

Primary Palliative Care Guidelines

3rd Edition 2020



hospices of northland

DISCLAIMER & ACKNOWLEDGEMENTS

At the time of writing, these guidelines are indicative of primary palliative care practice under the guidance of Northland Palliative Care Medical Specialist Dr Warrick Jones and Clinical Resource Nurse Walter Nasarek. Much of the information contained within these guidelines is based on "The Palliative Care Handbook" (McLeod, Macfarlane 2019). We acknowledge the authors for granting us permission to use this information freely when developing these guidelines.

These guidelines are provided to guide practice alongside personal clinical judgement and formulary information. Using these guidelines does not diminish practitioners from the necessity to exercise their own clinical judgement. The Hospices of Northland and their staff do not accept any responsibility for the use of these guidelines in practice and encourage collaboration in the practice of palliative care for the benefit of patients and their families.

When using parts of this publication please give full acknowledgement of the source (Primary Palliative Care Guidelines – Hospices of Northland) and supply North Haven Hospice with a copy. Information regarding medication can be found in the normal formulary sources. Some medications are used for indications, by routes or in doses that are not approved by New Zealand licensing. This is common practice and validated internationally. For further information: **'Use of Unapproved Medicines and Unapproved Use of Medicines'**. (http://medsafe.govt.nz/profs/RISS/unapp.asp)

Please note: This is a controlled document. The electronic version of this document is available online at <u>www.northhavenhospice.org.nz</u>.

The online document is the most up-to-date and in the case of conflict the electronic version prevails over any printed version.

In the electronic version the <u>Table of Contents</u> and other parts of the Guidelines have automatic hyperlinks embedded. The reader can click on the hyperlinks and will be taken to the other sections in the guidelines or to Internet sites for additional information.

Primary Palliative Care Guidelines

3rd Edition 2020

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Foreword to the Third Edition

Provision of Palliative Care is an integral part of health services. Primary Health Providers are key members of a patient's care team and as such are often the first point of contact for them. It is vital therefore that Primary providers have access to resources to assist them provide best practice assessment, care and support, so as to ensure patients and their whānau are able to "Live while they are dying".

This is now the second edition of the Primary (formerly Generalist) Palliative Care Guidelines for Northland. Our vision was to have up-to-date information readily available and easily understood. Knowledge should be shared rather than held by those in a specific speciality/discipline.

We wish to acknowledge our colleagues in both primary and specialist areas for their insightful feedback. We trust that the breadth of advice given in this document reflects this combined thought. There have been alterations to dose ranges to incorporate this broader spectrum of practice. Included also are additional guidelines on Referral Criteria, Advance Care Planning, Management at End of Life and Opioid Conversion.

We have endeavoured to maintain the validity of the information contained by benchmarking it against the latest Palliative Care Formulary. As we have used resources that have been freely distributed to us, we wish to extend an open hand to others using what we have put together. We would ask that if this document is altered or used in organisations outside of Northland, that you acknowledge the source of this information.

Hospice has been a part of health care within Northland for over 25 years. The growth and development of the hospice services Northland wide has expanded considerably. The utilisation of these services has increased with this development and hospice care is a more accepted service now than 25 years ago. Cancer is no longer the only diagnosis referred to hospices. Today hospices are caring for more people (of all ages) with life-limiting illnesses such as end stage organ failure (heart, kidney, lung), neurological disorders, accident victims etc., as well as those who have a malignant diagnosis.

Again, we would like to acknowledge the thorough and professional work of our Regional Nurse Educator/Advisor and our Resource Nurse in their reviewing and extension of these guidelines.

These guidelines are a work in progress and will be reviewed regularly to ensure supporting evidence is current. We welcome your feedback so that this can be incorporated into the next review.

I trust you will find these guidelines of great help to you as you journey with families as they seek to LIVE Every Moment while on the last journey of life.

He aha te mea nui o te ao? Maku a ki atu. He tangata He tangata He tangata

If you should ask me, what is the greatest thing in this world? I would answer, it is people, it is people, it is people.

(Anonymous, n.d.)

Leonie Gallaher General Manager North Haven Hospice Whangarei

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Palliative Care

What is palliative care?

Palliative care is a branch of health care that attends to only those with an advanced life-limiting illness. A life-limiting illness is one that has no cure. The focus of this area of care is the patient's and their family/whānau's total care i.e. physical/tinana, social/whānaungatanga, emotional/hinengaro, and spiritual/ wairua wellbeing. Care is specific to each person and focuses on helping them to live the best that they can for as long as they are able. This care can be provided in home or in another place such as a hospice, hospital or long term residential facility. Specialist palliative care is provided by a skilled team of health professionals who have undergone specific training and/or accreditation in palliative care. In Northland these are the four Hospices of Northland and the Hospital Palliative Care Liaison Team (based at Whangarei Hospital).

The care that Hospices provide is **free to patients**. All Northland hospices have a contract with the Northland District Health Board to provide palliative services to the residents in Northland. This contract only covers about 60% of the cost of providing this service. The rest is funded by donations, grants, fundraising and bequests.

What is the difference between specialist & primary palliative care?

Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand defined two separate levels for the provision of palliative care. These are:

Primary palliative care

Care provided by all individuals and organisations that deliver palliative care as a component of their service, but whose substantive work is not the care of people who are dying. It is palliative care provided for those affected by a life-limiting or life-threatening condition as an integral part of standard clinical practice by any health care professional who is not part of a specialist palliative care team.

In the context of end-of-life care, a primary palliative care provider is the principal medical, nursing or allied health professional who undertakes an ongoing role in the care of patients with a life-limiting or life-threatening condition. A primary palliative care provider may have a broad health focus or be specialised in a particular field of medicine. This care is provided in the community by general practice teams, Māori health providers, allied health teams, district nurses and residential care staff, etc. It is provided in hospitals by general ward staff, as well as disease-specific teams (eg, oncology, respiratory, renal and cardiac teams).

Primary palliative care providers assess and refer patients to specialist palliative care services when the patient's needs exceed their services capability.

Quality care at the end of life is realised when strong networks exist between specialist palliative care providers, primary palliative care providers, support care providers and the community – working together to meet the needs of all people.

Specialist palliative care

Palliative care provided by health professionals who have undergone specific training and/or accreditation in palliative care/medicine, working in the context of an expert interdisciplinary team of palliative care health professionals. Specialist palliative care may

be provided by hospice- or hospital-based palliative care services where patients have access to at least medical and nursing palliative care specialists.

Specialist palliative care will be provided through accredited services (or organisations) that work exclusively in palliative care and meet specific palliative care standards as they are developed nationally. Specialist palliative care practice builds on the palliative care provided by primary palliative care providers and reflects a higher level of expertise in complex symptom management, psychosocial support, grief and bereavement. Specialist palliative care provision works in two ways.

1. Directly – to provide direct management and support of patients, their families and whānau, where more complex palliative care need exceeds the resources of the primary palliative care provider. Specialist palliative care involvement with any patient and the family/whānau can be continuous or episodic depending on changing need. Complex need in this context is defined as a level of need that exceeds the resources of the primary palliative care team. This may be in any of the domains of care – physical, psychological, spiritual, etc.

2. Indirectly – to provide advice, support, education and training of other health professionals and volunteers to support the provision of primary palliative care.

Ministry of Health, 2012

What services do Hospices offer?

Hospice prides itself on the range of services that it offers. These include:

- Community care, which includes a palliative care liaison team based at Whangarei Hospital
- Inpatient care for respite (booked or acute), intensive symptom management and end of life care
- Shared care with other health professionals
- Counselling
- Social work
- Volunteer services
- Bereavement support
- Family/whānau support
- Chaplaincy support
- An extensive pool of equipment for homecare
- 24 hour telephone advice support
- Education for those providing palliative care in a primary health care setting
 - Syringe Driver Competency Training
 - Care Assistant Training
 - Fundamentals of Palliative Care (Hospice New Zealand)
 - Undergraduate Nursing Training and clinical placements
 - 5th year medical student training and clinical placements
 - One-off training for identified learning within an organisation

For more information on the Educational activities visit the North Haven Hospice website <u>www.northhavenhospice.org.nz</u> or if the Mid North https://www.hospicemn.org.nz/

Referrals to Specialist Support When is referral appropriate?

