: the need for any model of care to enable auditing and regular reviews to ensure ongoing quality improvement

Cultural and spiritual considerations: the need to address and incorporate any cultural and spiritual aspects important to the family/whānau.

International literature and best practice

Following an analysis of the implementation of the LCP and other models of care for people in their last days of life, the Last Days of Life Working Group conducted a literature review in relation to specific aspects of the LCP and other models of care in place to care for people in their last days of life. While internationally there is minimal robust evidence indicating the effectiveness of the LCP, service providers in New Zealand that have implemented the LCP have established that standard of care for people and their families has improved as a result of the LCP.

Limited international evidence exists on how the workforce can accurately diagnose imminent dying and this has been raised as a significant challenge in New Zealand across all health settings. However, tools and guidance have been developed and implemented with good results, including the Gold Standards Framework Prognostic Indicator Guidance, and the Supportive and Palliative Care Indicators Tool (SPICT).

Family/whānau perspectives

An investigation of the family/whānau experience of care of loved ones in their last days of life highlighted two key requirements of care for people from a consumer perspective.

Responsive workforce available any time of the day or night, to provide appropriate advice and support every day of the week that treats the person who is dying and their family/whānau with compassion and empathy within appropriate cultural and spiritual aspects. The workforce is fully trained in all aspects of care and is accessible and available for advice and the delivery of care and treatment for the person.

Clear and simple communication with the person and their family/whānau which includes advice about when the person might be dying (if appropriate); the proposed approach to treatment and care of the person; the use of a care plan; and what opportunities exist for the family/whānau to contribute to the care of the person.

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Part 1: Principles of Care

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Principles of care for people in their last days of life

Ensuring excellent care for people in their last days of life is achieved by applying holistic principles of care to meet the individual needs of the person and their family/whānau across all sectors in all settings.

The principles are consistent with existing frameworks and requirements that underpin quality care for all people. These include the Health and Disability Code of Consumers' Rights, the Health Practitioners Competence Assurance Act 2003, competency requirements set out by the Nursing Council of New Zealand and the Medical Council of New Zealand. The principles guide care according to the Te Whare Tapa Whā model¹ which emphasises a holistic approach. Four dimensions are included in this approach:

- Te Taha Tinana: good physical health
- Te Taha Whānau: extended family health and wider social systems, belonging, sharing and caring
- Te Taha Hinengaro: mental health, inseparability of mind and body; expressing thoughts and feelings
- Te Taha Wairua: spiritual health, unseen and unspoken energies, faith and spiritual awareness.

Underpinning the key principles is an overarching requirement for services to implement an individual plan of care which addresses physical, social, cultural and spiritual issues. The plan should be agreed, coordinated and delivered with compassion. Where appropriate it must take into account any prior wishes expressed in an advance care plan or advance directive. The individual plan of care should be documented and undergo ongoing review.

The possibility that a person is dying should be recognised and communicated clearly to the person and the family/whānau (when there are no barriers to communication) and should include discussion about how the person's condition is likely to change (including the likelihood of their dying), the wishes of the person and their family (including the preferred place of death) and the agreed goals of care.

Te Taha Tinana (physical health)

Care of the person is delivered by doctors, nurses, and other health workers who have the skills, knowledge and experience needed to care for dying people and their families/whānau. Overarching decisions are the responsibility of the lead medical practitioner whether that be a general practitioner or hospital based specialist with a clear process for ensuring continuity of care 24/7. These providers can access support from specialist palliative care services as required. In some situations these high level decisions can be made by a Nurse Practitioner.

Clinical interventions are reviewed in the best interests of the individual person with decisions made and actions taken in accordance with the person's unique needs and wishes. These actions undergo ongoing review, are revised accordingly and are provided with empathy and kindness.

Continuity of care for the person is enabled by effective communication between staff and with family/whānau about the management of the person's changing condition and the planning and management of their care.

The dying person is supported to eat and drink as long as they wish to do so, and their comfort and dignity is prioritised.

¹ Durie 1985

Anticipatory prescribing for symptoms of pain, excessive respiratory secretions, agitation, nausea and vomiting, and dyspnoea are in place and are delivered responsively and according to the individual needs of the person.

Te Taha Whānau (family health)

Communication with the person, and family/whānau is clear and respectful. The person has the opportunity to discuss their cultural needs and these are recognised and addressed as far as is possible.

Opportunities are provided for the person and family/whānau to provide input to the care of the person.

The reasons for decisions and/or changes in relation to the care provided to the person is promptly communicated and carefully explained to family/whānau including what is required following death.

Support for family/whānau continues beyond the death of the person as appropriate.

Following death the wishes of the individual and the family/whānau are considered and respected.

Te Taha Hinengaro (psychological health)

The person, and family/whānau are provided with opportunities to express their thoughts and feelings, values and beliefs, regarding all aspects of care or what the future may hold and these are considered, addressed and reviewed as appropriate. There may be worries that can be allayed to put the person, family/whānau at ease.

Te Taha Wairua (spiritual health)

The person and family/whānau have the opportunity to express their spiritual needs and these are acknowledged. Understand that the importance of addressing spiritual issues empowers the person and family/whānau and facilitates appropriate goal setting and treatment planning that meet the person's individual needs and desires.

Part 2: Components of Care

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Components of care for people in their last days of life

All services providing last days of life care are expected to provide components of care as a minimum to ensure quality care for people in their last days of life. The components of care provide the platform for auditing and data collection.

1. Baseline Assessment

A baseline assessment enables baseline information to be collected at the time it is thought the person is in their last days for life. This change in condition acts as a prompt to ensure conversations in the last days of life occur with the person and with their family/whānau.

1.1 Lead medical practitioner or nurse practitioner identified

A lead medical practitioner or nurse practitioner is identified to lead the care of the person in their last days of life. The lead practitioner or their nominated representative is clearly documented, and continuity of care is available out of hours to ensure 24/7 contact is available.

Person receiving care and family/whānau: Person and family/whānau members are clear who is responsible for care and that someone will be available for support outside of normal working hours if required.

Health care practitioners: There will be a clear process for contacting the lead practitioner, their designated representative or a representative of the multidisciplinary team both within working hours and out of hours.

Will ensure that the key person overseeing the person's care is committed to the person and their family/whānau.

Will have access to specialist palliative care advice and support 24/7 if the situation is assessed as becoming complicated or above their levels of expertise.

Service/organisation: Will provide access to specialist palliative care support 24/7 and ensure that there are clear processes in place within the service/organisation for contracting this support.

System: The DHB recognises the importance of the relationship between primary and specialist palliative care. Structure is provided to ensure that 24/7 availability of advice and support from specialist palliative care in situations where the need is complex across all care settings.

1.2 Baseline assessment completed

A baseline assessment is conducted to identify priorities of care for the person, symptoms and care needs. These needs may include pain, skin integrity, bowel elimination needs, mouth care, and pressure relief (for example). The baseline assessment should include a possible diagnosis about the person's changing condition and this should be documented. As part of the baseline assessment, it is important for conversations to take place with the person and the family/whānau about what is contributing to the person's changing condition and options for the plan of care, and that these conversations are clearly documented.

Person receiving care and family/whānau: Knows whether there are changes occurring in their condition, what these changes are, and how their care will be managed as a result of the changes occurring.

Health care practitioners: Understands the importance of completing a baseline assessment to identify the priorities of care and will have a conversation with the person and their family/whānau about options for an individualised plan of care for the person.

Service/organisation: Provides any necessary tools and documentation to record the findings of these assessments and to document ongoing evaluation of care

System: The DHB recognises the need to have an educated, skilled workforce to provide the assessment and this may require planning with regards workforce development.

1.3 Medication prescribed on an as needed basis for the five most common symptoms in the last days of life

Medication is prescribed for the person on an as needed basis as appropriate to address the five most common symptoms experienced in the last days of life. Anticipatory prescribing is recommended as this will ensure that there is minimal delay and distress in responding to symptoms. These symptoms are recognised as actual or potential problems and are:

- pain
- agitation/delirium/terminal restlessness
- respiratory tract secretions
- nausea and vomiting
- breathlessness (dyspnoea).

Any unnecessary medications or invasive or unnecessary procedures with no clear benefit should be reviewed in the person's best interests and discontinued as appropriate.

Note that as with all clinical guidelines, the aim is to support but not replace clinical judgment and decision-making.

Person receiving care and family/whānau: Comfortable and free of pain and other symptoms. The family/whānau is included in discussions about how these symptoms will be managed, if that is the person's wish.

Health care practitioners: Will have the appropriate skills and knowledge to undertake a comprehensive assessment of the person's current symptoms and deliver the appropriate pharmacological and non-pharmacological management. This will include in particular, but not exclusively to, the five most commonly occurring symptoms at the end of life. This will be reviewed on a regular basis and changes in the care plan will be discussed with the person and family/whānau wherever possible.

Service/organisation: Will ensure that there is a framework in place to enable pre-emptive prescribing to occur and access to the appropriate medications to treat pain and other symptoms experienced by people in their last days of life.

Will ensure that education and training around the management of symptoms in the last days of life is accessible by staff.

System: The DHB in conjunction with any national based programs for quality indicators will provide a way of monitoring best practice around the management of symptoms in the last days of life.

1.4 Assessment of person's ability to communicate

Clear and ongoing communication with the person is fundamental and all decisions which lead to a change in the care of the person should be clearly communicated to

the person and this conversation documented. The person's ability to communicate is assessed and information is collected and documented about:

- preferences the person may have to allow a natural death
- whether an advance care plan or advance directive is in place
- the person's wishes in relation to organ and/or tissue donation
- the person's wishes in relation to their preferred place of death, burial or cremation.

In situations where the person is unable to communicate because of the extent of their deterioration, conversations take place with the family/whānau about these aspects and this is documented.

Person receiving care and family/whānau: Is provided with an opportunity to talk about preferences for care and any wishes after death. If English is the second language, there is an ability to access support to make sure any preferences are understood.

Health care practitioners: Will make sure that there is an opportunity to have a conversation with the person and/or the family/whānau so that preferences about the person's care are documented and addressed.

Service/organisation: Will ensure there are private areas for discussions to take place with the person, family/whānau as required and provide access to interpreting services, if these are required.

System: The DHB will ensure that an environment is created across all services to enable privacy for sensitive and compassionate conversations to take place.

1.5 Communication barriers are identified and addressed

Potential barriers to full communication should be identified. This may include language barriers in which case identification of appropriate additional support, such as the provision of a translator, should be made available.

It is important to have accurate information about appropriate contact people to ensure that in the last days of life the appropriate person can be contacted. In some situations, the next of kin may not be the appropriate contact person. In some situations the person and/or their family/whānau appoint a spokesperson who acts as the key contact. It is therefore important to establish and document up to date contact information for those most important to the person including:

- next of kin
- whether there is a key spokesperson for the family/whānau and who this person is
- the person holding an Enduring Power of Attorney if the person in their last days of life does not have the capacity to make their own decisions.

Person receiving care and family/whānau: It is important that wishes are known as to who are the key contacts for family/whānau and that those family/whānau can be contacted if the person's condition changes. If the person is no longer in a position to speak for themselves, the person identified as the spokesperson is clearly documented.

Health care practitioners: Will ensure that the person's identified key spokesperson, Enduring Power of Attorney and/or next of kin contacts are recorded and documented correctly.

Service/organisation: Will provide access to support if needed to make sure that person and their family/whānau preferences in relation to their care are understood,

including providing access to a translator if this is required. Will ensure that there is an ability to record this information accurately so that all health care practitioners are aware of these details.

System: Consideration and future planning with regard to how information can be shared across care settings, to provide accurate information around key details for example improved electronic records and IT.

1.6 The person is aware that they are dying

A conversation should be offered with the person to explain the changing nature of their condition and the possibility they may be entering into the last few days of life. This may or may not be appropriate or wanted by the person and these views should be respected. Engaging in such conversations can be very difficult and resources are available to assist, examples of guidance are provided in Section 4. Local policies and guidelines about how to break bad news and have compassionate conversations may also be available.

Person receiving care and family/whānau: Has the opportunity to be informed about any changes in their condition and if there is a possibility that the person may only have a few hours to days to life that they are as prepared as possible.

Health care practitioners: Will be skilled or have access to an appropriately skilled person to have compassionate conversations that may include breaking bad news with both the person and the person's family/whānau according to the person's wishes.

Service/organisation: Policies and/or guidelines are in place to support and guide health professionals regarding conducting conversations about death and dying and the difficulties associated with these conversations.

Provision or access to recognised training, qualifications around communication skills and compassionate communication.

The service or organisation, can provide or refer staff for support, and clinical supervision as required, recognising the impact that caring for people in the last days of life can have on maintaining healthy professionals.

System: The DHB recognises the challenges associated with conversations regarding death and dying and has structures and support in place for health professionals conducting such conversations.

1.7 Equipment is available to support the person's care needs

People who are in their last days of life may require access to specialised resources or equipment to support their care needs. Where a service is providing care to people who are in their last days of life, equipment needs to be available to support any potential requirements the person may have. This equipment could include, for example, any equipment that may be necessary to support a continuous subcutaneous infusion (CSCI) of medication; a pressure-relieving mattress; hospital bed, sliding sheets, etc.

Person receiving care and family/whānau: The person has access to resources and/or equipment, which may help to make their last days of life more comfortable.

Health care practitioners: Will ensure regular review of the person so that any care needs requiring access to resources and/or equipment are recognised and provided without delay. Are aware of the referral process to other members of the Allied Health Team that can provide guidance and assessment for access of this equipment.

Service/organisation: Will ensure that the service can access resources and equipment in a timely manner that may be needed to support people in their last days of life irrespective of care setting. This will include processes for organising, and delivering of equipment in a rapid discharge home to die scenario.

System: Ensuring that there are clear funding processes for accessing these equipment resources in the last days of life including equipment that will be necessary for a rapid discharge home to die.

1.8 Cardioverter Defibrillator Implant considerations

If the person has an Implantable Cardioverter Defibrillator in place, conversations need to occur with the person and their family/whānau about whether this should be deactivated and if so, how this should occur. Conversations and the plan of care in relation to the Implantable Cardioverter Defibrillator Implant is clearly documented.

Person receiving care and family/whānau: Comfortable and free from distressing symptoms in the last days of life.

Health care practitioners: Will ensure that if the person has an Implantable Cardioverter Defibrillator in place that they have a conversation with the person and/or their family/whānau about what can occur in the last days of life when an Implantable Cardioverter Defibrillator is in place, whether this should be deactivated, and if so, how this should occur.

Service/organisation: Will provide access to a clearly documented process and guidelines for health professionals about the implications of Implantable Cardioverter Defibrillators in the last days of life. This should also include a clear pathway to access appropriately skilled staff members e.g. cardiology technicians and equipment for deactivation if required.

System: Ensuring that the appropriate information and access to skilled health care professionals are identified in any care setting that may be providing care in the last days of life.

1.9 Provision of food and fluids

The provision of food and fluids in the last days of life is an important aspect of care. Conversations should take place with the person and their family/whānau about the role of food and fluids and any risks that can occur. The person should be supported to continue to maintain an oral intake for as long as is safe and warranted, if they wish to do so. It is recommended that written material be made available to the family/whānau about food and fluid in the last days of life to ensure that they fully understand any risks and benefits.

Person receiving care and family/whānau: Is able to eat and drink if they feel able to do so.

Health care practitioners: Will discuss with the person and their family/whānau any benefits and risks of maintaining oral intake of food and fluid and will support the person to be able to eat and drink for as long as they are able or wish to do so. This may also include conversations with regards to parenteral feeding and fluids.

Will access appropriate written resources to support this discussion if needed.

Will document clearly an individual plan for fluids and food and this will be reviewed at least on a daily basis.

Service/organisation: Will ensure that appropriate written information is made available for health professionals to provide to the person and the family/whānau about the risks and benefit of food and fluid in the last days of life. That there is a

process for referral to other services that may be able to aid further discussion on this topic and ensure that an individual plan of care is made.