Specialist Palliative Care support for those with a diagnosis of an advanced/ progressive life-limiting illness may be required when:

- Symptoms relating to their illness are not able to be managed effectively
- The patient and their family/whānau require more intensive care of their holistic issues related to the illness – these could be spiritual, psychosocial, psychological
- Respite care is required to maintain care at home
- Occasionally in-patient care is required for the final stages of their disease
- Staff members require support to care effectively for those in their care.

How do I make a referral for palliative care support?

In Northland there are four Hospice services providing specialist palliative care based in Whangarei, Kaipara, Kerikeri and Kaitaia. In general, Hospice service is available to anyone with an illness for which there is no cure, is getting worse and is going to result in death. People can refer themselves, or a friend, family/whānau member, doctor or nurse may refer them to the service.

People have to be agreeable to having Hospice involved. Hospice staff always check that what is offered is acceptable and wanted. If you are not sure if referral is appropriate or what your local Hospice is able to offer, please contact them directly for further advice.

See <u>Appendix Six for Referral Guidelines</u> (page 67)

www.northhavenhospice.org.nz		
North Haven Hospice admin@northhavenhospice.c	09 437 3355 org.nz	
Hospice Kaipara manager@hospicekaipara.or	0800 395 467	
Hospice Mid Northland <u>clinicalmanager@hospicemr</u>	09 407 7799 n.org.nz	
Far North Community Hospice admin@fnpacc.org.nz	09 408 0092	
Whangarei Hospital Palliative Care Liaison Team	09 430 4100 – ask the operator to transfer you to the Palliative Care Liaison Team	

At the time of referral it is helpful to include copies of important letters and copies of test results as well as discharge summaries from recent hospital admissions. This will help the hospice gain a clearer more in-depth picture of the current situation.

Referrals can be made to all Northland Hospices by phone, or preferably by using the electronic referral form on Care Select (via Medtech and Concerto) or on PalCare.

All of the Hospices of Northland document their patient notes on PalCare (a webbased patient management system) and, if you wish, you can be provided access to these notes to assist you in the patients' on-going care.

Hospice New Zealand Standards for Palliative Care

The vision of Hospice New Zealand is that everyone with a life-limiting condition, their family and whānau, have access to the best possible palliative care. Our Standards address and reflect changes within palliative care and hospice and focus on the future. They support hospices to develop their services and maintain a continuous quality improvement approach to their service planning process.



Moku ano enei rā, mo te rā ka hekeheke; he rākau ka hinga ki te mano wai!

Let these few days be for me, for the declining sun; a tree falling through many floods of waters

Whilst these standards have been written for hospices in the first instance, our long-term vision is that the other providers of palliative care across many settings will adopt, or use, the Standards to enhance and support their care and services.

Standard I — Assessment of needs

Initial and ongoing assessments are comprehensive and person-centred, and incorporate the person's physical, psychological, cultural, social and spiritual experiences, needs, preferences and priorities.

Standard 2 — Developing the care plan

The team works in partnership with the person, their family, whānau and carers, to communicate, plan, set goals and make informed decisions about their care plan.

Standard 3 — Providing the care

Care provided is empathetic, informed by evidence, and aligned with the person's values, culture, goals and preferences as documented in their care plan.

Standard 4 — Supporting and caring for the family, whānau and carers

The person's family, whānau and carers' needs and preferences are assessed and they are provided with appropriate support, guidance and resources.

Standard 5 — Transitions within and between services

Palliative care is accessible to all people who need it and it is integrated and coordinated across the person's experience to ensure seamless transition within and between services.

Standard 6 — Grief support and bereavement care

The person at the centre of care, and their family, whānau and carers, have access to grief support and bereavement care services and they are provided with information about loss, grief and bereavement.

Standard 7 — Culture of the organisation

The Hospice service has a philosophy, values, culture structure and environment that supports the delivery of personcentred palliative and end-of-life care.

Standard 8 — Quality improvement and research

Hospice services are engaged in quality improvement and research to improve service provision and the development of palliative and end-of-life care.

Standard 9 — Staff qualifications and training

Staff and volunteers are skilled, competent, qualified, and engaged in continuing professional development appropriate to their role and the capability of the Hospice service.

For more information on the Standards please contact Hospice NZ www.hospice.org.nz

Advance Care Planning

Advance Care Planning (ACP) is the process of thinking about, talking and planning for the future health care and the end of life care. This makes it much easier for families and healthcare providers to know what the person would want particularly if they can no longer speak for themselves.

(https://www.hqsc.govt.nz/our-programmes/advance-care-planning/)

Advance Care Planning is more than one conversation. If started early (even before a diagnosis of a life-limiting illness is made) decisions are natural and an integrated part of a patients care. Decisions around care at the end of life are able to be discussed openly and honestly without the burden of emotion so that care can be planned proactively.

Care Conversations

Considerations could be given to the following conversation topics:

- Legal requirements e.g. wills, enduring powers of attorney (EPOA), guardianship for young children, financial affairs, organ donation
- Choice for nutrition food, fluids, intravenous supplements, nasogastric or PEG tube feeding
- **CPR** full CPR or just compression or just mouth to mouth or just defibrillation •
- Medical interventions e.g. antibiotics; diagnostic tests e.g. blood tests, xrays/CAT scan, MRI scan, use of intravenous access/hydration e.a. Central lines, Portacaths; hospitalisation, ventilation/life support, surgery, chemotherapy
- End of life care what is important to them where they wish to die, with whom around – what don't they want - what denotes quality of life to the patient/their family/whānau
- Allowing natural death (AND) this is a way of looking at the dying process • as a natural part of life and allowing it to occur in such a way that maximises dignity and comfort above life-preserving or prolonging measures and care interventions. Allowing a natural death does not stop the use of medications to ease discomfort and distress
- **Funeral requirements** planning with the person present to discuss things • such as clothing to be worn, casket choice, venue choice, order of service, readings, hymns/music to be played, people who they would like to speak at their funeral, photos to be used etc.

Documenting Care Decisions

When conversations have been held and options discussed or choices made, it is important that these are documented accurately either in the patient notes or in their own Advance Care Plan. An Advance Care Plan is a document which clearly outlines choices and requests for care which helps enduring powers of attorneys and health carers to advocate for patient choices. Patients should be encouraged to record an electronic version of their ACP via Whānau Tahi so that it can be viewed by all health providers (both primary and secondary sector).

For more information go to the Advance Care Planning website: https://www.hasc.govt.nz/our-programmes/advance-care-planning/

Primary Palliative Care Guidelines

Managing symptoms for those with life-threatening conditions requires thorough assessment, appropriate intervention and attention to detail. Many physical symptoms that arise during this period have underlying holistic roots so listening to the "words behind the words" is important.

Anticipatory care and prescribing is fundamental to seamless care with minimal crisis incidents. Empowering patients and family/whānau members and other team members to know what to do in the "what if" scenarios ensures the patient can remain where they wish to be and are able to do so by managing their care in partnership with the professionals.

The following guidelines are written as an overview of how to manage the more common issues that occur within primary palliative care. They are not prescriptive and it is acknowledged that there are many guidelines within palliative care that may differ from these ones. These are for Northland and have been adapted to suit what is accepted practice in Northland under the guidance of Dr Warrick Jones, Northland Palliative Medicine Specialist and the Hospices of Northland Specialist Teams.