System: Provide some national based resources around food and fluids in the last days of life. Will consider mechanisms and indicators for audit around how food and fluids in the last days of life are managed.

1.10 Relevant agencies are advised of the person's deterioration

It is likely that those people who have been identified as in the last days of life, will have had a number of services or agencies involved in their care. This could include, for example, the person's general practitioner, district nursing services, and any specialist referral teams (such as hospice or cardiology). Informing these agencies/services where possible of the change in the person's condition and expectation that they will die in the next few hours or days, will be important in terms of any future appointments made, continued care of close family/whānau members and out of courtesy.

Person receiving care and family/whānau: Services who have been involved in the care of the person are kept informed of the change in the person's condition.

Health care practitioners: Where possible identify and document services and/or agencies involved in the care of the person and will advise them of the change in the person's condition. Will have understanding of the Privacy Act 1993 and what is appropriate content and right method of communication.

Service/organisation: Will have processes in place to ensure that contact can be made with relevant services and/or agencies in a straightforward and timely manner.

Provides support and education on maintaining privacy of any information that is shared with other agencies and health care professionals involved in the persons care.

System: Recognises the importance of the relationship between organisations and agencies involved in the care of people in their last days of life and will support mechanisms to ensure ease of communication.

Will provide mechanisms for managing and maintain privacy of health care information.

1.11 Family/whānau is aware that the person is dying

Clear and regular communication with the family/whānau is fundamental to quality care of people in their last days of life. Conversations should take place with the family/whānau, and these conversations documented, to indicate that the person's condition has changed and that it is thought the person is in their last days of life.

Person receiving care and family/whānau: Health care practitioners communicate with the person and the family/whānau clearly and regularly about the deteriorating condition of the person and will advise if the person is thought to be dying in a way the family/whānau understands.

Health care practitioners: Will ensure that conversations take place with the person's family/whānau to advise them of any deterioration and/or changes in the person's condition and will make sure the family/whānau understand that the person is thought to be in their last days of life. A summary of these conversations must be clearly documented.

Service/organisation: Policies and/or guidelines are in place to support and guide health professionals regarding conducting conversations about death and dying and

the difficulties associated with these conversations. Provision of an appropriate place to record any conversations and the outcomes.

System: The DHB recognises the challenges associated with conversations regarding death and dying and has structures of support in place for health professionals conducting such conversations.

1.12 Information is provided to the family/whānau about the facilities available

It is important that the family/whānau have information about the facilities that are available to enable them to support the person who is in their last days of life. In a hospital setting for example this could include information about car parking, public transport, kitchen facilities, cash machines, phones, spiritual supports and chaplaincy services (refer to section 1.14).

If the person is being cared for in their own home this information could include contact details for the district nursing team, specialist palliative care services, after hours contact details for the lead practitioner or their designated representative, and what to do in an emergency (for example).

Conversations with family/whānau should be documented.

Person receiving care and family/whānau: Family/whānau know what facilities are available to them while they support the person and if the person is being cared for at home, the family/whānau know how and who to contact if the person's condition changes.

Health care practitioners: Will make sure that information is provided to the family/whānau about any facilities that are available for them. If the person is being cared for in a private residence, will make sure they have information about who to contact if the person's condition changes and how they can make contact.

Service/organisation: Written information is developed which provides family/whānau with advice about facilities available to them which is tailored to the individual care system.

System: DHBs have a process for ensuring that this information resource is of a high standard and being received in a timely manner.

1.13 Cultural needs are discussed and addressed

A conversation takes place with the person and the family/whānau about the cultural needs of the person. This conversation should be documented and could include identification of any specific customs, traditions or cultural practices that are important and how these could be appropriately addressed in the plan of care for the person.

Note that it is important to identify the person's ethnicity since ethnicity can indicate particular ways a person may wish to be cared for when they are in their last days of life.

Person receiving care and family/whānau: Care and treatment is provided in a way that reflects customs, traditions, or cultural practices that are important to the person.

Health care practitioners: Will as part of any baseline or ongoing assessments provide an opportunity to discuss with the person and family/whānau their preferences regarding any customs, traditions or cultural practices and these are incorporated into the individual plan of care for the person.

Once these preferences have been identified the health care practitioner will ensure where possible that these are met. This may well include referrals to other professionals such as Whānau Care or Pacific Island Services.

Will document these preferences clearly ensuring that if cultural practices have been identified that these are delivered at the appropriate time e.g. related to fundamental care, after death care or funeral care.

Ensure that they have an understanding of the role of the Treaty of Waitangi and its implication in providing health care and support.

Service/organisation: Will ensure that there is access to education and training with regards to cultural competency and care as well as processes in place to access specialised cultural support that may be required. That the organisation or service provides care that acknowledges the key principles of the Treaty of Waitangi.

System: The DHB recognises the importance of an appropriate cultural approach to care of people in their last days of life. Health practitioners are able to access education/training in cultural context particularly if they are internationally qualified.

1.14 Opportunity is provided for the person, family/whānau to discuss what is important to them including wishes, feelings, faith, beliefs and values. This may or may not include religious or spiritual needs and beliefs

It is recognised that for some people and their family/whānau who now have an understanding that they are in the last few hours to days of life, that the things that were once important to them may well change. This is an opportunity for those caring for this person and their family/whānau to have a conversation about what is important to them now. For some this may be a re-exploration of their faith, for others it may be the need to see a particular person, pet or place, or to have access to music, photographs or films.

For some this may also include direct wishes related to their after death care or funeral arrangements.

Person receiving care and family/whānau: Should be given the opportunity to express what their thoughts, wishes, needs and beliefs are in a way that is not judgmental and is safe.

Health care practitioners: Will provide an opportunity to have conversations with the person and the family/whānau to identify what is important to them at this time.

To clearly document those wishes thoughts and needs and indicate whether these are important now, related to after death care or with regards to funeral arrangements.

Where possible facilitate the wishes and needs of that person and their family/whānau. This may include referral to chaplaincy teams or appropriate spiritual providers.

Service/organisation: Provide access and referral procedures to services that include chaplaincy, spiritual providers of all denominations. Provide access to education, training and advice on how to have these conversations and to be able to access information on provision of care that may be related to differing faiths or religion.

System: The DHB recognises the importance of enabling an approach to care where people in their last days of life are able to express their thoughts, wishes, needs and beliefs and that the workforce providing care to people at this stage of their life is

able to access necessary education and training to enable them to approach conversations with confidence.

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2. Ongoing Assessment of the Plan of Care

Individual care needs are identified and a plan of care appropriate to the needs of the unique person is agreed with the person and the family/whānau and in place. Ongoing assessment of the person and their family/whānau occurs.

2.1 & 2.2 Identify individual care needs and develop an individualised care plan including ongoing regular reviews of the persons care

An individualised care plan is developed in collaboration with the person and the person's family/whānau which addresses physical, social, cultural and spiritual issues. Once developed, the individual plan of care should be documented and undergo regular review. Regular assessments of the person's changing condition will ensure that any changes or additional symptoms can be addressed in a timely manner. The person's family/whānau should have an opportunity to participate in the care of the person if this is what they wish to do.

Person receiving care and family/whānau: Care is provided according to the person's unique needs. This will have been developed following the initial conversations and needs identified within the baseline assessment.

Health care practitioners: Will offer a summary of the plan of care where possible and this is discussed with the person and family/whānau members. This must include the frequency of ongoing assessments and reassessments and recognise the needs of the person as central, understanding that needs can change rapidly during the dying process.

Provision of written information such as "what to expect when someone is dying" at this time will help assist the family/whānau members to understand what changes may occur to the person in relation to the dying process.

Will provide the family/whānau with the opportunity to assist with the person's care if wished, and will provide support and education as to how to do this.

Service/organisation: Recognises the importance that frequent assessments will have on how family/whānau members will experience end of life care and value the role that all health care providers have in providing excellent care.

Provide appropriate documentation for health care providers involved to clearly document an individualised plan of care, including regular reviews, assessments and evaluations of care.

System: The DHB recognises that whilst maintaining an individualised plan of care is important, standardising some of the documentation to a regional approach can enhance care and that may include transferring the person from one care setting to another within a region. Also assists with the ongoing process of monitoring for quality indicators and auditing processes and plans of care.

2.3 Conversations take place with the family/whānau about the person's changing condition

Conversations with the family/whānau should occur on an ongoing basis and are particularly important to convey any changes occurring in the person's condition. These conversations occur in a way that is clear and respectful.

Person receiving care and family/whānau: Informed if the person's condition changes and involved in conversations about options for the ongoing care of the person.

Health care practitioners: Will have conversations with the family/whānau when the person's condition changes and discuss options to manage the care of the person. A summary of these conversations should be documented.

Service/organisation: Enables access to education, training and advice on how to have these conversations.

System: The DHB recognises the challenges associated with conversations about death and dying and has structures of support in place for health professionals conducting such conversations.

2.4 Ongoing opportunities are provided to address and alleviate any concerns that worry the person or wishes they may have

Ongoing conversations with the person and their family/whānau are important to ensure that any changes in the person's emotional response can be discussed and addressed and the individual plan of care can be reviewed if required to accommodate any changed wishes of the person and their family/whānau.

Person receiving care and family/whānau: The person has the ability to express any wishes or concerns they may have and are able to express these in an ongoing way.

Health care practitioners: Will ensure that regular conversations take place with the person to ensure that if there are any changes in the person's wishes or concerns that these can be discussed and addressed. A summary of conversations should be clearly documented.

Service/organisation: Policies and/or guidelines are put in place to support and guide health professionals regarding conducting conversations about death and dying and the difficulties associated with these conversations. Provision of an appropriate place to record any conversations and the outcome.

System: The DHB recognises the challenges associated with conversations regarding death and dying and has structures of support in place for health professionals conducting such conversations.

2.5 Changing spiritual needs of the person are discussed and addressed

It is recognised that things that may have been important to the person at the time the baseline assessment was conducted may change quickly once a person is in the last few hours to days of life. It is important for ongoing conversations to occur to enable the person to convey their wishes regarding their spiritual needs, and for these wishes to be addressed.

Person receiving care and family/whānau: Should be given the opportunity to express their changing spiritual needs in a way that is non-judgmental.

Health care practitioners: Will provide an opportunity to have conversations with the person and the family/whānau to identify what is important to them at this time. Conversations will be clearly documented. Where appropriate, there may be a need for referral to chaplaincy teams or appropriate spiritual providers.

Service/organisation: Will provide access and referral procedures to services that include chaplaincy and spiritual providers of all denominations. Education, training and advice on how to have these conversations and to be able to access information on provision of care that may be related to differing faiths or religion.

System: The DHB recognises the challenges associated with conversations regarding death and dying, in particular relating to the person's spiritual needs and has structures of support in place for health professionals conducting such conversations.

3. Care After Death

Every service that provides care for people in their last days of life should have their own policies in place regarding the care of the person and the family/whānau after death. However, there are specific aspects expected as a minimum to be addressed and incorporated into these policies.

3.1 The person's death is verified

Person receiving care and family/whānau: The legal process is undertaken correctly to ensure that a medical certificate showing cause of death is available so the family/whānau can proceed with funeral arrangements as soon as possible.

Health care practitioners: Will be familiar with the local policy and procedures for verification of death and how to complete the appropriate paperwork.

Will know how to access the policy and paperwork that is required.

Service/organisation: Will provide policy and procedures and ensure that staff will have access to training and education as to how these should be carried out to meet legal requirements. These policies and procedures will be reviewed on a regular basis.

The necessary legal documentation is available for staff to complete medical certificate of cause for death (HP4720) and possibly a permission to cremate.

System: DHBs have a process so that healthcare providers and service organisations are familiar with the legal requirements of after-death documentation.

3.2 The person/tūpāpaku is treated with dignity and respect

Person receiving care and family/whānau: That the wishes and preferences are carried out where possible and family/whānau are supported if they wish to participate in after death care.

Health care practitioners: Will be familiar with what is required for after death care according to local policy and procedure. This may include washing of the person, removing any medical or nursing equipment, dressing the person in clothes identified by the family, or in clean gowns.

Any personal belongings are returned to the family/whānau in a respectful way.

All appropriate involved healthcare/social services that have been previously identified are aware of the death.

Service/organisation: Will ensure access to, and provide, education/training on what is expected for after death care.

System: DHBs have a process to ensure that healthcare providers and service organisations are equipped to ensure that the person/tūpāpaku is treated with dignity and respect at the time of death.

3.3 Information is provided to the family/whānau about what to do next

Person receiving care and family/whānau: Family/whānau are aware of any processes that need to occur following the person's death including funeral arrangements.

Health care practitioners: Has a conversation with the family/whānau to ensure that they are provided with clear information about what they need to do next. Will provide written material and information if required.

Service/organisation: Develops written resources which will provide information to family/whānau about what they need to do following the person's death, such as funeral arrangements.

System: DHBs have a process for ensuring that this information resource is of a high standard and being received in a timely manner.

3.4 Bereavement assessment is conducted

Person receiving care and family/whānau: Family/whānau are able to access information about bereavement support and counselling if they feel they need this and/or they are not coping well with the person's death.

Health care practitioners: Has a conversation with the family/whānau about access to bereavement support and conducts a bereavement assessment if the family/whānau indicate they wish for one, or if the health practitioner considers the family/whānau are not coping well following the person's death.

Service/organisation: Develops a process for bereavement assessment to occur, including documentation.

System: DHBs support the implementation of bereavement and counseling services for all who require the need.

3.5 Spiritual, religious, cultural needs are considered and addressed

Person receiving care and family/whānau: Family/whānau are provided with an opportunity to express any particular spiritual, religious, or cultural needs that may be important at this time.

Health care practitioners: Will provide an opportunity to have conversations with the family/whānau to identify what is important to them at this time.

Service/organisation: Provide access and referral procedures as required to services. Education, training and advice on how to have these conversations and to be able to access information on provision of care that may be related to differing faiths or religion.

System: The DHB recognizes the importance of enabling an approach for family/whānau to be able to express their thoughts, wishes, needs and beliefs and that the workforce providing care is able to access necessary education and training to enable them to approach conversations with confidence.

3.6 Environment is able to accommodate a blessing room. Karakia/prayer offered in respect of cultural needs

Person receiving care and family/whānau: Family/whānau is able to access private space if required to accommodate any needs for prayer, karakia, or other cultural or spiritual needs.

Health care practitioners: Respects the family/whānau need for privacy if this is required and ensure that an environment is available which is suitable to meet the needs of the family/whānau.

Service/organisation: Ensures that the environment across all settings can enable private areas for grieving family/whānau.

System: DHBs support the need to ensure services can provide a place of privacy.

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Summary of components of care for people in their last days of life, resources, and communication needs

1. Baseline Assessment

Principle	Reference	Component	Resources	Page No	Communication need	
Physical (Te Taha Tinana)	1.1	Lead medical practitioner or nurse practitioner identified	-	-	Clearly documented Out of hours contact is available for family/whānau	
	1.2	Baseline assessment completed	Example baseline assessment form	37	Assessment clearly documented in notes and forms the basis of an ongoing symptom care plan	
	1.3	Plan for management of the five most common symptoms in the last days of life	Nausea and vomiting:	<ul style="list-style-type: none"> Guideline for developing an individualised medical management plan for end of life: nausea and vomiting Nausea and Vomiting Algorithm 	51 53	Preferences for management clearly document Allergies identified
			Pain:	<ul style="list-style-type: none"> Guideline for developing an individualised medical management plan for end of life: pain Pain Algorithm Pain in patients with impaired renal function 	54 56 57	Family/whānau are aware and have access to medications prescribed Clear guidance for family on use of medications Current prescribed medications are assessed, non-essential medications discontinued
Respiratory secretions:			<ul style="list-style-type: none"> Guideline for developing an individualised management plan for end of life: respiratory secretions Respiratory secretions algorithm 	58 59		

Principle	Reference	Component	Resources	Page No	Communication need
			Delirium/agitation: <ul style="list-style-type: none"> Guideline for developing an individualised medical management plan for end of life: delirium (and associated restlessness or agitation) Delirium/agitation algorithm 	60	
			Breathlessness (dyspnoea): <ul style="list-style-type: none"> Guideline for developing an individualised medical management plan for end of life: Dyspnoea Breathlessness algorithm 	62	
				63	
				65	
	1.4	Assessment of person's ability to communicate completed	<ul style="list-style-type: none"> Access to interpreters if required Organisational resources already developed and in place to provide guidance 	-	Conversation documented including: <ul style="list-style-type: none"> Language preference Preferences to allow a natural death documented Advance care plans/advance directives sighted Preferences for organ and/or tissue donation Preferences about place of death identified Preferences about burial or cremation Potential barriers to communication
	1.5	Contact information for those most important to the person is collected and documented	Example baseline assessment form	37	Conversation documented including: <ul style="list-style-type: none"> Identification of next of kin Identification of key spokesperson for the family/whānau Enduring Power of Attorney in Place Barriers to communication
	1.6	Person is aware that they are dying	Breaking bad news flowchart	71	Conversation documented about the person's changing condition which clearly conveys the

Principle	Reference	Component	Resources	Page No	Communication need
					person may only have a few hours or days to live Documentation of who this has been communicated to
	1.7	Equipment is available to support the person's care needs	-	-	Conversation documented which clearly identifies any changes in the person's condition which may be required access to specialised equipment
	1.8	If an Implantable Cardioverter Defibrillator is in place conversation takes place to establish whether and how this should be deactivated	Heart Rhythm New Zealand. 2014. Heart Rhythm New Zealand Position Statement: <i>Management of Implantable Cardioverter Defibrillators (ICD) and Pacemakers for patients nearing end of life.</i>	-	Conversation documented about the implications of an Implantable Cardioverter Defibrillator in the last days of life and the person/family/whānau preference regarding whether the ICD should be deactivated and how this should occur
	1.9	Conversations take place about the benefits and risks of nutrition and hydration in the last days of life	Organisation resources in place about food and fluid in the last days of life	-	Conversation documented including: <ul style="list-style-type: none"> • Benefits and risks of maintaining oral intake of food and fluid • Any requirement for parenteral feeding and fluids.
	1.10	Relevant service and/or agencies are	-	-	Identification of relevant services and persons that need to be notified

Principle	Reference	Component	Resources	Page No	Communication need
		contacted to notify them of the person's deterioration			
Family (Te Taha Whānau)	1.11	Family/whānau aware the person is dying	What to expect when someone is dying Supporting care in the last hours or days of life: information for families/whānau/carers	68 70	Conversation documented and individuals who have been informed or should not be informed identified
	1.12	Family/whānau provided with information about facilities available to them in the setting	Organisation resources in place about facilities available to them in the service in which the person is being cared for in	-	Family/whānau aware of facilities available Documentation of information provided to family/whānau
	1.13	Conversations take place regarding the cultural needs of the person, family/whānau	W.H.Ā.N.A.U: Personalising care at the end of life	72	Conversation documented including: <ul style="list-style-type: none"> • Identification of any beliefs and family traditions that may be important • Important aspects about the person and/or the family/whānau that the service should know about
Psychological (Te Taha Hinengaro) and Spiritual (Te Taha Wairua)	1.14	Conversations take place with the person and family/whānau about what is important to them at this time	Spiritual Care Assessment Tool Based on FICA Approach	75	Conversation with person and family/whānau documented which includes: <ul style="list-style-type: none"> • Wishes, thoughts, needs of the person and family/whānau • Any important considerations for after death care or funeral arrangements • Consider referral to chaplaincy teams or appropriate spiritual providers

2. Ongoing Assessment

Principle	Reference	Component	Resources	Page no:	Communication need
Physical (Te Taha Tinana)	2.1	Individual care plan developed and put in place	<ul style="list-style-type: none"> Identifying the Dying Patient Identifying the Dying Patient: Algorithm Guideline for Developing and Individualised Medical Management Plan for End of Life: General Principles 	44 47 48	Conversation documented including: <ul style="list-style-type: none"> Summarising the plan of care Frequency of ongoing assessments and reassessments Possible rapidly changing needs of the person in the dying process Opportunity for family/whānau to participate in care of the person if they wish to do so
	2.2	Regular review of the person takes place	-	-	Conversation documented about the changes in the condition of the person
Family (Te Taha Whānau)	2.3	Conversations take place with the family/whānau about the person's changing condition	-	-	Conversation documented to ensure that the family/whānau understand what changes are occurring in the person's condition as part of the dying process
Psychological (Te Taha Hinengaro)	2.4	Conversations regularly take place with the person about concerns or wishes	-	-	Conversation documented which includes discussion with the person about their wishes, thoughts and feelings
Spiritual (Te Taha Wairua)	2.5	Conversations regularly take place to enable the person to discuss feelings about what is important to them at this time	-	-	Conversation documented which may have detail but may not.

3. Care After Death

Principle	Reference	Component	Resources		Communication need
Physical (Te Taha Tinana)	3.1	The person's death is verified according to local or regional protocols	Local and/or regional protocols	-	Communication to services involved in post death arrangements within the service are documented
	3.2	The person/tūpāpaku is treated with dignity and respect	-	-	Preference for person undertaking verification of death
Family (Te Taha Whānau)	3.3	Information is provided to the family/whānau about what they need to do next	Organisation resources in place about facilities available to them in the service in which the person is being cared for in	-	Documentation of information provided and discussions had about next steps
Psychological (Te Taha Hinengaro)	3.4	A bereavement assessment is conducted to identify complex bereavement	<ul style="list-style-type: none"> Bereavement Information Form Bereavement Assessment Form 	73 74	Person undertaking bereavement assessment is notified in a timely manner
Spiritual (Te Taha Wairua)	3.5	Assessment of family/whānau's spiritual needs is conducted	Spiritual Care Assessment Tool Based on FICA Approach	75	Identified person to undertake and document this conversation
	3.6	Arrangements are made in terms of blessing room/space and karakia/prayer is offered in respect of cultural needs of the family	-	-	Communication to service manager that room may be required

Part 3: Examples of approaches to care for people in their last days of life

Examples of approaches to care used for people in their last days of life

A number of services involved in the care of people in their last days of life have developed a range of tools and resources to provide practical guidance based on best practice and evidence to support quality care for people in their last days of life, and their families/whānau. These tools and resources have been developed based on local and regional identified needs. They can be adapted by service providers to suit local and regional needs.

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Example A: Planning for End of Life Care²

Definition of end-of-life is when death is expected within hours-days during this admission. This includes care during and around the time of death, and immediately afterwards.

End-of-Life does not mean 'no care' it is a change in focus from active treatment to best supportive palliative care.

As with all clinical guidance this document aims to support but does not replace clinical judgement.

The patient is required to be assessed and a care plan should be developed in line with the patients: (if able), family/whānau wishes and needs.

Family/whānau contact details	
If the patient's condition changes, who should be contacted first?	<div style="text-align: right; margin-bottom: 5px;">1st Contact:</div> Name:..... Relationship:..... Telephone no:..... Mobile no:.....
If the patient's condition changes, when should they be contacted?	At any time <input type="checkbox"/> Not at night time <input type="checkbox"/>
If the first contact is unavailable, who should be contacted?	<div style="text-align: right; margin-bottom: 5px;">2nd Contact:</div> Name:..... Relationship:..... Telephone no:..... Mobile no:.....
When to contact	At any time <input type="checkbox"/> Not at night time <input type="checkbox"/>
Next of Kin if different from above	Name:..... Relationship:..... Telephone no:.....

END-OF-LIFE CARE PLAN

The patient will require daily review by the medical team. End of life cares need to be continually reviewed and discontinued if the patient's condition improves.

Always consider if the Hospital Specialist Palliative Care Team needs to be consulted, to help in patient management when there are complex symptom management or emotional issues.

² Source: Waitemata District Health Board End of Life Care Project Steering Group (2014)

Advance Care Plan	
Does the patient have an existing Advance Care Plan or Directive documenting their wishes at end-of-life?	<input type="checkbox"/> Yes <input type="checkbox"/> No
Is an Existing Power of Attorney for Health in place?	<input type="checkbox"/> Yes <input type="checkbox"/> No Name..... Relationship..... Contact no:.....
Recognition of Dying	
The patient is aware they are dying?	Document clearly in clinical notes what was said and by whom. Date and time of conversation:.....
The family/whānau is aware the patient is dying?	Document clearly in clinical notes what was said and by whom. Date and time of conversation:..... Name of family informed.....
*Both the patient/whānau awareness & understanding of the diagnosis is communicated and documented See guidelines on “communication” and “breaking bad news”	
Preferred Place of care	
Patients preferred place of care	<input type="checkbox"/> Home <input type="checkbox"/> Hospital <input type="checkbox"/> Hospice
Family/Whānau preferred place of care	<input type="checkbox"/> Home, <input type="checkbox"/> Hospital <input type="checkbox"/> Hospice
*If home see “Rapid Discharge Checklist”	

Clinical Goals – Medical Staff	
Current medications reviewed and non-essential medications discontinued	<input type="checkbox"/> Yes <input type="checkbox"/> No
PRN subcutaneous anticipatory medications charted. See “Anticipatory Prescribing” guidelines.	<input type="checkbox"/> Yes <input type="checkbox"/> No
Inappropriate interventions discontinued e.g. blood tests, NEWS, routine observations, blood glucose monitoring, oxygen therapy	<input type="checkbox"/> Yes <input type="checkbox"/> No
The need for artificial hydration/nutrition is reviewed by the MDT (a reduced need for food/fluids is part of the normal dying process)	<input type="checkbox"/> Yes <input type="checkbox"/> No
Do Not Resuscitate status recorded on CPR Decision Form	<input type="checkbox"/> Yes <input type="checkbox"/> No
Implantable Cardioverter Defibrillator (ICD) is deactivated	<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> N/A
Organ donation considered and information leaflet given to patient/family	<input type="checkbox"/> Yes <input type="checkbox"/> No
Cultural	
If able, the patient is given the opportunity to discuss their cultural needs e.g. needs now, at death and after death.	Document clearly in clinical notes what was said and by whom. Date and time of conversation:.....
Family/Whānau is given the opportunity to discuss their cultural needs at this time e.g. needs now, at death and after death.	Document clearly in clinical notes what was said and by whom. Date and time of conversation:.....
Refer to appropriate cultural support e.g Māori Health Service, Asian Support, Pacific Island Support as appropriate	<input type="checkbox"/> Yes <input type="checkbox"/> No Service/s involved:..... Names of person/s involved:.....

Religious and Spiritual	
<p>If able, the patient is given the opportunity to express what is important to them at this time e.g. wishes, feelings, faith, beliefs, values (needs now, at death and after death)</p> <p>The family/whānau is given the opportunity to discuss what is important to them at this time e.g. wishes, feelings, faith, beliefs, values (needs now, at death and after death)</p> <p>Offer Hospital Chaplain Service or contact patient's preferred support person if required.</p>	<p>Document clearly in clinical notes what was said and by whom.</p> <p>Date and time of conversation:.....</p> <hr/> <p>Document clearly in clinical notes what was said and by whom.</p> <p>Date and time of conversation:.....</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Contacted:</p>
Information & Explanation	
<p>Family/Whānau given information of facilities available e.g. visiting times, parking, tea and coffee, quiet area, toilets</p> <p>Information sheet <i>“What to expect when someone is dying”</i> given to family/whānau if appropriate.</p> <p>Give <i>“Bereavement Information”</i> leaflet and list of Funeral Directors if required.</p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p>
After Death Care	
<p>If not already received give family/whānau <i>“Bereavement Information”</i> leaflet and list of Funeral Directors if required.</p> <p>Discuss as appropriate with family/whānau viewing of the body/tūpāpaku</p> <p>Community providers are notified of the patient's death e.g. GP, District Nurse, Hospice</p> <p><i>See Policy and Guidelines “Death of an In-patient”</i></p>	<p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p><input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Contacted:.....</p>

All documents e.g. Information leaflets, guidelines, policies and checklists are available on the Palliative Care intranet site: “end-of-life and bereavement care.”

Example B: Improving Care of the Dying Guideline³

PATIENTS ID LABEL

IMPROVING THE CARE OF THE DYING GUIDELINE

Primary diagnosis _____

Associated Co-morbidities _____

SEE END OF LIFE CARE GUIDE BEFORE YOU COMMENCE.

Prior to instituting ICOD, ensure:

- The consultant, along with relevant multi-disciplinary members of the team, are in agreement with the diagnosis of dying
- A family meeting is arranged (phone contact if this is not feasible)
- Ask family/whānau if they would like to have support/advice from someone in the Māori or Pacific Health Units
- If the patient is Māori or Pacific – consult with the relevant Unit staff for support and/or advice to health professionals
- Consider Social worker referral:
 - If requested by patient/family
 - To assist family with information/resources
 - To co-ordinate staff/family meeting to assist communication and planning
 - Where complex psycho-social or health literacy issues are present
 - When the dying person has no identifiable/contactable next of kin.

Family Discussion –*may* include and **must** be documented in patient notes

- Active acute medical treatment is no longer in the patients best interests
- The goals of care are now optimal symptom management and family /patient support
- Is there an existing Advance Plan of Care and/or EPOA for medical treatment? **If YES obtain copies for patient file**
- Cardio-pulmonary resuscitation is no longer indicated and purple form complete and signed.
- Food/fluids by mouth, if safe to swallow, will be offered for comfort
- Medications will be rationalised to ensure comfort

- Most appropriate site of care discussed

- Specific wishes – religious, spiritual/cultural etc discussed
- Other issues identified – eg health literacy, family disputes, disagreements
- Family carer's wishes regarding contact i.e. anytime, during nights etc. (Document on patients admission form)

Medical Management Guidelines:

Pharmacological Management

- Cease all medications except those essential for symptom management/patient comfort
- Subcutaneous PRN medications written (see suggested algorithms attached)

Discontinue/cancel inappropriate interventions

- IV fluids/enteral feeding/TPN
- Antibiotics
- Routine vital sign recording
- Blood tests
- X-ray imaging
- Deactivate implanted defibrillator (if applicable)
- Other – specify _____

Medical Agreement to the care plan: (Consultant or registrar to sign)

NAME _____ Time/Date _____

NB: If potential patient complexity eg, severe pain, confusion/agitation, complex psychosocial factors, family distress a referral to the Palliative Care Service is advised.

Contact: _____ or after hours ph: _____

³ Source: Hutt Hospital

Part 4: Tools and resources to guide the care of people in their last days of life

Tools and resources

Some services involved in the care of people in their last days of life have developed a range of tools and resources to provide practical guidance based on best practice and evidence to support quality care for people in their last days of life, and their families/whānau. These tools and resources provide useful guidance for services and can be adapted as appropriate based on local and regional identified needs.