It is difficult to prioritise issues and therefore these have been placed within the holistic quadrant that they fall in and then alphabetical ordered for ease of access and to place equal importance on all issues.

It is acknowledged that there are many more issues (other than what is represented here) for those who are dying and those who are caring for them. For assistance with any areas of palliative care, please seek the specialist advice of your local specialist palliative care team. <u>Hospices of Northland Contacts</u> (page 9).

These guidelines are formatted in the following way for ease of use:

- Definition of symptom (if not obvious)
- Symptoms
- Possible Causes
- Holistic considerations of symptom
- How to treat reversible causes
- How to palliative symptoms
- How to treat symptoms in pharmacological way

In addition a colour code has been added as a page border:

- Common conditions
- Emergencies
- End of Life Care

In Palliative Care the following assessment tools are regularly used to assess symptoms and the functional status of patients Appendix Five (page 63):

- <u>AKPS</u> (Australia-modified Karnofsky Performance Scale)
- IPOS (Integrated Palliative Outcome Scale)
- <u>SES</u> (Social / Emotional / Spiritual Assessment)

Useful questions to ask yourself or the patient during assessments

- Would you be surprised if this patient dies within the next 12 months or on this admission to hospital?
- What is important for me to know how to care for you in the best possible way?
- If I could change one thing for you today what would that be?
- Tell me how it is for you right now and how I can help.
- What do you need right now to make a difference?

Managing Pain

Guidelines for the General Management of Pain

What is pain?

Pain is subjective and is essentially what someone says it is, where it is and how it is. It is described as an unpleasant sensory and emotional experience associated with actual or potential tissue damage (International Association for the Study of Pain, 1994).

Pain assessment

Pain can be the result of many different factors. A thorough assessment of the patient will help to elicit areas other than those that are physical that may have some relevance to their pain. Remember that the pain that you see may be the "tip of the iceberg".

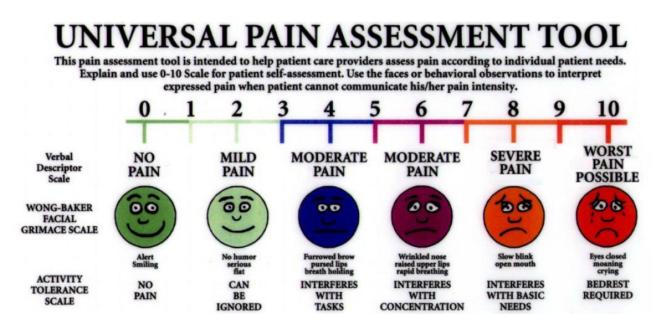
Consider the following assessing their pain using the **PQRSTU format**:

Ρ	Palliative factors Provoking factors	"What makes it better?" "What makes it worse?"
Q	Quality	"What is your pain like? Give me some words that tell me about it."
R	Radiation	"Does the pain go anywhere else?"
S	Severity	"How severe is it?" Measured on numbered scale
т	Time	"Is it there all the time?" "Does it come and go?"
U	Understanding	"What does this symptom mean to/for you?" "How does this symptom affect your daily life?" "What do you believe is causing this pain?" Does their pain have meaning?

Visual Analogue Scale

Using a simple face scale (using 1-10) as a guide can help to guide where a person sees their pain.

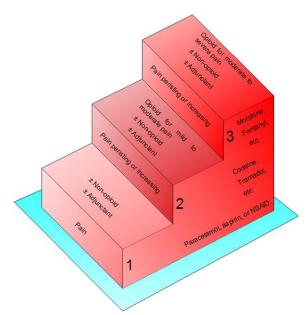
Example of a Visual Analogue Scale



http://www.nes.scot.nhs.uk/media/660731/painassessmenttoolfacesscaletool.pdf

Using the Analgesic Ladder as a guide

The WHO's analgesic ladder is a systematic way of managing increasing or uncontrolled pain. The three steps are as follows:



<u>Step 3</u> – strong opioids – e.g. Morphine, Methadone, Oxycodone, Fentanyl

<u>Step 2</u> – weak opioids – e.g. Codeine, Dihydrocodeine, Tramadol

<u>Step 1</u> – non-opioids e.g. Paracetamol

Types of Pain

<u>Somatic pain:</u> "arises from bone, muscle, ligament, subcutaneous tissue, or skin. It is often experienced as sharp or dull and is typically well localized by the patient. Bonica's Management of Pain Fourth Edition (2009)

<u>Visceral pain:</u> "arises from organs such as lung, liver, or bowel and is broadly understood to arise from tissue that is embryologically mesodermal in origin. It is characteristically described as dull and achy and is usually poorly localized; typically the patient will use their entire hand to describe the location of the pain. Visceral pain is often also referred to distant sites, such as liver pain being experienced in the ipsilateral shoulder." Bonica's Management of Pain Fourth Edition (2009)

Neuropathic pain: "is generally described as dull, achy, itchy, or burning. The skin can be sensitive to light touch ("allodynia") and there may be brief stabbing episodes of neuralgic pain. The burning may be superficial as in the experience of scalded skin or can be deep, as if there is a feeling of having been burned deep inside. The spontaneous use of the word "burning" by the patient predicts the presence of neuropathic pain." Bonica's Management of Pain Fourth Edition (2009)

<u>Mixed pain:</u> "is the clinical situation where there is both nociceptive (i.e., somatic and/or visceral) and neuropathic pain. A common example is chest wall pain from lung cancer; there may be poorly localized deep ache consistent with visceral (pleural) pain, sharp and well-localized somatic pain from contiguous rib invasion, and burning numbness of the overlying skin due to invasion of intercostal nerves."

Bonica's Management of Pain Fourth Edition (2009)

Breakthrough/Incident pain: "is transient increase in pain to greater than moderate intensity superimposed on an otherwise stable pattern or level of pain of mild to moderate intensity. Breakthrough pain includes (1) incident pain that may arise from some activity or physical function (e.g., coughing, standing up), (2) pain that routinely increases as the duration of analgesic medication in reaching its limit (end-of-dose failure), and (3) spontaneous exacerbation of a stable level of pain for nonspecific reasons."

Bonica's Management of Pain Fourth Edition (2009)

Consider the use of co-analgesics for the management of different types of pain:

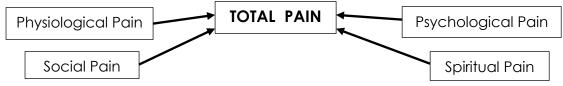
- Bone Pain NSAIDs, Bisphosphonates
- Skeletal Muscle Spasm pain Diazepam, Clonazepam, Baclofen
- Smooth Muscle Spasm pain Hyoscine Butylbromide
- Tenesmus Dexamethasone, Prednisone
- Raised Intracranial pressure Dexamethasone, NSAIDs
- Liver Capsule Stretch pain Dexamethasone