Table 2: Summary of tools and resources provided in this section

Reference	Tool/resource	Page Number
Physical		
A	Identifying the Dying Patient	44
B	Identifying the Dying Patient: Algorithm	47
C	Guideline for Developing an Individualised Medical Management Plan for End of Life: General Principles	48
D	Guideline for Developing an Individualised Medical Management Plan for End of Life: Nausea and Vomiting	51
E	Nausea and Vomiting: Algorithm	53
F	Guideline for Developing an Individualised Medical Management Plan for End of Life: Pain	54
G	Pain: Algorithm	56
H	Pain in patients with impaired renal function	57
I	Guideline for Developing an Individualised Medical Management Plan for End of Life: Respiratory Secretions	58
J	Respiratory Secretions: Algorithm	59
K	Guideline for Developing an Individualised Medical Management Plan for End of Life: Delirium (and associated restlessness or agitation)	60
L	Delirium/agitation: Algorithm	62
M	Guideline for Developing an Individualised Medical Management Plan for End of Life: Dyspnoea	63
N	Breathlessness: Algorithm	65
O	Rapid Discharge Checklist for the Dying Patient	66
Family		
P	What to expect when someone is dying (information for family/whānau)	68
Q	Supporting care of people in their last hours or days of life (information for family/carers)	70
R	Breaking bad news flow chart	71
S	W.H.A.N.A.U: Personalising Care at End-of-Life	72
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Spiritual		
U	Spiritual Care Assessment Tool based on FICA approach	75

Tool A: Identifying the Dying Patient

Contents

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1.2	Scope	1
1.3	Definitions	1
2.	Identifying the Dying Patient	2
2.1	Identifying dying	2
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1. Overview

1.1 Purpose

- Identifying that someone is dying is a *process* with significant implications and one which is best carried out by the doctors involved in the patient's care.
- It is important that dying is identified as early as possible as this can ensure that the appropriate care and communication needed by patients and families is anticipated and provided. It also allows the clinical team to prioritise the goals of comfort and support based on the patient's preferences.

1.2 Scope

This document applies to End of Life Care in the Medical and Surgical Divisions.

1.3 Definitions

End of Life Care Definitions, as adopted by Waitemata District Health Board (WDHB).

End of Life

The end of life phase begins when a judgement is made that death is imminent (expected within hours-days during this admission). It may be the judgement of the health/ social care professional or team responsible for the care of the patient, but it is often the patient or family who first recognises death is imminent.

End of Life Care

End of life care is the provision of supportive and palliative care in response to the assessed needs of the patient and family/ whānau during the end of life phase. It focuses on preparing for an anticipated death and managing the end of a life-limiting or life-threatening condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both the person and the family/ whānau to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family. (*The New Zealand Palliative Care Glossary, 2013*)

Imminent death

In Waitemata DHB, imminent death is when death is expected within hours-days during this admission. (*Waitemata DHB End of Life Care Project Steering Group, 2013*).

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⁴ Source: Waitemata District Health Board End of Life Care Project Steering Group

2. Identifying the Dying Patient

2.1 Identifying dying

There may be clinical indicators that a patient is imminently dying. An advanced cancer patient with no chance of a cure may be entering the dying phase if they have been deteriorating over a period of days or weeks and two of the four criteria listed below are present:

The patient is:

- Bed bound
- Semi-comatose
- Only able to take sips of fluids
- No longer able to take oral medication.

Such criteria may not be appropriate in patients who do not have cancer but may still provide a useful guide.

2.2 Process of Dying

While there may be many different ways of dying the most common mode of dying involves the following:

- A period of increasing weakness and tiredness resulting in the person spending more and more of their time in bed.
- A period of withdrawal with the person spending less time awake and increasing time asleep, decreasing intake of food and medicine, and decreased interaction with others.
- A period of unconsciousness with no waking.
- Cooling of peripheries as the blood circulation is diverted to central processes.
- Irregularities of heart beat due to metabolic or vascular changes.
- Stiffness caused by immobility.
- Breathing patterns change as the person becomes more deeply unconscious and control of breathing is driven by the build-up of carbon dioxide in the system. When the level of carbon dioxide is low, there is no drive to take a breath and so there may be long gaps without breathing. Then when the carbon dioxide builds up in the system this will eventually cause the body to take several big breaths to expel carbon dioxide. This pattern of intermittent breathing is called cheyne stokes breathing.
- Difficulties in swallowing often occur in the days or hours before death and may lead to pooling of saliva at the back of the throat. This can cause noisy breathing often referred to as the 'death rattle'. This can be very distressing for relatives and carers but is not thought to cause upset for the unconscious patient.

2.3 Managing the Dying Process

Some people die without pain or distress even when death is expected. However there are five symptoms specifically associated with the dying process. It is important that there is a plan for if/ when they arise so that symptom management is optimised. Not every dying patient experiences these symptoms, but some may experience all five.

The five symptoms associated with dying are:

- Pain
- Nausea and vomiting
- Agitation and distress
- Respiratory tract secretions
- Breathlessness.

Often clinical staff have the skills and knowledge to effectively manage the symptoms of dying. However, there are occasions when the input of a specialist palliative care service will be required, particularly when symptoms prove refractory or difficult to control.

2.4 Anticipatory Prescribing

- It is important to anticipate potential symptoms and healthcare professionals need to be enabled to respond quickly should a symptom arise or when swallowing becomes difficult. Anticipatory prescribing of drugs is important to ensure a patient is not left in pain and distress for a period of time until a drug can be prescribed. It is important to refer to the Waitemata DHB guidelines for developing an Individualised Medical Management Plan for End of Life.
- The Specialist Palliative Care Team should be contacted when there is concern or uncertainty about prescribing for patients at the end of life.
- For further advice regarding anticipatory prescribing or prescribing for symptom management in the dying patient please see the End-of-Life and Bereavement pages on the Waitemata DHB intranet site.

2.5 Conclusion

In providing end-of-life care it is essential that:

- Every effort is made to optimise symptom management.
- Dignity, respect and privacy are provided and maintained.
- The individual needs and preferences of the patient are ascertained and fulfilled insofar as possible.
- Communication is optimised for all people involved (patients, families and staff) .
- The patient and family feel unhurried and valued .
- Staff are enabled and supported to deliver the highest standard of end-of-life care possible.

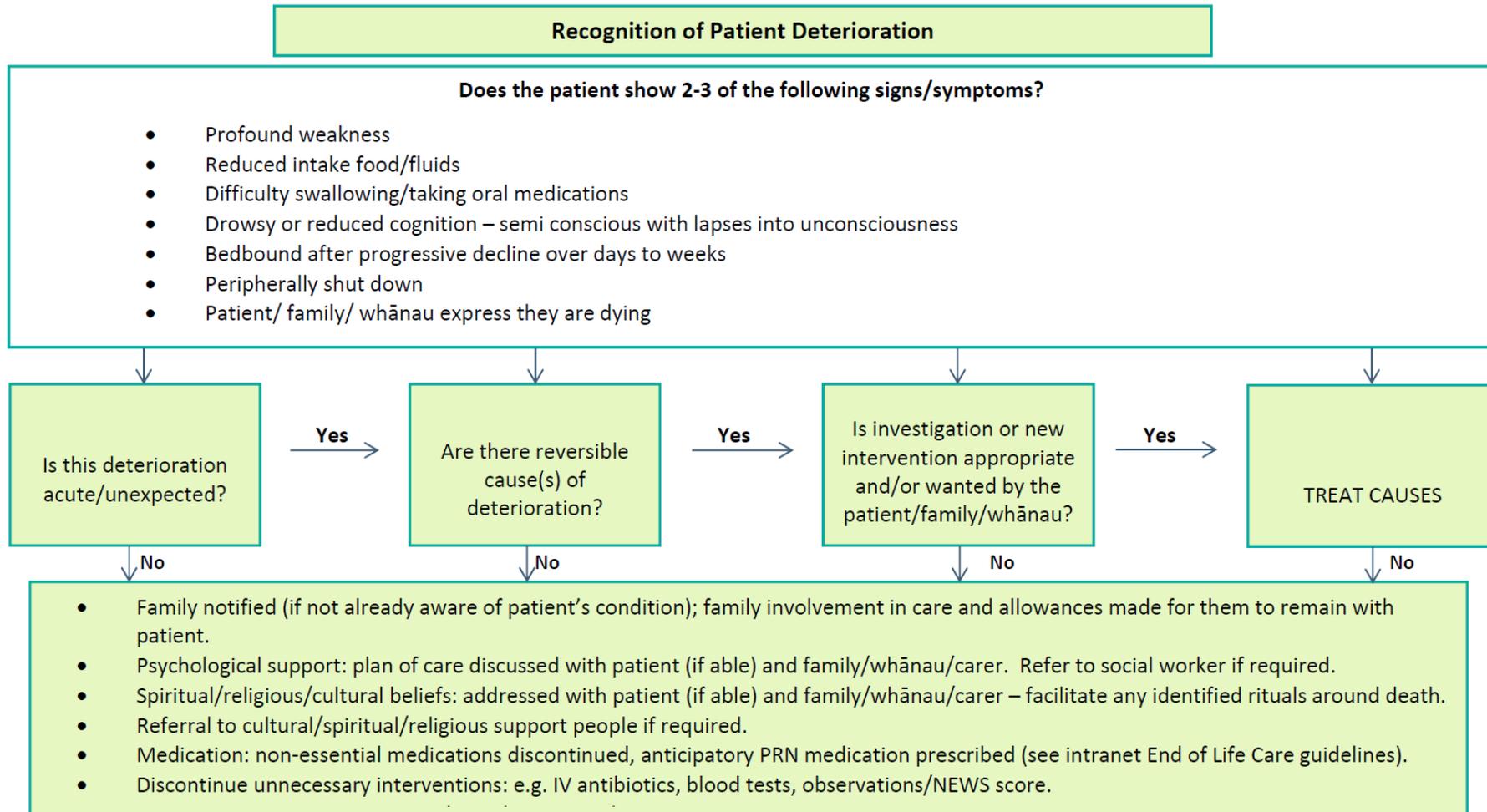
Standard of Care

The standard of end of life care by which we should judge the care that we delivery is whether we would be content if that same care was given to our own family or to ourselves.

Reference Table

1	<i>Hospice Friendly Hospitals (2008) When a Patient is Dying booklet, Hospice Friendly Hospitals Programme</i>
2	<i>Lynn J., 2004. Sick to Death and Not Going to Take it Anymore!, University of California Press, Berkeley, CA: 2004.</i>
3	<i>Murray, S. A., Kendall, M., Boyd, K. & Sheikh, A. (2005) Illness trajectories and palliative care. British Medical Journal, 330:7498. doi:10.1136/bmj.330.7498.1007PMCID: PMC557152</i>
4	<i>The New Zealand Palliative Care Glossary.</i> http://www.cancercontrolnz.govt.nz/sites/default/files/NZ%20Palliative%20Care%20Glossary.pdf

Tool B: Identifying the Dying Patient: Algorithm



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⁵ Source: Waitemata District Health Board End of Life Care Project Steering Group

Tool C: Guideline for Developing an Individualised Medical Management Plan for End of Life: General Principles

IDENTIFYING A DYING PATIENT AND COMMUNICATING DIAGNOSIS TO PATIENT

Recognising someone is dying and predicting time of death is difficult. Signs and symptoms suggesting dying can be subtle

- Last weeks of life are often characterized by progressive physical decline, frailty, lethargy, worsening mobility, reduced oral intake and poor response to medical interventions
- Last days to hours of life may be characterized by further decline in oral intake, patient entirely bedbound, physical symptoms such as delirium, respiratory changes and cardiovascular changes (e.g. peripheral vasoconstriction)

Recognition of dying and communicating this to the patient and family/whānau allows them time to express end of life care preferences and attend to important matters before they die.

How you communicate this information is critically important, as is attention to differing cultural attitudes to these discussions.

EXPECTED STANDARD OF CARE

Inform Medical/Surgical Consultant under whom patient is admitted that patient may be dying.

Senior Medical Team Member (Consultant or Registrar) will communicate diagnosis of dying to the patient/family/whānau and to other medical and nursing team members.

Medical and Nursing team will document a Personalized Care Plan incorporating appropriate medical, nursing and allied health interventions. **See 'Planning for End-of-Life Care' document.**

MEDICATION MANAGEMENT: KEY PRINCIPLES

Communicate medication plan to your patient and their family/whānau. Clear explanations reduce confusion/anxiety about what is occurring and why.

Subcutaneous route (subcut) is preferred if patient is unable to swallow.

Individualize each patient's medication plan according to their need and the risk benefit ratio of the current or proposed interventions.

Review your patient and the medication chart daily.

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⁶ Source: Waitemata District Health Board End of Life Care Project Steering Group

MEDICATION MANAGEMENT: KEY PRINCIPLES (continued)

Stop nonessential medications/those that are no longer conferring benefit to reduce tablet burden. This may include antihypertensives, oral hypoglycaemics, diuretics, antibiotics etc, depending on the patient.

Continue current medications if withdrawal could cause adverse effects. This may include anti-anginals, heart failure medications, steroids if steroid dependent, benzodiazepines if benzodiazepine dependent.

Consider risks and benefits of administration of hydration by parenteral route before commencing or stopping intravenous or subcut fluids.

Prescribe appropriate medications for existing symptoms as needed (PRN), subcut and orally if still able to swallow and if necessary via continuous subcutaneous infusion (CSCI).

Prescribe PRN medications (“anticipatory” prescribing) for anticipated symptoms that may occur in dying patients subcut (and orally if still able to swallow).

ANTICIPATORY PRESCRIBING FOR ASYMPTOMATIC PATIENTS

Common symptoms in dying patients include delirium (at times with restlessness and agitation) and accumulation of respiratory secretions. Occasionally dyspnoea, nausea, vomiting or pain may occur.

Explain to patient and family/whānau that these symptoms may develop and that you are prescribing PRN medications in anticipation of these possibly occurring.

Reassure patient and family/whānau that pain is not inevitable and may not occur if not already present.

If more than 3 successive doses of any prescribed drug are required within the minimum administration period (e.g. if prescribed Q1H PRN and 3 doses are required in 3 hours), review your patient and consider whether it would be preferable to administer these via continuous infusion syringe driver (NIKI T 34). **See Palliative Care Intranet site for more information.**

PRESCRIBING FOR SYMPTOMATIC PATIENTS: GENERAL PRINCIPLES

Some medications can be administered via the subcutaneous (subcut) route, either PRN or via continuous subcutaneous infusion (CSCI), although not all drugs can be mixed together in the same syringe. For most drugs commonly used in palliative care, the oral dose is the same as the subcut dose. Notable exceptions are opioids. **The doses of oral opioids (morphine, oxycodone or methadone) should be divided by 2 to get the equianalgesic subcutaneous dose.**

CONVERSION CHART

Drug	Indications	Recommended oral:subcut ratio	Comments
Buscopan® (hyoscine butylbromide)	Respiratory secretions Colicky abdominal pain	NOT APPLICABLE: Has extremely low oral bioavailability	Do not use Buscopan® orally for respiratory secretions as it has very low (<10%) systemic bioavailability when given orally
clonazepam	Sedation Seizures Some pain states	1:1	Seldom used as clonazepam can be adsorbed into tubing
cyclizine	Nausea/vomiting	1:1	Can crystallize with some drugs, check compatibility tables
dexamethasone	Raised intracranial pressure Several pain states	1:1	Can crystallize with some drugs, check compatibility tables
diclofenac	Pain		Seldom used
fentanyl	Pain Dyspnoea	NOT APPLICABLE, not given orally	Can be used intranasally or submucosally
haloperidol	Nausea/vomiting Delirium	1:1	
hyoscine hydrobromide (Scopoderm®)	Respiratory secretions Nausea/vomiting	NOT APPLICABLE, not given orally	
ketamine	Pain	NOT APPLICABLE, seldom given orally	
levomepromazine (Nozinan®)	Nausea/vomiting (4 th line) Delirium (3 rd line) Sedation (2 nd line)	1:1 (or 2:1 for patients on higher oral doses)	
methadone	Pain	1:1 or 2:1 (for patients on higher oral doses)	Divide oral dose by 2 to get subcut dose. For patients on low doses (≤ 20 mg) the 1:1 ratio may be required
metoclopramide	Nausea/vomiting	1:1	
midazolam	Anxiolytic Sedation Seizures	NOT APPLICABLE: Has low oral bioavailability	
morphine sulphate and tartrate	Pain Dyspnoea	2:1 or 3:1	Divide oral dose by 2 (or 3 if patient is opioid toxic)
octreotide	antisecretory	NOT APPLICABLE, not given orally	
oxycodone hydrochloride	Pain Dyspnoea	2:1	This is a conservative conversion and some patients may need higher doses

Tool D: Guideline for Developing an Individualised Medical Management Plan for End of Life: Nausea and Vomiting

Key principles

The key principles in effective management of nausea and vomiting are:

1. Use a parenteral route to ensure absorption of the drug: subcutaneous (subcut) route preferred
2. Choose **one** drug. Give it regularly, at appropriate doses to **prevent** symptoms (ie not PRN)
3. Choose a second drug and prescribe it PRN for breakthrough symptoms.