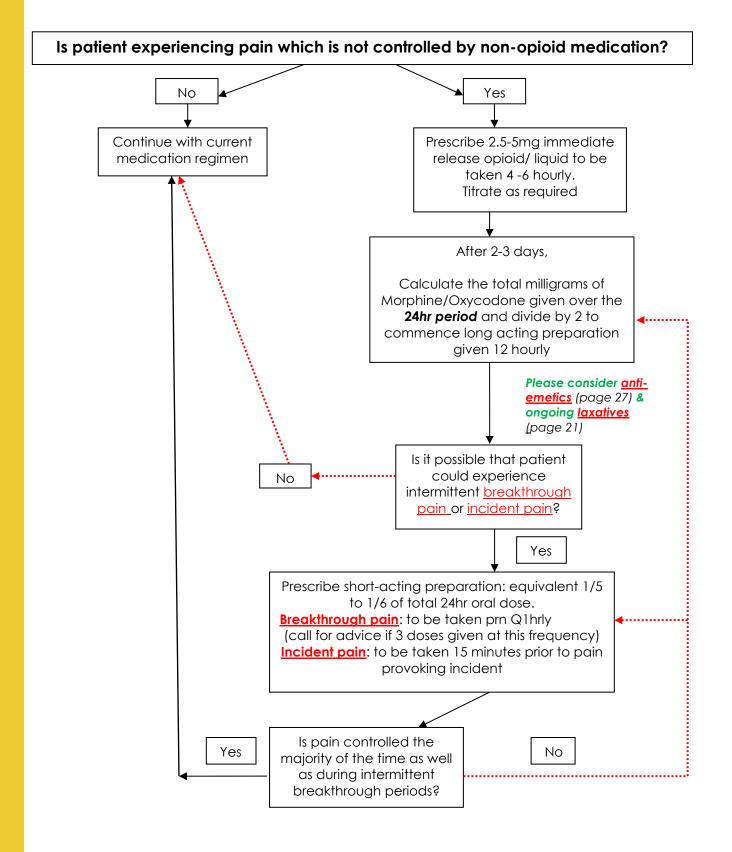
(McLeod, Vella-Brincat, MacLeod, 2012,, p 12)

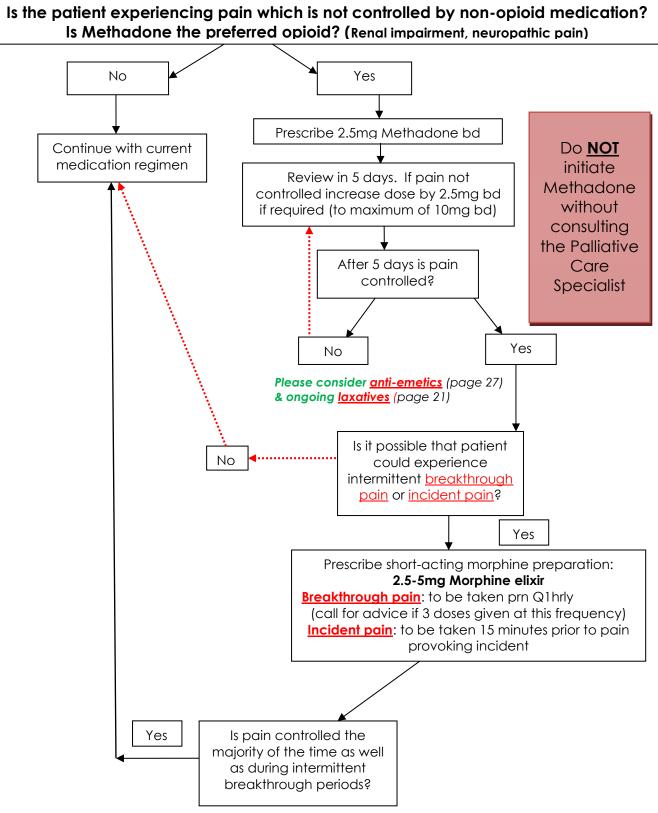
KEEP IN MIND THAT PAIN IS NOT ALWAYS PHYSICAL

Psychological pain is any mental, or mind, or non-physical suffering. This can be from causes related to emotions.

Consider discussing issues that could be causing emotional and spiritual distress and explore these sensitively with your patient. The skills of specially trained professionals in this field e.g. counsellors, social workers and pastoral care staff can help to reveal and support issues in these areas.



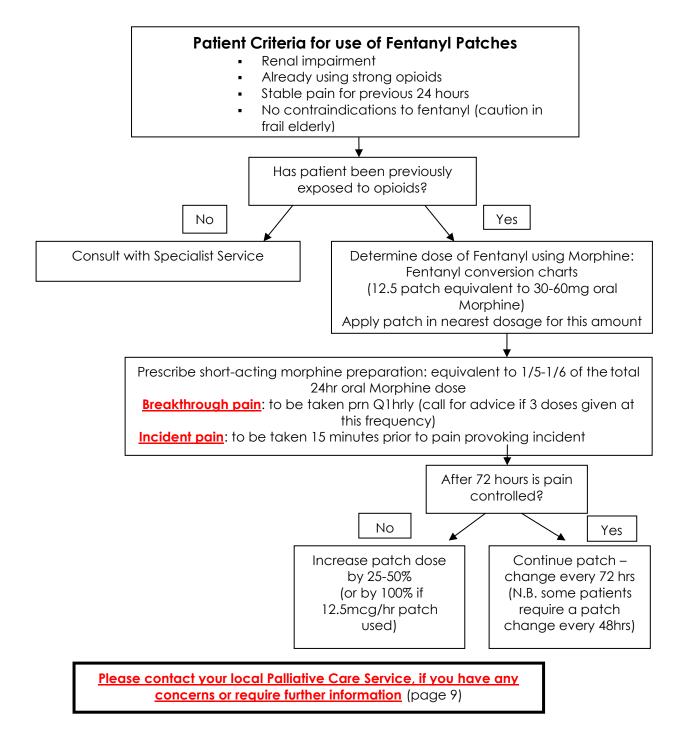




Note:

- 1. **PRN Methadone should not be used** unless under guidance of Specialist Palliative Care) (see box above for alternatives)
- 2. For doses over 10mg bd or if pain is not controlled, please consult your specialist service <u>Hospices of Northland Contacts</u> (page 9)

Management of Fentanyl Patches (for those with stable pain)



Reference: Janssen-Cilag Durogesic resource information

Managing Gastrointestinal Issues

Bowel Management – Constipation

Constipation is: irregular and infrequent (compared to what is not normal for that patient) or difficult evacuation of the bowels.

Symptoms include: Anorexia, vomiting/nausea, abdominal discomfort, diarrhoea or faecal overflow, abdominal distension, confusion, anxiety, bowel obstruction, pain.

Causes include: Hypercalcaemia, spinal cord abnormalities/injuries, drugs, dehydration, low fibre diet, immobility, intestinal obstruction, nerve compression/neuropathy, haemorrhoids, anal fissure, diabetes and hypothyroidism.

Holistic Reflection

PQRSTU assessment: Consider this framework as a tool to assess the symptom holistically. <u>See PQRSTU guidelines</u> (page 58)

Emotional Considerations: Fear regarding other issues surrounded defecation e.g. pain can impact on regularity. Is the presence of toilet equipment "outside of the usual place" causing emotional anguish?

Spiritual Considerations: Are there issues regarding ongoing defecation e.g. colostomy. Has the "routine" changed? How does this affect the person and their lifestyle?

Has the patient/family/whānau changed their language around describing themselves? i.e. has their identity changed?

Social Considerations: How does constipation affect family/whānau life? How is this affecting your relationship with your partner/friends?

Bristol Stool Chart

This chart is a good visual resource to "describe" faecal matter. This also gives a good indication of how long it has been in the bowel. (i.e.) Type 1-3 have been in the bowel longer and therefore have less water content and may be harder to pass. This knowledge influences management.