Anticipatory prescribing in asymptomatic patients

Use one or more of the following antiemetics:

ANTIEMETIC	USUAL DOSE and FREQUENCY	ROUTE	MAXIMUM DAILY DOSE	COMMENTS
haloperidol	0.5 – 1 mg Q4-6H PRN	subcut	5 mg/24H	DO NOT USE in Parkinson's disease/similar disorders Also useful for delirium
metoclopramide	10 mg Q6 – 8 H PRN	subcut	100 mg/24H	Use if prokinetic required DO NOT USE in Parkinson's disease/similar disorders Avoid if bowel obstruction with colicky abdominal pain
levomepromazine (Nozinan [®])	6.25 mg Q4-6H PRN Generally used as a 3 rd line antiemetic especially in ambulatory patients	subcut	25 mg/24H	A broad spectrum antiemetic Can be very sedating in some patients <ul style="list-style-type: none"> • avoid if sedation undesirable • not generally recommended for ambulant patients

Symptomatic patients or already on medication for nausea and/ or vomiting

If symptoms are well controlled on current oral PRN or regular antiemetic, stop oral antiemetic and continue administration via subcutaneous (subcut) route in anticipation that patient may soon be unable to swallow.

If symptoms are not well controlled

- review patient, exclude reversible causes and treat reversible causes if appropriate
 - it may not always be appropriate to attempt to reverse causes in patients at end of life; the burden of treatment may outweigh the benefit
 - it may be appropriate to treat easily reversible causes such as raised intracranial pressure with corticosteroids
- choose the most appropriate antiemetic for the postulated cause
 - e.g metoclopramide (prokinetic) for gastric stasis; haloperidol for opioid induced nausea

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⁷ Source: Waitemata District Health Board End of Life Care Project Steering Group

OR

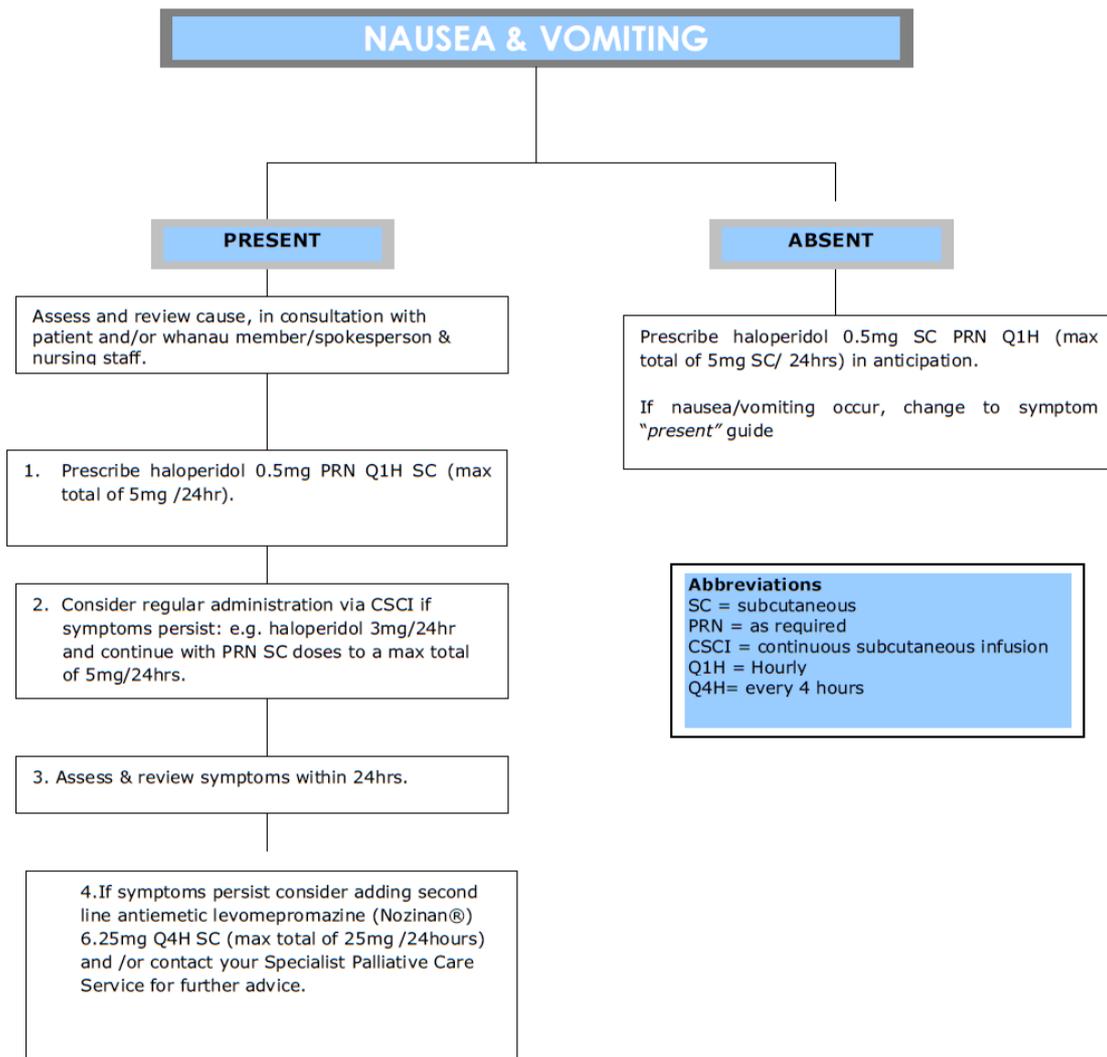
- use levomepromazine (a broad spectrum antiemetic useful for most causes of nausea and vomiting) PROVIDED that sedation is acceptable to the patient and family
- administer the chosen antiemetic regularly via continuous subcutaneous infusion (CSCI)
- prescribe a second line antiemetic for PRN use in case the drug you have chosen is ineffective.

For all commonly used antiemetics, the subcut dose is the same as the oral dose.

The following antiemetics are commonly used subcut:

ANTIEMETIC	USUAL PRN DOSE and FREQUENCY	USUAL STARTING SUBCUT DOSE IN CSCI	USUAL MAXIMUM TOTAL DAILY SUBCUT DOSE IN CSCI
metoclopramide	10 mg Q6-8H	30 mg /24 hrs	up to 100mg/24 hrs if high dose prokinetic required
haloperidol	0.5 – 1 mg Q4-6H	1 mg/24 hours	5 mg/24 hours
cyclizine	25 – 50 mg Q8H	150 mg/24 hrs	150 mg/24 hrs
levomepromazine (Nozinan®)	3.125 - 6.25 mg Q4-6H	6.25 – 12.5 mg/24 hours	25 mg/24 hours

Tool E: Nausea and Vomiting Algorithm



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⁸ Source: Waitemata District Health Board End of Life Care Project Steering Group

Tool F: Guideline for Developing an Individualised Medical Management Plan for End of Life - Pain

Patients who do not already have pain may not develop pain in the last hours to days of life. It is wise to provide for the possibility that a new event, such as a pulmonary embolus (which is common in patients with malignancy) may cause pain. Review outcome of your interventions daily.

Note the equianalgesic ratio between opioids
1mg morphine IV/subcut = 1mg oxycodone IV/subcut = 10 micrograms fentanyl IV/subcut

Instruct nursing staff to seek medical advice if they have any concerns about the possibility of narcosis before administering an opioid. Signs to look for include respiratory depression (e.g. respiratory rate below 10/minute), excessive sedation (which may be due to other causes in dying patients) and pinpoint pupils (abnormal miosis, pupils that fail to dilate in the dark and remain <2mm diameter).

Asymptomatic opioid naïve patients: anticipatory prescribing

PATIENT CONDITION	DRUG	USUAL DOSE AND FREQUENCY	ROUTE	COMMENTS	MAXIMUM DAILY DOSE
opioid naïve patients with estimated CrCL ≥30ml/min	morphine	2.5 mg Q30min PRN	subcut	Can use 1 mg in the frail elderly or those with neurological conditions such as motor neurone disease (MND)	no maximum dose/24H
opioid naïve patients with estimated CrCL <30ml/min	oxycodone OR	2.5 mg Q30min PRN	subcut	Can use 1 mg in the frail elderly or those with neurological conditions such as motor neurone disease (MND)	
	fentanyl Use this if estimated CrCL < 10 ml/min	25 mcg Q30min PRN	subcut	Can use 10 mcg in the frail elderly or those with neurological conditions such as MND DO NOT DILUTE FOR SUBCUT USE	

Symptomatic opioid naïve patients

Follow the recommendations in the table above. Review after 6 – 8 hours. If patient has required ≥ 3 PRN doses start a continuous subcutaneous infusion (CSCI) with the anticipated 24-hour requirement of opioid. Review daily and adjust CSCI and PRN dose as needed.

In some patients it may be appropriate to start a CSCI with 5 – 10 mg morphine (or oxycodone) or 50 – 100 micrograms of fentanyl over 24 hours without first waiting for response to PRN opioids.

PATIENTS ALREADY ON OPIOIDS (OPIOID EXPERIENCED) MAY BE OPIOID HABITUATED

If already using a transdermal fentanyl patch, do not alter the strength of the patch. Leave patch at current dose and add the most appropriate additional opioid.

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⁹ Source: Waitemata District Health Board End of Life Care Project Steering Group

Pain controlled

If symptoms are controlled on oral PRN or long acting opioids, stop oral opioid and prescribe via subcutaneous (subcut) route in anticipation that patient may soon be unable to swallow:

Divide total daily dose of long acting regular morphine or oxycodone by 2 to get total daily equianalgesic subcut dose. Administer via continuous subcutaneous infusion (CSCI) over 24 hours

Divide oral PRN dose of morphine or oxycodone by 2 to get equianalgesic subcut PRN dose.

- PRN subcut opioids can be administered up to Q30min PRN for pain.
- As a guide an appropriate PRN dose of morphine or oxycodone is $1/6^{\text{th}}$ of the total 24 hour dose in the CSCI.
- If patient requires ≥ 3 PRN doses in 24 hours consider starting a CSCI with the amount the patient has required in the preceding 24 hours.

Pain not controlled

If symptoms are not controlled on oral PRN or long acting opioids:

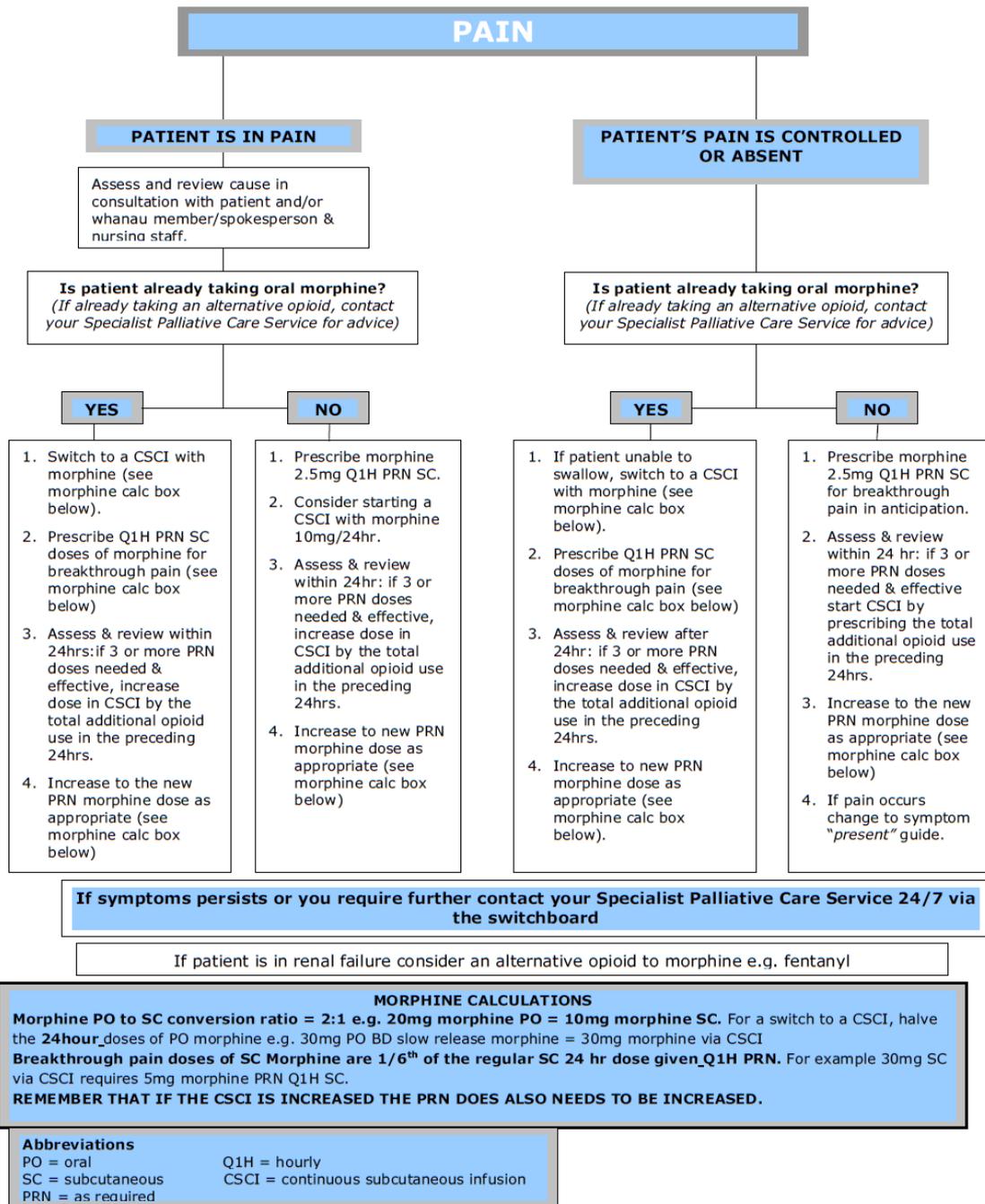
Review patient. Assess the cause of the pain.