See Bristol Stool Chart Appendix Four (page62)

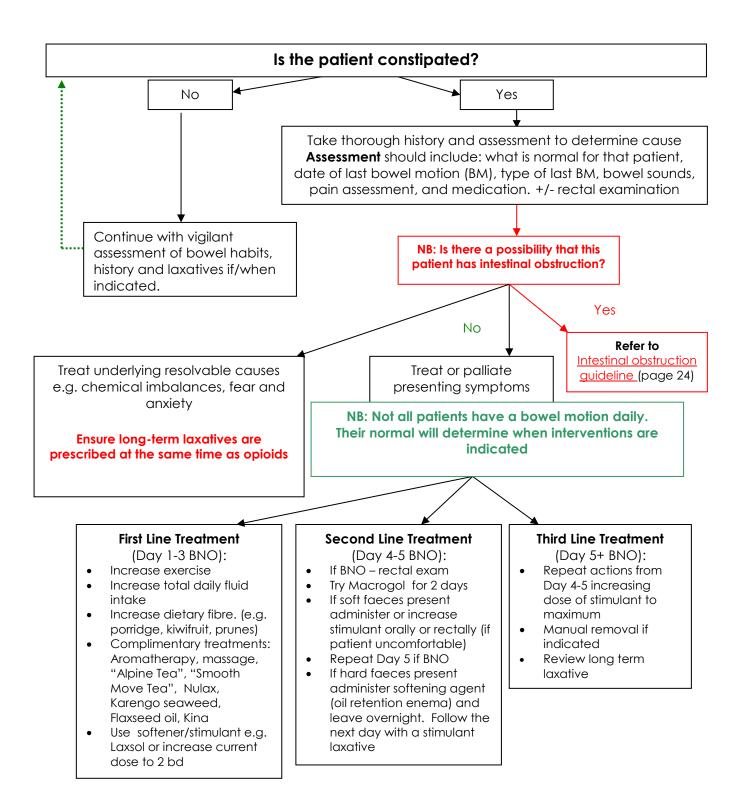
Types of Laxative and Uses

Туре	Action	Example	Prescribing and Administration Hints	
Stimulant	Stimulate the peristaltic movement	Senna (in Laxsol™)1-2 bd Bisacodyl (Dulcolax™) 5mg bd Fleet™	 Contraindicated in suspected obstruction Can increase abdominal pain If given rectally must be inserted at least 4cm into the rectum against the mucous membrane of the rectum not into the faeces – blunt end first 	
Stimulant/Softener	Stimulate the peristaltic movement	Dantron and Poloxamer (Pinorax ^{™)}	 Contraindicated in suspected obstruction Can increase abdominal pain 	
Lubricant	Lubricate the anorectum and have a stimulant effect	Glycerine suppository	 Insert into the faeces – pointed end first Avoid using lubricant with suppositories 	
Softeners	Change consistency of faeces Not the laxative of choice where peristaltic action impaired e.g. stroke, Parkinsons, impaction, bowel obstruction	Docusate Sodium (in Laxsol™) 1-2 bd	 If given rectally must be inserted at least 4cm into the rectum against the mucous membrane of the rectum not into the faeces – blunt end first 	
Osmotic Agents	Draw water into the faeces	Lactulose (Duphalac) Macrogol 3350 (Lax- Sachets™) 1-2 sachet up to qid_– similar to an osmotic as it draws water but does not affect the electrolyte balance	 At least 125mls of water needs to be taken at the time of administration 	

Manual Evacuation Guidelines

Manual evacuations are to be avoided if possible.

- Obtain prescription for relaxant
- Obtain consent and explain procedure
- Left lateral position
- Use plenty of lubricant
- Remove small amounts of faeces with one finger



Bowel Management – Diarrhoea

Diarrhoea is: an increase in the frequency of bowel motions, or increased stool liquidity.

Symptoms include: watery, loose stool, passing stools more than three times per day. Person may experience an urgency to pass faeces.

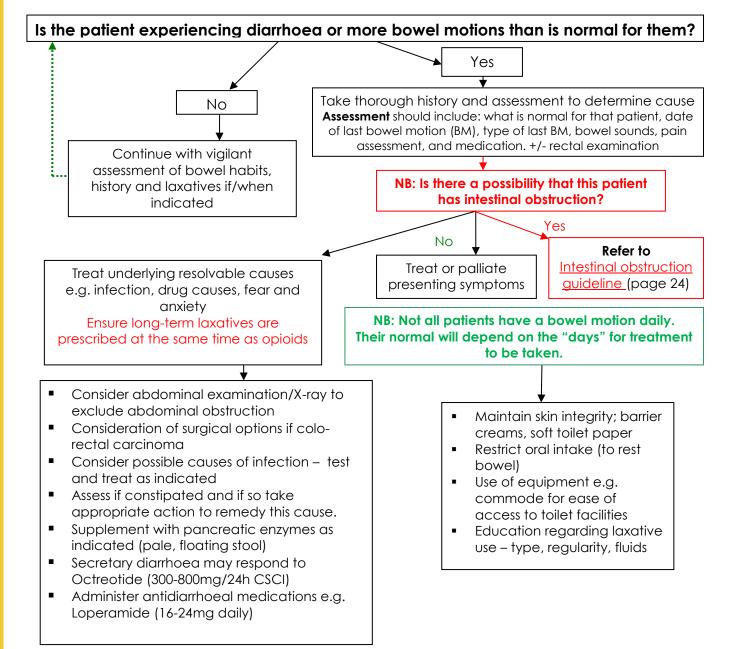
Causes: faecal impaction, carcinoma, spinal cord compression, incomplete gastrointestinal obstruction, malabsorption, food intolerance, overfeeding (e.g. PEG) concurrent disease e.g. diabetes, hyperthyroidism, inflammatory bowel disease, radiotherapy to torso, drugs, bowel surgery, fistula formation between small and large bowel, anxiety.

Holistic Reflection

Emotional Considerations: Fear regarding other issues surrounded defecation e.g. Will I make it to the toilet? Do you experience pain on defecation? Is the presence of toilet equipment "outside of the usual place" causing emotional anguish?

Spiritual Considerations: Are there issues regarding ongoing defecation e.g. colostomy. Has the "routine" changed? How does this affect the person, and their lifestyle?

Social Considerations: How does diarrhoea affect family/whānau life? How is this affecting your relationship with your partner/friends?



Bowel Management – Intestinal Obstruction

Intestinal Obstruction is: "a blockage of the forward flow of gastric and intestinal contents through the gastrointestinal tract and can occur in the large or small bowel".

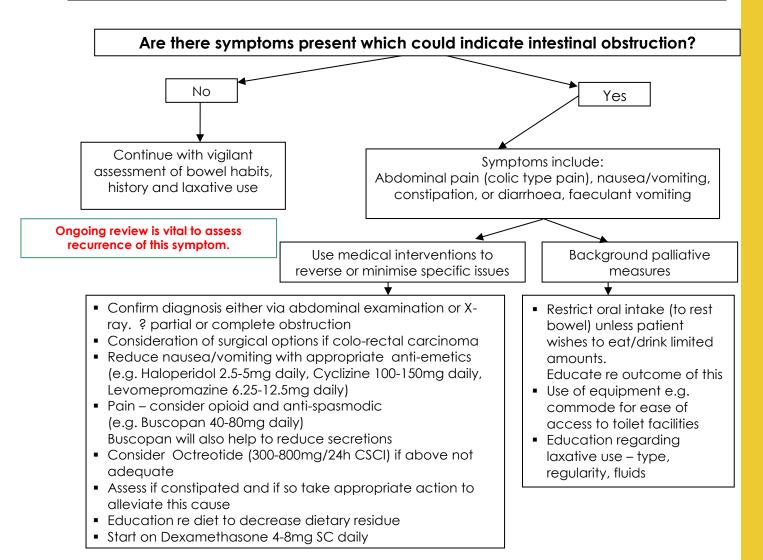
(Fraserhealth 2014)

Symptoms include: colic pain, vomiting, dehydration

Causes: Can be mechanical or paralytical; blockage of intestine by tumour or inflammation, aggravated by drugs (anticholinergics, opioids), radiation fibrosis, autonomic nerve disruption due to tumour.

Holistic Reflection

Emotional Considerations: Fear regarding what obstruction means long-term. **Spiritual Considerations**: How does this affect the person, their perception of self and their lifestyle? **Social Considerations**: How does this diagnosis impact on the remainder of life? How does diagnosis affect family/whānau life? How is this affecting your relationship with your partner/ friends?