- Simple things may cause pain. Exclude pressure sores, urinary retention and constipation. Drugs may not be required for these conditions.
- Some pains may benefit from medications other than opioids e.g.
 - Buscopan[®] (hyoscine butylbromide) for colicky abdominal pain
 - Corticosteroids (e.g. dexamethasone) for headache from raised intracranial pressure or pain from nerve root/cord compression
- Exclude delirium
 - Delirious patients may cry out in distress which may not be due to pain
 - It is difficult to do an accurate pain assessment in the setting of delirium

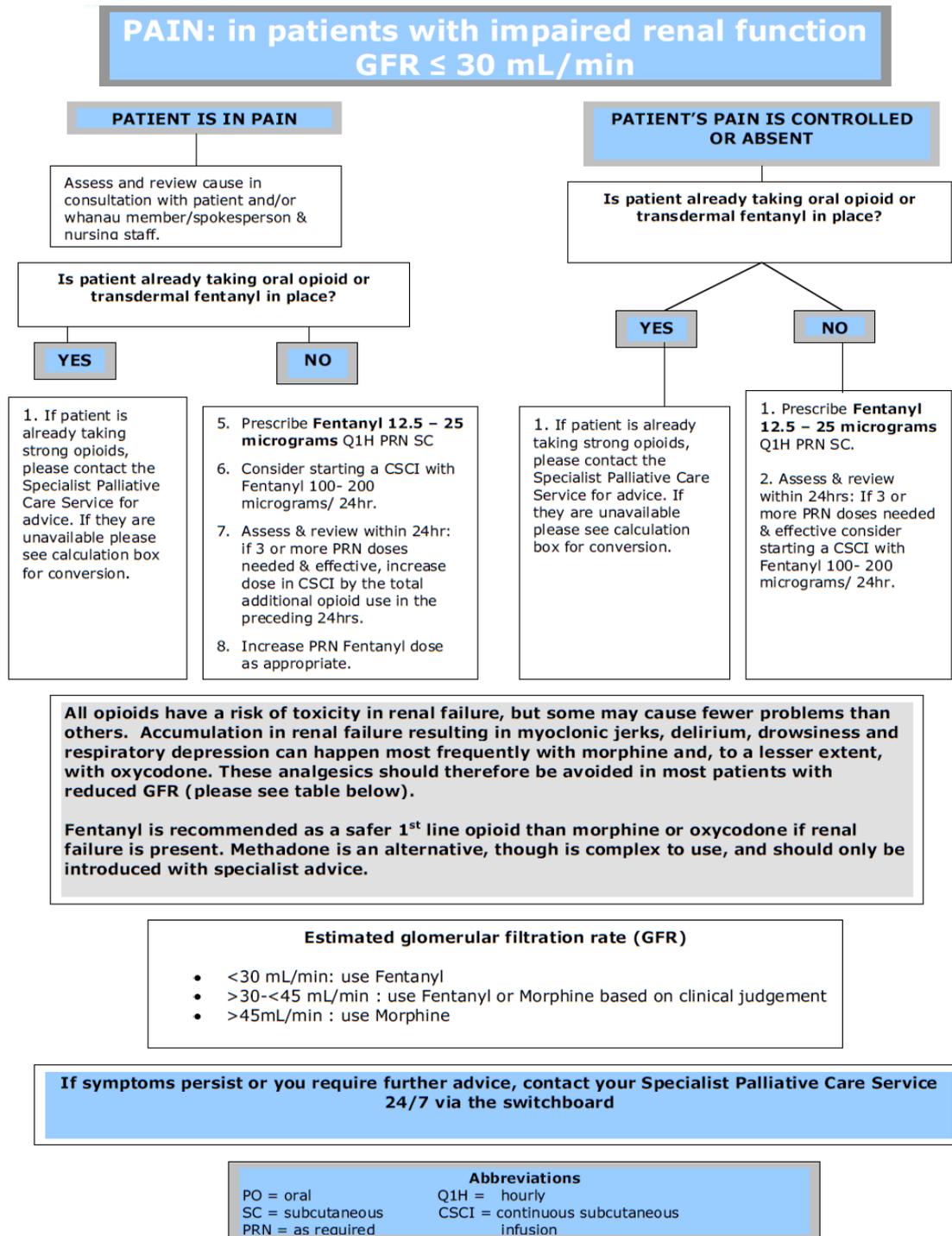
Stop oral PRN and long acting opioids and prescribe via subcut route. This may improve absorption and pain control.

- **Divide total daily dose of long acting regular morphine or oxycodone by 2** to get total daily equianalgesic subcut dose. Administer via CSCI over 24 hours.
- **Divide oral PRN dose of morphine or oxycodone by 2** to get equianalgesic subcut PRN dose
 - PRN subcut opioids can be administered up to Q30min PRN for pain
 - Review after 6 – 8 hours. If patient needed ≥ 3 PRN doses increase the amount of opioid in the CSCI by the corresponding amount. Review daily and adjust CSCI and PRN dose as needed.

Tool G: Pain Algorithm



Tool H: Pain in patients with impaired renal function - algorithm



Tool I: Guideline for Developing an Individualised Medical Management Plan for End of Life: Respiratory Secretions

Respiratory secretions may develop if patients are unable to clear oropharyngeal secretions. These may generate noisy breathing however it is thought this is not unduly distressing to most patients. Often a small volume can generate a lot of noise as air moves across fluid in the airway.

General Management

1. Explain symptoms to family and whānau.
2. Minimise patient turns as these disturb fluid and may increase symptoms. Gravity generally ensures that fluid settles and air will move across the top of accumulated fluid, usually without distressing the patient.

Occasionally cardiovascular fluid overload or respiratory tract infection may contribute to respiratory distress. Antisecretory medications are of no use in these situations:

1. If cardiovascular fluid overload is present
 - a stat dose of frusemide may help
 - stopping IV fluids (or reducing flow rate) may be required.
2. If respiratory tract infection is resulting in copious purulent sputum, a stat dose of an appropriate antibiotic is helpful in some patients.

Anticipatory prescribing in asymptomatic patients

ANTISECRETORY	USUAL DOSE and FREQUENCY	ROUTE	MAXIMUM DAILY DOSE	COMMENTS
hyoscine butylbromide (Buscopan®)	20 mg Q1-2H PRN	subcut	120 mg/24H	Some centers use hyoscine hydrobromide ¹ or Scopoderm® patches

Prescribing in symptomatic patients or for patients already using antisecretory medication

Prescribe continuous subcutaneous infusion (CSCI) *and* PRN for breakthrough symptoms. If patient is currently symptomatic, give a stat dose at the same time the CSCI is commenced.

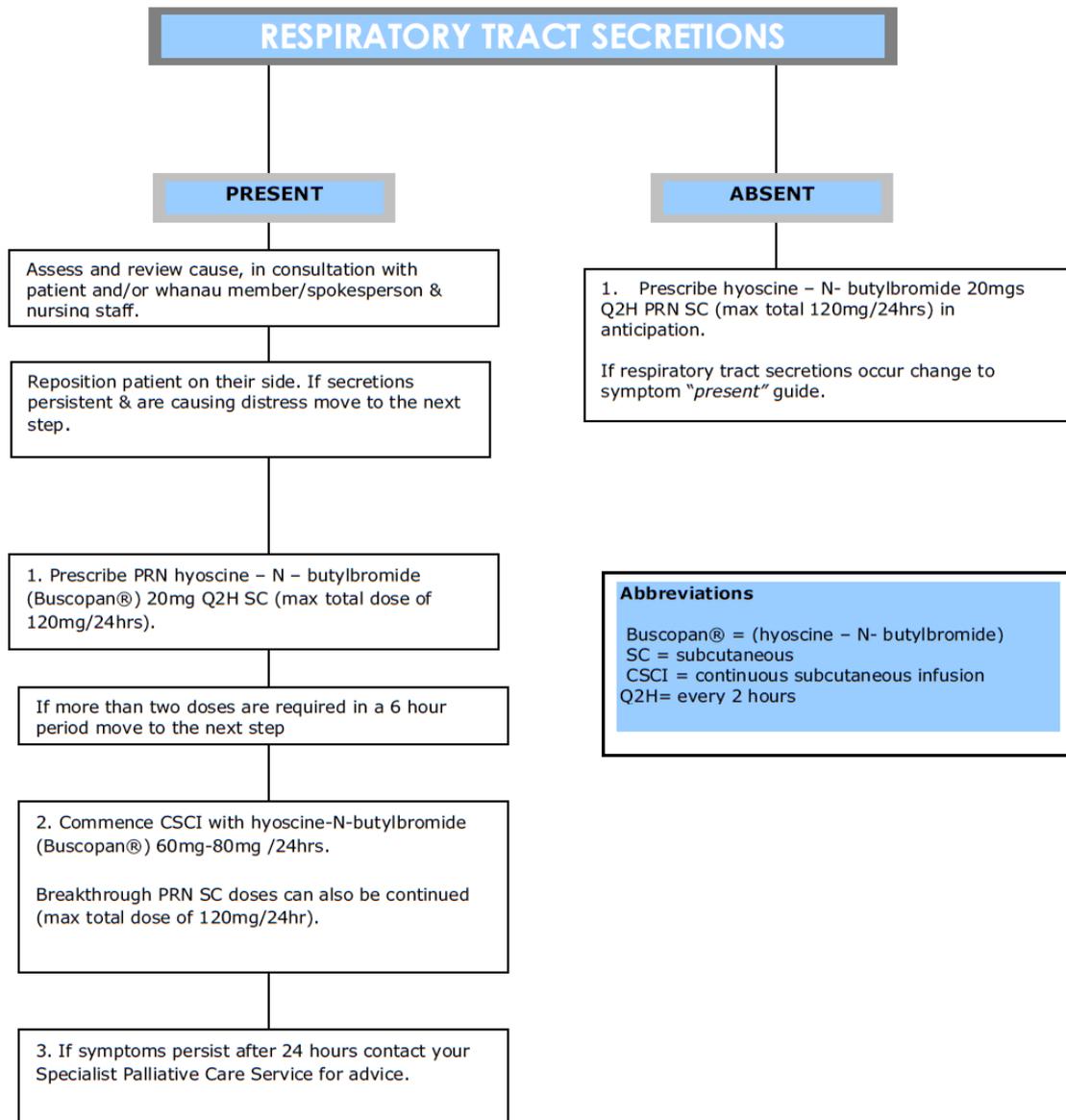
ANTISECRETORY	USUAL SUBCUT DOSE PRN	USUAL SUBCUT DOSE IN CSCI NIKI T43
hyoscine butylbromide (Buscopan®)	20 mg Q1-2H	60 mg/24 hours

Review after 24 hours: If ≥ 3 PRN doses Buscopan® have been required in previous 24 hours increase the dose in the CSCI to incorporate patients actual 24 hour requirement (usual maximum 24 hour dose is 120 mg).

¹ Hyoscine hydrobromide: usual dose and frequency 0.4 mg Q2H PRN; can be included in CSCI at a usual starting dose of 1.2 mg/24 hour; maximum daily dose 2.4 mg/24 hours;

¹²

Tool J: Respiratory Tract Secretions - Algorithm



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Tool K: Guideline for Developing an Individualised Medical Management Plan for End of Life: Delirium (and associated restlessness or agitation)

Delirium, restlessness or agitation is extremely common in dying patients. The cause is often multifactorial. Many causes are not reversible. The burden of investigations in a dying patient is often best avoided.

Readily treatable causes (pain, urinary retention, hypoxia, dehydration, opioid toxicity) should be excluded as treatment may improve comfort in the dying phase.

Anticipatory prescribing in asymptomatic patients

MEDICATION	USUAL DOSE and FREQUENCY	ROUTE	MAXIMUM TOTAL DAILY DOSE	COMMENTS
haloperidol In conscious patients use first line. The goal is to improve clarity	0.5 - 1 mg Q2H PRN Start with the lower dose first	subcut	5 mg/24H	DO NOT USE in Parkinson's disease/similar disorders Also useful for nausea/vomiting
midazolam Prescribe for all patients in case this is needed In unconscious patients use first line. In conscious patients use second line if haloperidol is ineffective for restlessness or agitation and sedation is needed The goal is to manage restlessness or agitation if sedation is necessary. Clarity will not improve and may worsen	2.5 – 5 mg Q30 min PRN Start with the lower dose first Can use 1 mg in the frail elderly, renal impairment or those with neurological conditions such as motor neurone disease	subcut	no maximum daily dose	Benzodiazepine dependent patients may need higher doses Use 15 mg/3 ml ampoules (the concentration is higher than 5mg/5ml ampoule hence volume for subcut administration of a given dose is lower) Also effective for seizures though higher doses may be needed (5 – 10 mg)
levomepromazine (Nozinan®) use if midazolam ineffective	6.25 mg Q1H PRN	subcut	25 mg/24 hours	Also useful for nausea/vomiting Can be very sedating in some patients (avoid if sedation is undesirable) Not generally recommended for ambulant patients

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¹⁴ Source: Waitemata District Health Board End of Life Care Project Steering Group

If patient is already using haloperidol or midazolam regularly or has required ≥ 3 PRN doses/24 hours, start a continuous subcutaneous infusion (CSCI) with the total dose the patient has needed in the preceding 24 hours. If patient is not already on medication for delirium use guidelines below

A. Patient not distressed; sedation not required

	DRUG	USUAL DOSE and FREQUENCY	ROUTE	COMMENTS	MAXIMUM TOTAL DAILY DOSE (REGULAR + PRN USE)
Prescribe regular <i>and</i> PRN haloperidol	haloperidol	1 mg nocte	subcut	or incorporate 1 mg/24 hours in CSCI	5 mg/24H
DO NOT USE in Parkinson's disease or similar disorders Also useful for nausea and vomiting	haloperidol	0.5 - 1 mg Q2H PRN	subcut	for breakthrough symptoms	

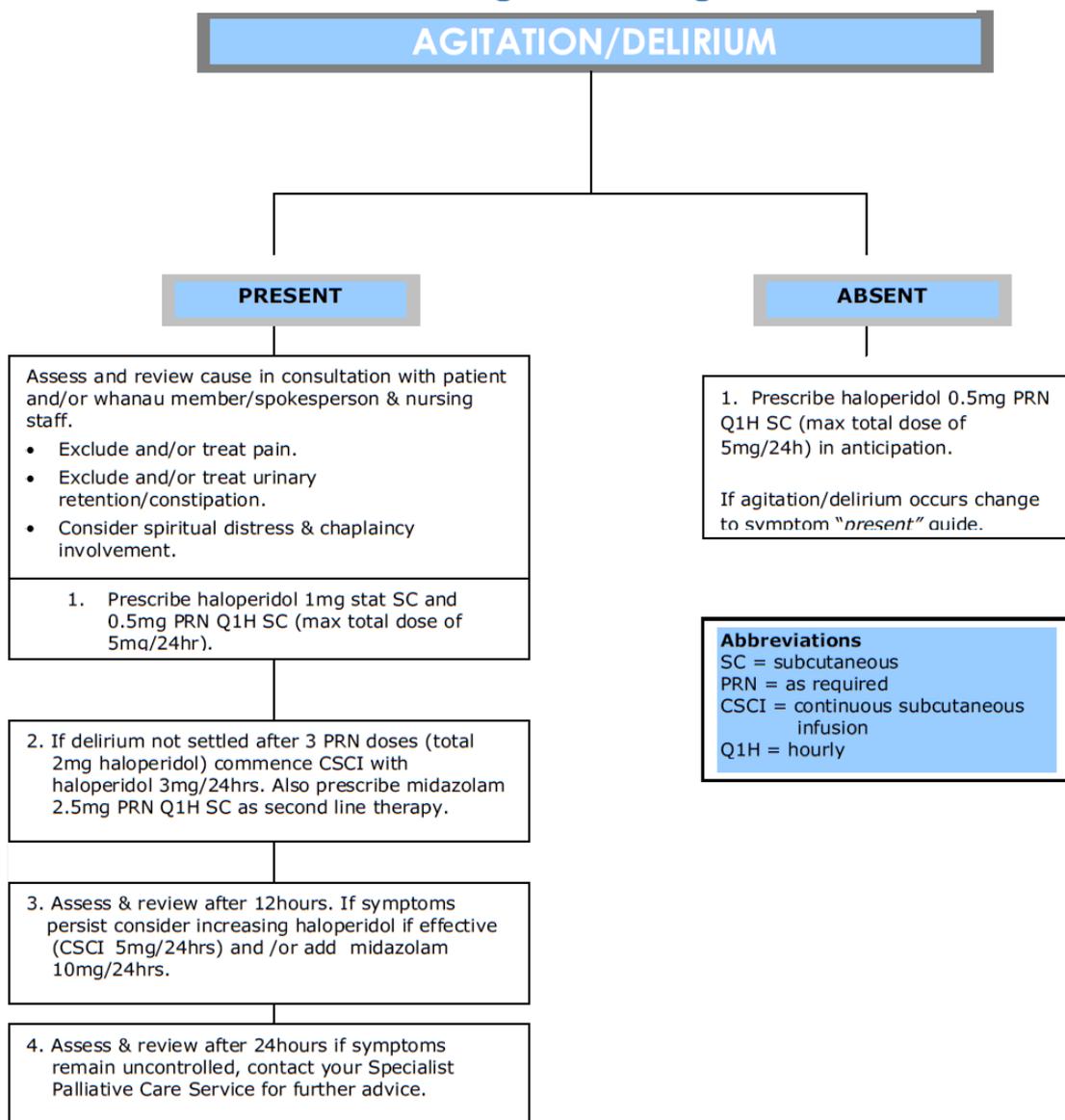
Review after 24 hours. If ≥ 3 PRN doses haloperidol were required in previous 24 hours, increase dose in CSCI to incorporate patient's actual 24 hour requirement.