<u>Please Note</u>: Oral medication is not always absorbed adequately. If intestinal obstruction is suspected be aware of this and use other modes of delivery for drugs e.g. subcutaneous. Please consult your specialist service for advice regarding this. <u>Hospices of Northland Contacts</u> (page 9)

Malignant Ascites

Malignant Ascites is: "free fluid in the peritoneal cavity"

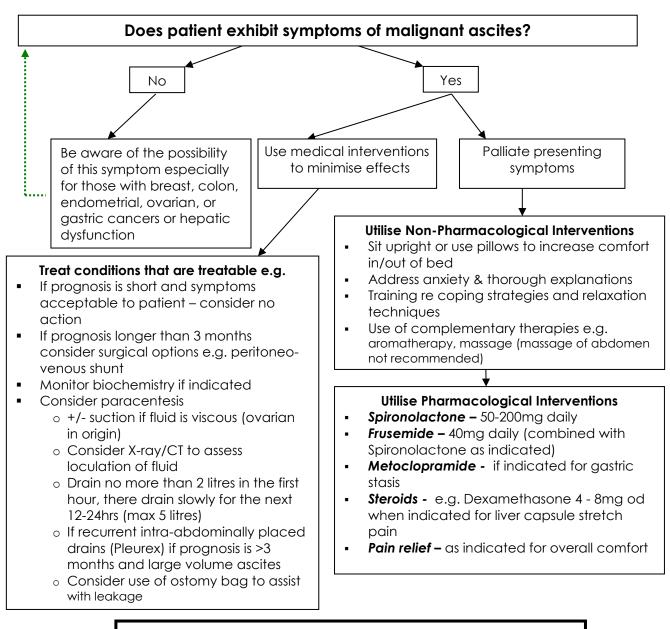
(Kane, P. 2006)

Symptoms include: breathlessness, squashed stomach →nausea/vomiting, pain/discomfort, increased abdominal size/girth

Causes: Fluid build-up can be attributed to failure of the lymph system to adequately drain, tumour in the peritoneal cavity, low serum albumin (such as in Liver Failure) or excess fluid production

Holistic Reflection

Emotional Considerations: Anxiety regarding perception of self, body image and mobility **Spiritual Considerations**: How does this affect the person, their perception of self and their lifestyle? **Social Considerations**: How does this diagnosis impact on the remainder of life?



Mouth Care

Mouth Care Management: involves the management of any abnormal condition within the oral cavity

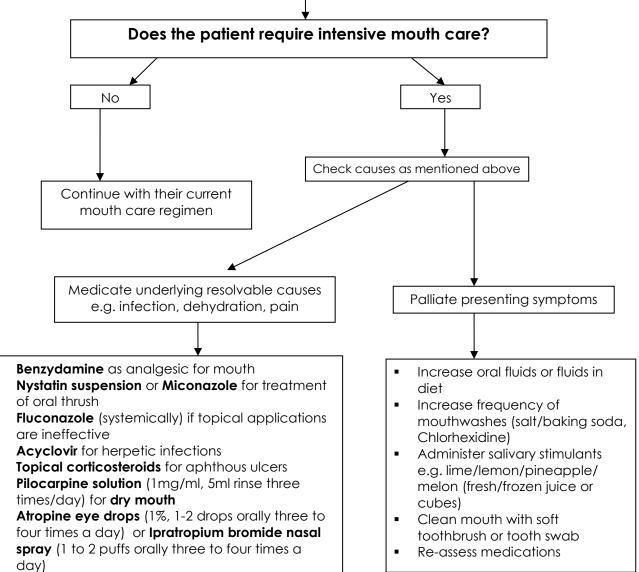
Symptoms include: sore mouth, dry mouth, ulceration of mouth, tongue, gums or lips, infection of oral cavity

Causes can include: radiotherapy, chemotherapy, infection (e.g. fungal, herpes), decreased fluid intake, decreased nutritional status, oral tumour, inability to brush/care for teeth/mouth, oxygen therapy, mouth breathing, mental-, nutritional and physical state

Holistic Reflection

Emotional Considerations: Anxiety regarding perception of self because of state of oral cavity.
Dependency issues with not being able to care for oral cares independently.
Spiritual Considerations: How does this affect the person, their perception of self and their lifestyle?
Social Considerations: How does this diagnosis impact on the remainder of their life

Using a pen torch and spatula conduct a full oral assessment with particular regard to tongue, teeth, mucous membranes, lips and type/quantity of saliva. Dentures must be removed prior to examination.



Radiotherapy for hypersalivation

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Nausea and Vomiting

Nausea is: "an unpleasant feeling of the need to vomit often accompanied by autonomic symptoms"

Vomiting is: "the forceful expulsion of gastric contents through the mouth"

Watson, Lucas and Hoy, 2006

Causes within table below

Holistic Reflection

PQRSTU assessment: Consider this framework as a tool to assess the symptom holistically. <u>See PQRSTU guidelines (page 58)</u>

Emotional Considerations: Fear and anxiety can be both cause and consequence.

Spiritual Considerations: Cultural considerations e.g. Maori/Asian/Pacific peoples.

How does this affect the person, their self identity and their lifestyle?

Social Considerations: How is not eating affecting family/whānau life? How is this affecting your relationship with your partner/friends?

Is there pressure from other people for you to eat? Does the smell of cooking/food around you cause you to feel sick?

	What is the cause of the Nausea/Vomiting?				
	Higher Vomiting Centre – Cerebral Cortex	Vomiting Centre Stimulation	Vagal and Sympathetic Afferent stimulation	Chemo-receptor Trigger Zone Stimulation	Vestibular Nerve Stimulation
Causes	 Sights, smells, memories Emotion Anxiety & fear 	 Primary or metastatic tumour Radiotherapy to head Raised intracranial pressure 	eating, gastric stasis, hepatomegaly • Cough • Bronchial secretions • Obstruction – high, mid, low, constipation • Chemical Irritants – blood, drugs	 Toxic – cancer, infection, radiation Drugs – Chemotherapy, Opioids, Digoxin etc Biochemical – Uremia, Hypercalcaemia 	 Opioids Cerebellar Tumour
Possible Solutions	 Relaxation Benzodiazepines Midazolam – 2.5mg SC/SL prn or Clonazepam 1 - 2 drops S/L prn 	Cyclizine 50mg O/SC 8hrly prn Review after 24hrs If more than 2 doses given consider use of Syringe Driver of 100 - 150mg Cyclizine SC over 24hrs Review after 24hrs If not effective use combination of Cyclizine/Haloperidol OR Change to Levomepromazine 5 - 12.5 mg SC over 24 hours	If bowel obstruction suspected ring Specialist Team for advise If not: Regular 6hrly Metoclopramide 10mg orally If more than 2 doses given consider use of Syringe Driver at 30 - 60mg Metoclopramide over 24hrs	OR SC 1.5mg prn Review after 24 hrs If more than 2 doses given consider use of Syringe Driver of 5 - 7.5mg Haloperidol SC over 24hrs Review after 24 hrs If not effective use combination of Cyclizine/Haloperidol OR Change to Levomepromazine 5 - 12.5 mg SC over 24 hours	Haloperidol Oral 1 - 2.5mg OR SC 1.5mg prn (limit to 3 doses) Review after 24 hrs If more than 2 doses given consider use of Syringe Driver 5 - 7.5mg Haloperidol SC over 24hrs Haloperidol SC over 24 hrs If not effective use combination of Cyclizine/ Haloperidol OR Change to Levomepromazine 5 - 12.5 mg SC over 24 hours
	If these doses are exceeded please consult your specialist service for advice regarding further options <u>Hospices of Northland Contacts</u> (page 9).				

Managing Respiratory Issues

Breathlessness (Dyspnoea)

Breathlessness or Dyspnoea is: a state or sensation of being breathless or out of breath.

Symptoms include: inability to catch breath, gasping, short breaths, shallow breathing. In addition cough, hiccup and pleural pain are common in people who have breathlessness.

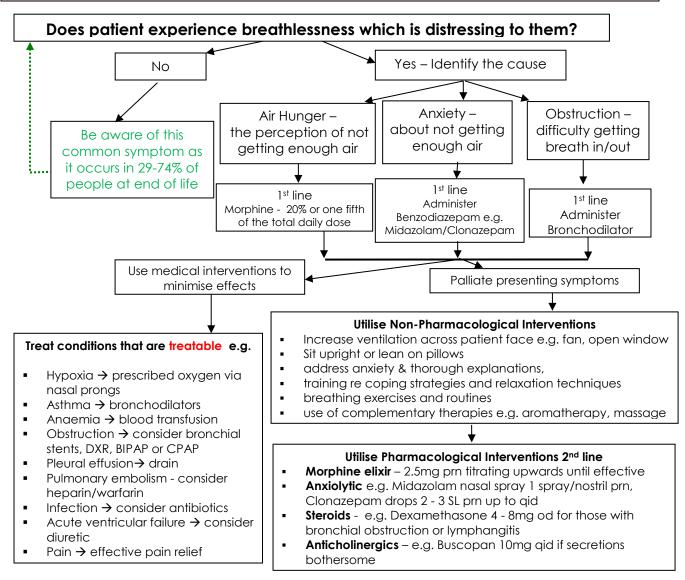
Causes include: Obstruction of airways, decreased lung volume (e.g. from effusions, infections, chronic conditions, lung collapse), increase lung stiffness (e.g. from pulmonary oedema, lymphangitis, carcinomatosis, pulmonary fibrosis, mesothelioma), decreased gas exchange (e.g. from pulmonary thrombus, tumour effect on pulmonary circulation), pain (pleurisy, infiltration of chest wall, rib or vertebral fractures), neuromuscular failure (e.g. paraplegia, motor neurone disease, phrenic nerve palsy, cachexia, paraneoplastic syndrome), congestive heart failure, ascites/pleural effusion, anxiety, anaemia, metabolic acidosis.

Holistic Reflection

Emotional Considerations: How does it feel to be out of breath all the time? How is your distress perceived by those around you?

Spiritual Considerations: What does being breathless mean to you? How does this affect the person, their perception of self and their lifestyle?

Social Considerations: How does being breathless affect your lifestyle and the lifestyle of those around you?



Cough

Cough is: a forceful exhalation of air to clear the airways as a means of defense to protect the airways

Symptoms include: constant exhalation of air

Causes include: see chart below

Holistic Reflection

Emotional Considerations: How does it feel to cough all the time? How does this affect your sleep and your overall wellness?

Spiritual Considerations: What does coughing mean to you? How does this affect the person, their perception of self and their lifestyle?

Social Considerations: How does constantly coughing affect your lifestyle? And the lifestyle of those around you?

Cause	First Line Treatment
Acute Respiratory Infection	Physiotherapy
	 Nebulised saline
	Antibiotics
Airways Disease	 Physiotherapy
	Bronchodilator
	 Inhaled corticosteroids
	Systemic corticosteroids
Malignant Obstruction/Tumour	As above
	 Nebulised local anaesthetic
Oesophageal reflux	Positioning
	Proton pump inhibitors e.g. Omeprazole
	Prokinetic agents e.g. Metoclopramide
Salivary Aspiration	Anticholinergic agent
Cardiovascular Causes	Cardiac drugs
Pulmonary Oedema	Assuming regular dose of Frusemide is not
	greater than 120mg PO daily \rightarrow 40mg
	oral/IV stat
Drugs which cause cough e.g. Captopril	Reduce dose or change drug
Cough with tenacious sputum	Steam inhalation
	Nebulised saline
	 Bronchodilators
	Physiotherapy

Pharmacological Interventions

Issue	Management	
Simple Linctus e.g. Gee's Linctus	Soothing first line suppressant	
Cough Suppressant e.g. Codeine, Pholcodeine,	Titrate dose to effect	
Morphine	May be useful in dry non-productive coughs	
	 In productive coughs suppressing cough may lead to infection 	
Oxygen	Useful in emphysema related cough	
Corticosteroids e.g. Dexamethasone 4mg mane	Often used to treat cough associated with	
	endobronchial tumours, lymphangitis or	
	radiation pneumonitis	

Hiccup

Hiccup is: the spasmodic contraction of the diaphragm

Symptoms include: sudden inspiration of air and closure of the vocal cords

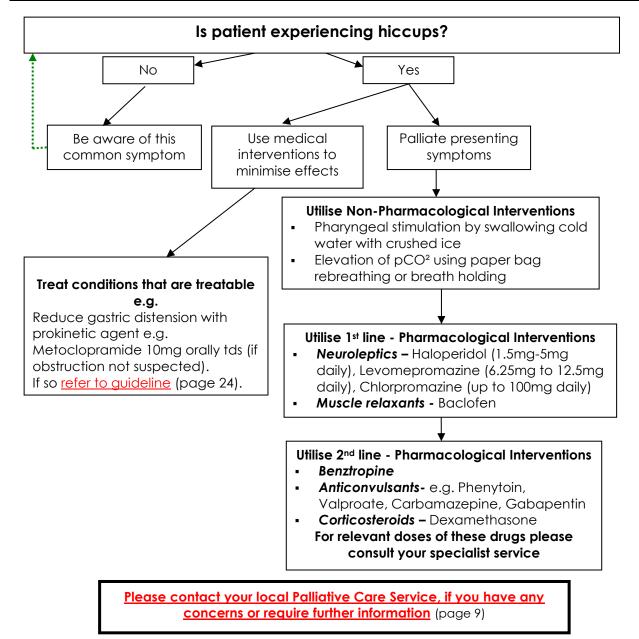
Causes include: Gastric distension, diaphragmatic irritation, phrenic or vagal nerve irritation, uraemia, neurological disease affecting the medulla e.g. brain cell tumour, infarction, encephalitis, liver disease

Holistic Reflection

Emotional Considerations: How does it feel to be hiccuping all the time? How is your distress perceived by those around you?

Spiritual Considerations: What does continually hiccuping mean to you? How does this affect the person, their perception of self and their lifestyle?

Social Considerations: How does hiccupping all the time affect your lifestyle? And the lifestyle of those around you.



Secretions

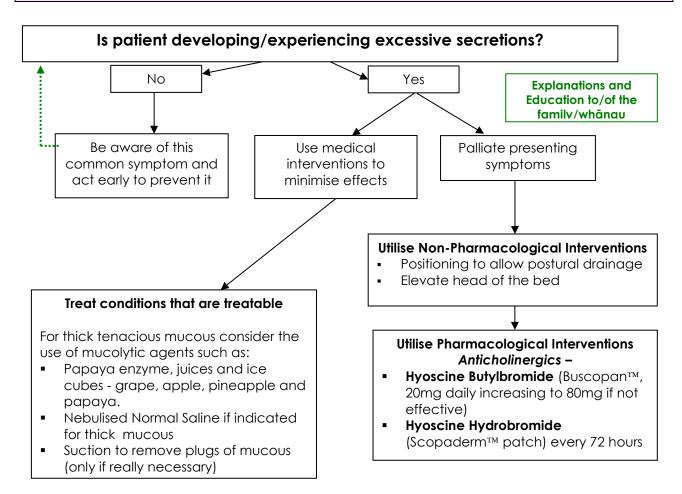
Noisy breathing/Secretions: occurs when a person is unable to physically clear respiratory secretions. This is a common symptom leading up to the end of life and is often referred to as the "death rattle". This is not obviously distressing for the patient but is so for the family/whānau

Symptoms include: noisy, gurgling, rattling sound associated with breathing

Causes include: weakening of physical strength to enable forceful expulsion of secretions from the back of the throat, weakening of cough reflex. Early identification of patients who could potentially develop/experience this symptom is the key to good management

Holistic Reflection

Emotional Considerations: What does this symptom mean for the family/whānau? **Spiritual Considerations**: Is there any considerations that need to be taken into account around this time? How does this affect the person, their perception of self and their lifestyle? **Social Considerations**: How does this symptom affect family/whānau staying close by?