B. Patient distressed; sedation required

	DRUG	DOSE and FREQUENCY	ROUTE	COMMENTS	MAXIMUM TOTAL DAILY DOSE
Prescribe regular <i>and</i> PRN midazolam	midazolam	10 mg/24 hours	CSCI	Start with 5 mg/24 hours in frail elderly or those with neurological conditions e.g. motor neurone disease (MND)	no maximum dose/24H
	midazolam	2.5 – 5 mg Q30MIN PRN Start with the lower dose	subcut	Can use 1 mg in the frail elderly or those with neurological conditions such as MND	

Review after 24 hours: If ≥ 3 PRN doses midazolam required in previous 24 hours, increase the dose in the CSCI to incorporate patients actual 24 hour requirement.

Tool L: Delirium/Agitation - Algorithm



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Tool M: Guideline for Developing an Individualised Medical Management Plan for End of Life: Dyspnoea

Dyspnoea is common in end stage disease. Over 50% of patients report this symptom in the last month of life. Dyspnoea is a subjective experience. Visible signs of respiratory distress may not be consistent with patient self-reported distress, which is equally important.

OXYGEN may be helpful in hypoxemic patients, however the need for oxygen should be guided by patient comfort and response rather than solely relying on pulse oximetry. Focusing on treating the “numbers” may cause heightened anxiety in patients and relatives. Instead focus the patient and relatives on comfort.

Patients may find masks, nasal prongs and humidified air uncomfortable. This equipment may be a physical barrier to precious opportunities for communication with family members. Discontinue if not contributing to patient comfort. Midazolam nasal spray may not be appropriate in the dying patient for practical reasons.

Anticipatory prescribing in asymptomatic patients

PATIENT CONDITION	DRUG	USUAL DOSE AND FREQUENCY	ROUTE	COMMENTS	MAX TOTAL DAILY DOSE
opioid naïve patients with estimated CrCl >30ml/min	morphine	2.5 mg Q30min PRN	subcut	Can use 1 mg in the frail elderly or those with neurological conditions such as motor neurone disease (MND)	no maximum dose/24H
opioid naïve patients with estimated CrCl <30ml/min	fentanyl	25 mcg Q30min PRN	subcut	Do not dilute for subcut use This is the preferred drug if estimated CrCl < 10 ml/min Use 10 mcg in the frail elderly or those with neurological conditions	
	OR oxycodone	2.5 mg Q30min PRN	subcut	Use 1 mg in the frail elderly or those with neurological conditions e.g. MND	
Patients with anxiety associated with shortness of breath	midazolam	2.5 – 5 mg Q30min PRN Start with the lower dose	subcut	Can use 1 mg in the frail elderly or those with neurological conditions such as MND Benzodiazepine dependent patients may need higher doses Use 15 mg/3 ml ampoules (the concentration is higher than 5mg/5ml ampoule hence volume for subcut administration of a given dose is lower)	

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Symptomatic patients or patients already on medication for dyspnoea

If already using an opioid or benzodiazepine for dyspnoea regularly or ≥ 3 times/ 24 hours PRN then convert to a continuous subcutaneous infusion (CSCI) in anticipation that patient may soon be unable to swallow.

Opioids

Converting current long-acting opioid to subcutaneous (subcut) route

Divide total daily dose of long acting regular morphine or oxycodone by 2 to get total daily equivalent subcut dose and administer via CSCI over 24 hours.

Converting as needed opioid to subcut route

Divide oral PRN dose of morphine or oxycodone by 2 to get equivalent subcut PRN dose.

- PRN subcut opioids can be given up to Q30min PRN if patient is symptomatic and needs treatment.
- If patient requires ≥ 3 PRN doses in 24 hours consider starting a CSCI with the amount the patient has required over the preceding 24 hours.

Prescribing as need opioid for PRN use

Prescribe the same opioid that is in the syringe driver Q30MIN subcut PRN for breakthrough dyspnoea. As a guide an appropriate PRN dose of morphine or oxycodone is $1/6^{\text{th}}$ of the total 24 hour dose in the CSCI.

- If ≤ 15 mg morphine or oxycodone in the CSCI use 2.5 mg.
- If > 15 mg morphine or oxycodone in the CSCI use $1/6^{\text{th}}$ of the total CSCI dose.

Benzodiazepines

Midazolam is the recommended benzodiazepine for subcut use. It is helpful if anxiety is associated with dyspnoea. Patients on oral benzodiazepines should be converted to midazolam if a benzodiazepine is to be used in a syringe driver.

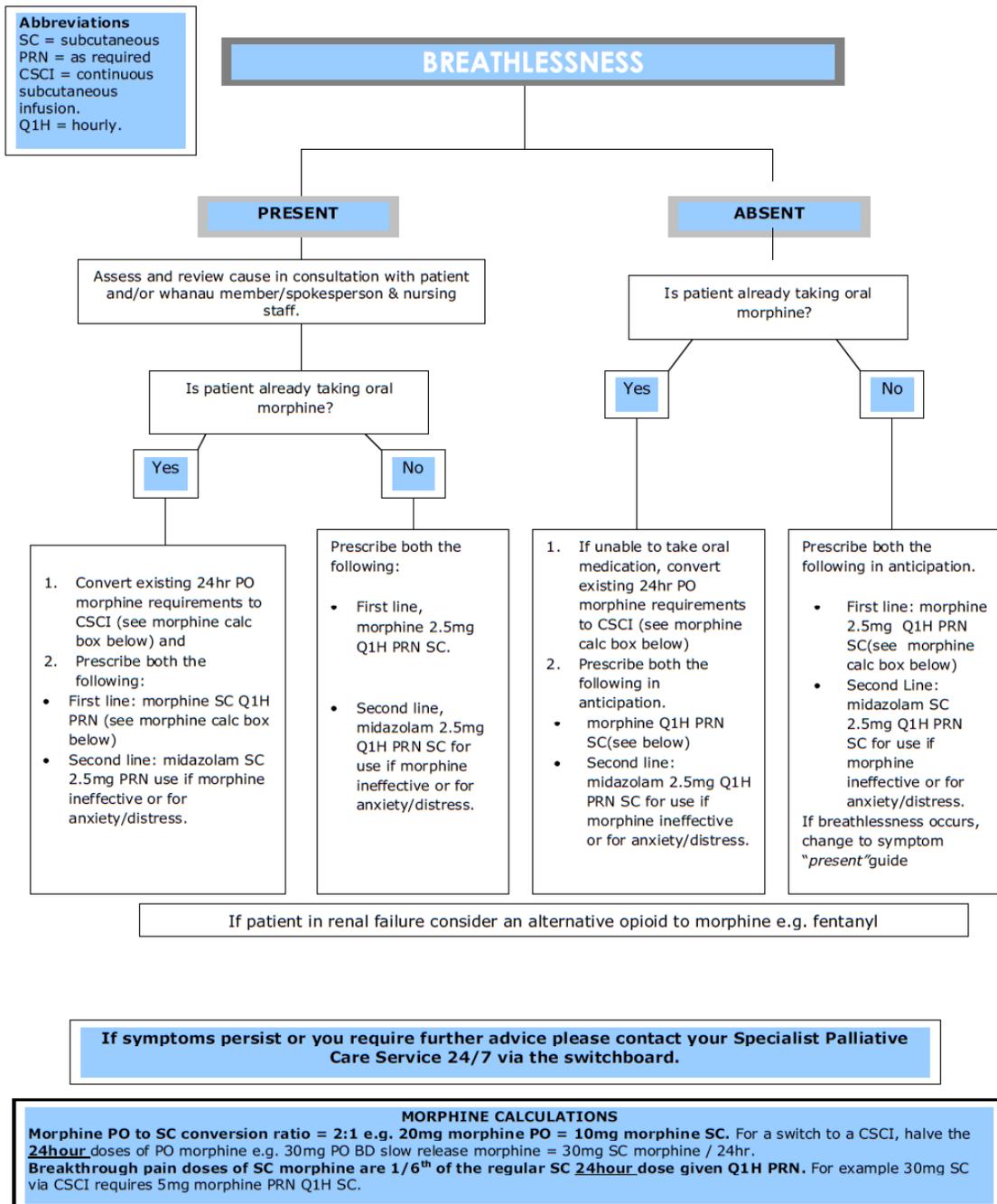
Doses equivalent to approximately 2.5mg subcut midazolam

DRUG	DOSE	HALF LIFE
diazepam	10 mg PO/PR	1-2 days
clonazepam	1 mg PO/SC	30 – 40 hrs
lorazepam	1 mg PO/IV	12 – 16 hrs
oxazepam	15 – 30 mg	3 – 21 hrs
temazepam	10 mg	5 – 15 hrs
midazolam nasal spray	5 sprays	1.5 – 2.5 hrs

To convert an oral benzodiazepine or intranasal midazolam to CSCI midazolam, calculate total use of midazolam equivalent in the last 24 hours. This is the 24 hours subcut dose of midazolam needed in the CSCI. Round up or down to nearest multiple of 2.5mg if necessary. Also prescribe midazolam for PRN use for breakthrough symptoms (as per anticipatory prescribing doses).

Example 1: Patient has been taking 1 mg lorazepam PO (equivalent 2.5 mg subcut midazolam) + used 7 nasal sprays of midazolam in last 24 hours (equivalent 3.5 mg subcut midazolam) = total midazolam equivalent 6 mg. Round *down* to 5 mg midazolam via CSCI over 24 hours.

Tool N: Breathlessness/Dyspnoea - Algorithm



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Tool O: Rapid Discharge Checklist for the Dying Patient

Patients with advanced disease require a range of services to ensure their physical, psychological, social and spiritual needs are met effectively and to enable them to live and die in the place of their choice if at all possible. As clinical circumstances can change rapidly these services need to be particularly well coordinated to prevent unnecessary suffering.

The aim of the rapid discharge checklist is to facilitate a safe, smooth and seamless transition of care from hospital to community patients who choose to be cared for in their own home for their last days of life.

The procedure relies on:

- Hospital staff recognising the priority of the discharge therefore minimising any potential delays
- Patient/ carer being aware of and involved in plan of care
- The hospice/ district nurse being consulted re: the discharge process
- Secondary care prescribing for subcutaneous administration of any regular or anticipatory medications for community use until GP can visit (particularly important if discharge is not within normal working hours)
- GP supporting the discharge.

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¹⁸ Source: Waitemata District Health Board End of Life Care Project Steering Group

Rapid Discharge Checklist for the Dying Patient

CHECKLIST	YES	NO	COMMENT
Does the patient have a preferred place of care?			
Patient/ family aware of prognosis			
Family/whānau/ carer support decision for discharge			
DNR complete			
Ambulance booked – aware of DNR			
District Nurse informed – aware of care needs and discharge date and time. Contact DN Liaison			
GP aware of discharge and arrangements made for GP to visit			
Hospice (if appropriate) are aware of discharge and will review ASAP			
Other MDT members aware if applicable eg social worker, OT, physio			
Reviewed by NASC and individual care package in place.			
Reviewed by OT and equipment delivered/ planned e.g. electric bed, mattress			
Current medication assessed and non-essential medication discontinued			
Discharge medication ordered: appropriate subcutaneous AND anticipatory medication prescribed			
If patient is being discharged with a NIKI T34 pump in-situ please complete ““ NIKI T34 Discharge Checklist”			
Patient/ family understand the discharge medication			
Oxygen arranged if applicable. See Palliative Care Intranet for advice re referral for palliative home oxygen			
Patient/ family aware of planned services/ visits/ equipment			

Tool P: What to expect when someone is dying (information for family/whānau)

Knowing what to expect as death approaches can help make this time less worrying for all concerned.

This information sheet describes the signs and symptoms that can commonly occur when someone is near the end of their life.

However, because each person is unique, these signs and symptoms may not all happen in every instance, nor will they necessarily happen in any particular order.

Sleep

In the final stages of illness, most people feel content to stay in bed, and may spend more time sleeping. At times they may not respond to you or be hard to wake.

Loss of Interest in Food and Fluids

It is common for people to have little interest in eating or drinking. Dehydration is not usually a problem as the body adapts to the reduced intake of fluids.

Ice chips, sips of fluid through a straw, or the use of a sipper cup, make it easier to give small amounts of fluids.

To help keep the mouth moist, mouth swabs soaked in iced water can be sucked.

Lip balm or Vaseline is also useful to prevent dry chapped lips.

Skin

The nose, ears, hands, and feet may feel increasingly cool to the touch. Extra blankets can be used to provide warmth.

Sometimes the skin may look flushed and hot but not feel hot to the touch.

Applying a cool, moist cloth to the forehead may be helpful.

The skin on the hands, feet and on the underside of the body may become darker.

Breathing Patterns

Breathing patterns may change; there can be periods of rapid, shallow breathing or shallow breathing with long spaces in between breaths. These symptoms are very common and do not usually cause distress to the patient.

As the patient becomes too weak to cough and swallow or is semi-conscious, they may develop rattling, noisy or gurgling breathing.

This is caused by a build-up of secretions normally found in the throat and lungs. This is usually more distressing for you than it is for them. Even small amounts of secretions can produce this symptom.

Medications may be prescribed by the doctors' to help reduce these secretions.

Suctioning is rarely used as it may cause more distress than the gurgling breathing.

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¹⁹ Source: Waitemata District Health Board End of Life Care Project Steering Group

Confusion

There may be increasing confusion about time, place and the identity of even close and familiar people. Displaying a clock can help with keeping track of the time and day. Introduce visitors by name, even if they are well known. Keep familiar objects close by such as photos or mementoes. They may like a pillow or soft blanket from home that is familiar to them. Keep a light on for reassurance if vision is affected.

Restlessness, delirium and agitation

These symptoms usually occur when a patient has become semi-conscious.

Signs include twitching, plucking at the air or at bedclothes, trying to get out of bed even if unable to stand alone and moaning or calling out constantly. Many families find this time difficult because they feel unsure how to help.

Restlessness may be due to treatable causes such as constipation or a full bladder, or may be caused by the irreversible effects of their disease.

Keep the person calm by sitting with them and speaking quietly. Quiet music, radio or aromatherapy can be soothing. Always assume they can hear you and they will find your voice comforting.

The doctor may prescribe a sedative.

When Death Occurs

You may wish to stay at the bedside for a while after death has occurred. Ward staff will help you if you are unsure of what happens next.

If you would like support at any stage from a Social Worker, Chaplaincy service, or a cultural service please ask your Nurse or Palliative Care team to arrange this for you.

Tool Q: Supporting care of people in their last hours or days of life (information for family/carers)

As the end of life approaches it can be difficult to estimate how much time is left, but this may now be as short as hours or days.

It can be difficult to absorb lots of information at a time like this, but we will do our best to explain things to you simply and clearly. If you have questions or just want to talk things over with one of the doctors, nurses or chaplain, please let us know.

Facilities available to you

- There are facilities to make hot drinks on the ward, please ask and we will be happy to show you. There are also toilet facilities available to you.
- Please ask if you would like to stay the night, we will endeavour to make things more comfortable for you.

Medication

Taking tablets and other medication usually becomes more difficult as it becomes harder to swallow safely. We will stop any medication that is not helpful. We will make sure that injections are available if needed, for instance to control pain, nausea/ sickness, breathlessness and other symptoms that may occur. They will only be given if and when needed, just enough and no more than is needed to help the symptom.

Reduced need for food and drink

- We will offer help and support with eating and drinking for as long as possible. However, as part of the dying process, most people gradually lose interest in food and drink. When a person stops eating and drinking it can be hard to accept even when we know they are dying.
- Sometimes fluids given by a drip may be offered, but a drip will only be recommended where it is helpful and not harmful.
- Good mouth care is very important. If you would like to help with this, let us know.

Comfort

We will offer help with personal cares regularly. However, we recognise that it is important for you to have time and space just to be together. This is sometimes a difficult balance to achieve so please let us know if we need to do things differently, for whatever reason.

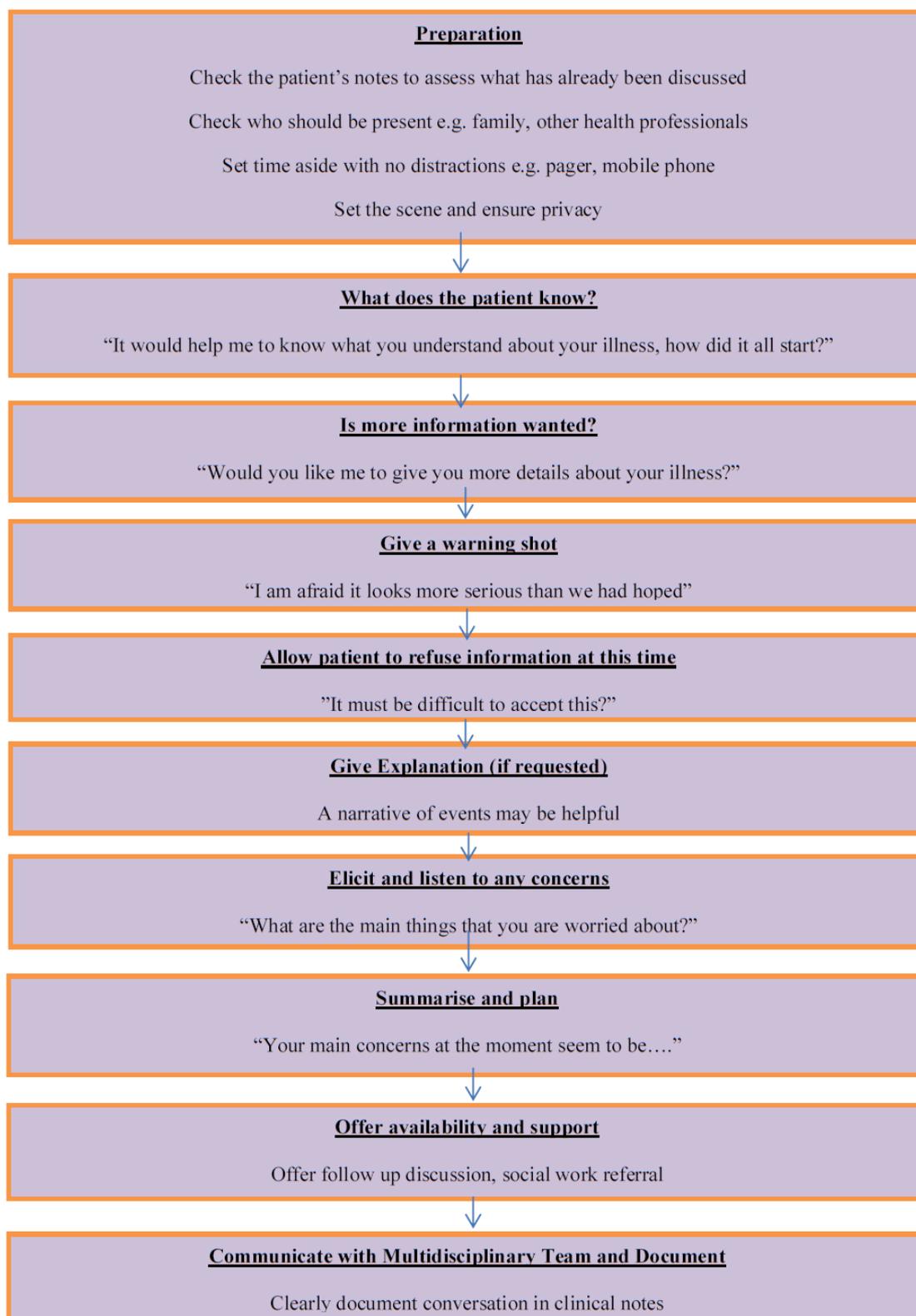
Feel free to share as much of the physical care as you want, or if you prefer, support by spending time together, sharing memories and news of family and friends.

We understand this may be all very unfamiliar to you. Please let us know if there are any questions that occur to you, no matter how insignificant you think they may be, or how busy we may seem.

We want to provide the best care we can.

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Tool R: Breaking bad news flow chart



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²¹ Source: Waitemata District Health Board End of Life Care Project Steering Group

Tool S: W.H.A.N.A.U: Personalising Care At End-Of-Life²²

This prompt card provides potential conversation starter questions to guide conversations and includes a background image of Te Whare Tapa Whā (Durie 1985) on one side, as a reminder of the need for a holistic approach to care. On the other side, information is provided to guide conversations to ensure that care for people can be personalised. The card could be laminated and provided to all staff who are involved in the care of people in their last days of life.

'W.H.Ā.N.A.U' - PERSONALISING CARE AT END-OF-LIFE

- ✓ **WHO TO ASK?** It may be better to talk with a whānau spokesperson, or with the whānau or family all together
- ✓ **HAVE** *time* and *space* to talk and *offer* thinking time
- ✓ **ASK** - don't assume what's important to you is the same for others
- ✓ **NEED** others to join these conversations? – friends, whānau
- ✓ **AGAIN** - people's needs change, so ask again
- ✓ **UNCOMFORTABLE** asking or responding to these questions?
Ask for help – colleagues, chaplains, cultural advisors

SOME USEFUL PROMPTS

What can we do now to help you and those people important to you to feel safe and comfortable?

Do you have beliefs and family traditions that are especially important to you?

What are the important things about you and your whānau that we need to know right now?

The diagram illustrates the Te Whare Tapa Whā model, which is shaped like a house. It has four main pillars or sections, each representing a different aspect of well-being: **Taha hinengaro** (Mental and emotional well-being) at the top, **Taha whānau** (Social well-being) on the right side, **Taha tinana** (Physical well-being) on the left side, and **Taha wairua** (Spiritual well-being) at the bottom. The pillars are interconnected, forming a cohesive structure.

²² Batten, Holdaway, Allan et al (2014)

Tool T: Bereavement Information and Assessment²³

Bereavement Information

This page will inform the Palliative Care Service who should receive information about the bereavement service.

Please Print Clearly	Place Patient label here	
Preferred Name:		
Date of Death:		
Place of Death:		
Nature of Illness:		
Time in NM service:		
Family/significant others present at death:		
Staff members most closely involved:		
Key family and/or significant others for follow up. Please include children where appropriate		
If there are more than two please attach another sheet.		
1.	Name:	
	Address:	
	Phone (home):	(work):
		(cell):
	Email:	
	Relationship to patient:	
	Office use only - Date bereavement letter sent:	
2.	Name:	
	Address:	
	Phone (home):	(work):
		(cell):
	Email:	
	Relationship to patient:	
	Office use only - Date bereavement letter sent:	
Comments/Info relevant to follow-up e.g. how they are coping, issues they have, children:		
Form completed by:		
<i>Please print name and designation clearly and complete the other side</i>		

²³ Source: Nurse Maude

Bereavement Risk Assessment

- Please tick the following boxes as appropriate –this information may trigger follow up from a counsellor

The patient was:	
<input type="checkbox"/> A child or adolescent	<input type="checkbox"/> The parent of young children
The illness and death:	
<input type="checkbox"/> The illness was lengthy and burdensome for the family	<input type="checkbox"/> The patient died from a stigmatised or inherited disease
<input type="checkbox"/> The death is perceived by the family to be sudden or unexpected	<input type="checkbox"/> The death was traumatic for the family
The bereaved person/family:	
<input type="checkbox"/> Is a child or adolescent	<input type="checkbox"/> Is a young spouse/partner
<input type="checkbox"/> Is an elderly spouse partner in a long marriage/relationship	<input type="checkbox"/> Shows signs of poor initial adjustment to the death
<input type="checkbox"/> Expressed dissatisfaction with their care giving role during the person's illness	<input type="checkbox"/> Is isolated after the death
<input type="checkbox"/> Lacks social support or feels unsupported	<input type="checkbox"/> Feels dissatisfied with help available during the illness
<input type="checkbox"/> Had an ambivalent or conflictual relationship with the patient	<input type="checkbox"/> Feels support is antagonistic or unsympathetic
The bereaved person/family has experienced:	
<input type="checkbox"/> Multiple losses or multiple stressful situations	<input type="checkbox"/> Mental health problems or has a family history of mental illness
<input type="checkbox"/> The death ends an unusually close partnership	
The family:	
<input type="checkbox"/> Lacks cohesion	<input type="checkbox"/> Has poor communication and/or has difficulty resolving conflict
<input type="checkbox"/> Has few adequate coping mechanisms	<input type="checkbox"/> Had high emotional distress prior to the death
In your opinion does this person/family need:	
<input type="checkbox"/> routine follow-up (letter and information)	<input type="checkbox"/> urgent follow-up by bereavement counsellor (must make a referral to counsellor – see form 1852)
<input type="checkbox"/> follow-up by bereavement counsellor (non urgent phone contact)	<input type="checkbox"/> not sure (please discuss with counsellor)
Completed by:	Date:
To be completed by Bereavement Counsellor	
<input type="checkbox"/> no follow-up required. Client advised to contact service if necessary	<input type="checkbox"/> follow-up required, enrolled with service
Completed by:	Date:

Please send completed form to:

Tool U: Spiritual Care Assessment Tool Based on FICA Approach²⁴

Background

The FICA Spiritual History Tool was developed by Dr Puchalski and a group of primary care physicians to help physicians and other healthcare professionals address spiritual issues with patients. Spiritual histories are taken as part of the regular history during an annual exam or new patient visit, but can also be taken as part of follow-up visits, as appropriate. The FICA tool serves as a guide for conversations in the clinical setting.

Suggested questions

These should be adapted to suit each person and revisited as patient circumstances change.

Faith	What things do you believe in that give meaning/value to your life? and/or: Do you consider yourself spiritual or religious? and/or: What is your faith or belief?
Importance and Influence	In what ways are they important to your life? and/or: What influences do they have on how you take care of yourself? and/or: How are your beliefs/values influencing your behaviour during your illness? and/or: In what ways do your beliefs/values help you in regaining your health/wellbeing?
Community	Is there a person or group of people who you love or who are very important to you? and/or: How is this supportive to you? and/or: Do you belong to a religious/cultural community?
Address	Is there anything we can do to help you while you are with us? and/or: Would it help to talk to someone about these issues?

An example of a spiritual assessment in a non-religious person

- F Naturalist
- I Feels at one with nature. Each morning she sits on her patio looking out over the trees in the woods and feels ‘centered and with purpose’
- C Close friends who share her values
- A After discussion about belief, she will try to meditate, focusing on nature, on a daily basis to increase her peacefulness

You can refer to the Chaplaincy Department at any time, but some specific situations may include:

- When one’s own belief system prohibits involvement in the spiritual/religious/cultural care of the patient

²⁴ Pulchaski and Larson (1998)

- When spiritual or religious/cultural issues seem particularly significant in the patient's suffering
- When spiritual or religious/cultural beliefs or values seem to be particularly helpful or supportive for the patient
- When spiritual or religious/cultural beliefs or values seem to be particularly unhelpful for the patient
- When addressing the spiritual or religious/cultural needs of a patient exceeds your comfort level
- When specific community spiritual or religious/cultural resources are needed
- When you suspect spiritual or religious/cultural issues which the patient denies
- When the patient or family have specific religious needs e.g. Confession, Holy Communion, Sacrament of the Sick, needs a prayer mat or private space to pray, sacred texts, etc
- When the patient's family seem to be experiencing spiritual/emotional pain or trauma
- When members of staff seem to be in need of support.

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Glossary of Terms

Advance Directive: Instructions that consent to, or refuse, specified medical treatment or procedure in the future.

Advance directives are defined in the Code of Health and Disability Services Consumers' Rights (the Code) as written or oral directives in which the patient makes a choice about a possible future health care procedure and this choice is intended to be effective only when the patient is no longer competent. For this reasons, advance directives are also, though less frequently, referred to as 'living wills'.

Right 7(5) of the Code gives every consumer the legal right to use an advance directive in accordance with common law.

Advance Care Plan: An advance care plan is the desired outcome of the Advance Care Planning process. An advance care plan is an articulation of wishes, preferences, values and goals relevant to all current and future care. It is not intended to be used only to direct future medical treatments and procedures when the person loses capacity to make their own decisions (becomes incompetent).

An advance care plan may itself be regarded as an advance directive and should be consistent with, and considered in conjunction with any advance directive that exists.

Advance Care Planning (ACP): Advance Care Planning (ACP) is a process of discussion and shared planning for future health care. It is focused on the individual and involves both the person and the health care professionals responsible for their care. It may also involve the person's family/whānau and/or carers if that is the person's wish. ACP provides individuals with the opportunity to develop and express their preferences for care informed not only by their personal beliefs and values but also by an understanding of their current and anticipated future health status and the treatment and care options available.

Care Pathway: A care pathway is a complex intervention for the mutual decision making and organisation of care processes for a well-defined group of patients during a well-defined period. Defining characteristics of care pathways include:

- i. An explicit statement of the goals and key elements of care based on evidence, best practice and patients' expectations and their characteristics
- ii. The facilitation of the communication among team members and with patients and families
- iii. The coordination of the care process by coordinating the roles and sequencing the activities of the multidisciplinary care team, patients and their relatives
- iv. The documentation, monitoring, and evaluation of variances and outcomes
- v. The identification of the appropriate resource. The aim of a care pathway is to enhance the quality of care across the continuum by improving risk adjusted patient outcomes, promoting patient safety, increasing patient satisfaction, and optimising the use of resources.

Death: The cessation of all vital functions of the body, including the heartbeat, breathing and brain activity (including the brain stem).

Dying: A person is considered to be dying when they are in the process of passing from life to death. It is characterised by a gradual failing of vital functions including

the cardiac, respiratory and central nervous systems, followed by an absence of criteria that define life (spontaneous heartbeat, breathing and brain function). The dying phase is generally considered to be minutes to hours in duration, but can occasionally be just seconds.

End of Life: The end of life phase begins when a judgement is made that death is imminent. It may be the judgement of the health/social care professional or team responsible for the care of the patient, but it is often the patient or family who first recognises its beginning.

End of Life Care: End-of-life care is the provision of supportive and palliative care in response to the assessed needs of the patient and family/whānau during the end of life phase. It focuses on preparing for an anticipated death and managing the end stage of a life-limiting or life-threatening condition. This includes care during and around the time of death, and immediately afterwards. It enables the supportive and palliative care needs of both the person and the family/whānau to be identified and met throughout the last phase of life and into bereavement. It includes management of pain and other symptoms and provision of psychological, social, spiritual, and practical support and support for the family.

Last Days of Life: The last days of life identifies the period when a person is actively dying. It is the period of time when death is imminent and may be measured in hours or days.

Life-Limiting Condition: A life-limiting condition is one for which there is no reasonable hope of cure and from which the person will die. Some of these conditions cause progressive deterioration rendering the person increasingly dependent on family and carers.

Liverpool Care Pathway (LCP): The LCP is an evidence-based, integrated care pathway that was developed to transfer the hospice model of care into other care settings. The LCP guides health care professionals to deliver best practice care to dying patients and their families/whānau in the last days and hours of life, irrespective of diagnosis or care setting.

Te Ara Whakapiri: The path of closeness and unity.

Whānau: Whānau means the extended family, family group, a familiar term of address to a number of people – in the modern context the term is sometimes used to include friends who may not have had any kinship ties to other members.