Managing Skin Issues

ltch

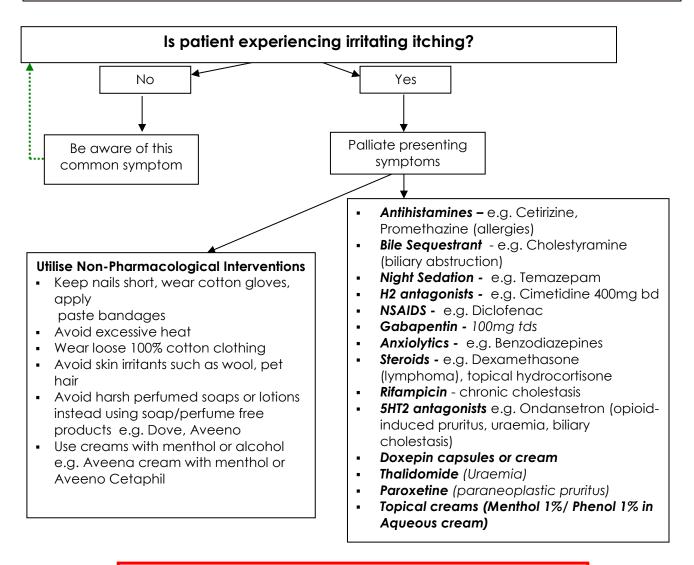
Itch is: an irritating skin sensation causing a desire to scratch

Symptoms include: an intense desire to continually scratch

Causes include: hepatic/renal disease (obstructive jaundice, cholestatic and uraemic itch), drug allergy, drugs (opioids, vasodilators), endocrine disease, iron deficiency, lymphoma, provocative sensory influence such as rough clothing, parasites

Holistic Reflection

Emotional Considerations: What does this symptom mean for the family/whānau? **Spiritual Considerations**: Is there any considerations that need to be taken into account around this time? How does this affect the person, their perception of self and their lifestyle? **Social Considerations**: How does this symptom affect family/whānau staying close by?



Sweating

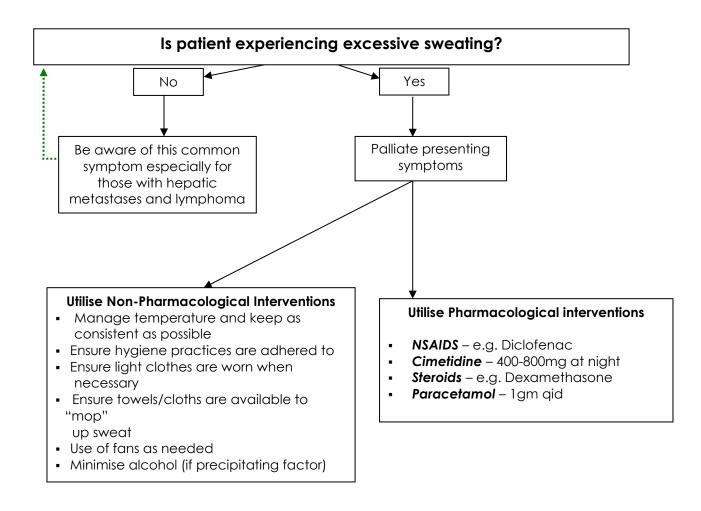
Sweating is: the secretion of fluid from the skin by sweat glands within and under the skin

Symptoms include: an overproduction and secretion of sweat for no apparent usual cause

Causes include: environmental temperature changes, emotion, lymphomas, hepatic metastases and carcinoid, intense pain, anxiety and fear, infection, drugs (alcohol, tricyclic antidepressants and opioids)

Holistic Reflection

Emotional Considerations: What does this symptom mean for the family/whānau? **Spiritual Considerations**: Is there any considerations that need to be taken into account around this time? How does this affect the person, their perception of self and their lifestyle? **Social Considerations**: How does this symptom affect family/whānau staying close by?



Wound Management

Wounds and their management are an integral part of holistic care. They are a result of impairment of the skin integument that is not healed or not healing

Symptoms include: a wound/ulcer that has not healed. Odour and exudate are the main manifestations of this symptom

Causes include: primary skin tumour, invasion of nearby tissue by tumour, metastatic involvement, anaerobic activity within a cavity, erosion of blood vessels as the wound enlarges

Holistic Reflection

Emotional Considerations: What does this symptom mean for the family/whānau? **Spiritual Considerations**: Is there any considerations that need to be taken into account around this time? How does this affect the person, their perception of self, their body image and their lifestyle? **Social Considerations**: How does this symptom affect family/whānau staying close by?

For in-depth information regarding management of wounds go to "Guidelines for Wound Management in Palliative Care" by W. Naylor https://www.nzwcs.org.nz/images/publications/woundmanagementguidelines-text.pdf

Also consider topical agents for use:

- Malodourous Wounds Metronidazole 2%w/w cream
- Painful dressing changes Morphine 5mg in 5ml Intrasite gel (these are dispensed separately and combined at the time of dressing change)

Managing CNS Issues

Anxiety and Fear

Anxiety and Fear: is a common symptom of excessive uneasiness and being afraid and frightened

Symptoms include: inability to relax, expressing feelings of anxiousness, isolating behaviours

Causes include: medical condition (e.g. delirium, depression, hormone secreting tumour), drug reaction (steroids, bronchodilators), may be a symptom of an impending medical catastrophe, learned phobic reaction (e.g. to needles, chemotherapy, death)

Holistic Reflection

PQRSTU assessment: Consider this framework as a tool to assess the symptom holistically. <u>See PQRSTU guidelines (page 58)</u>

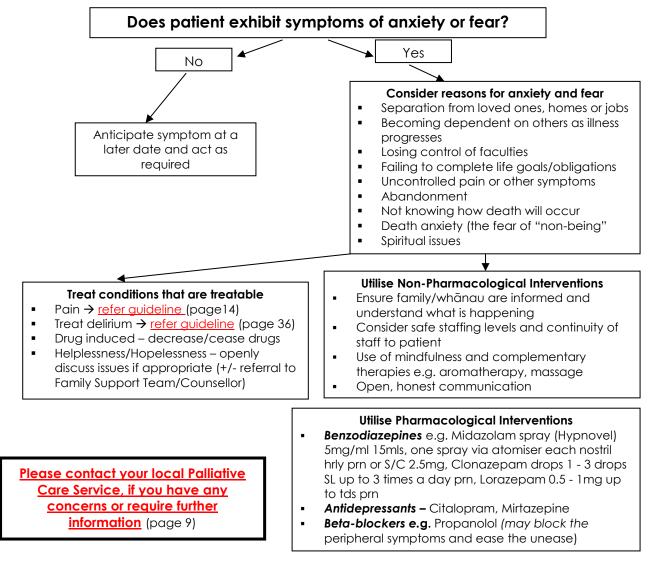
Emotional Considerations: How can emotional issues be identified and addressed at this time? Is there time to address these prior to death?

Spiritual Considerations: How can feelings of hopelessness and helplessness (by

patient/family/whānau) be addressed? Would the patient like to see/benefit from a chaplain visiting? How does this affect the person, their perception of self and their lifestyle?

Social Considerations: Is the patient safe where they are at the moment? Can they remain there until they die? What other support does the family/whānau need at this time?

Physical Considerations: How can we make this person safe? How is this symptom affecting physical needs for this person?



Delirium

Delirium is: "a reversible toxic state"

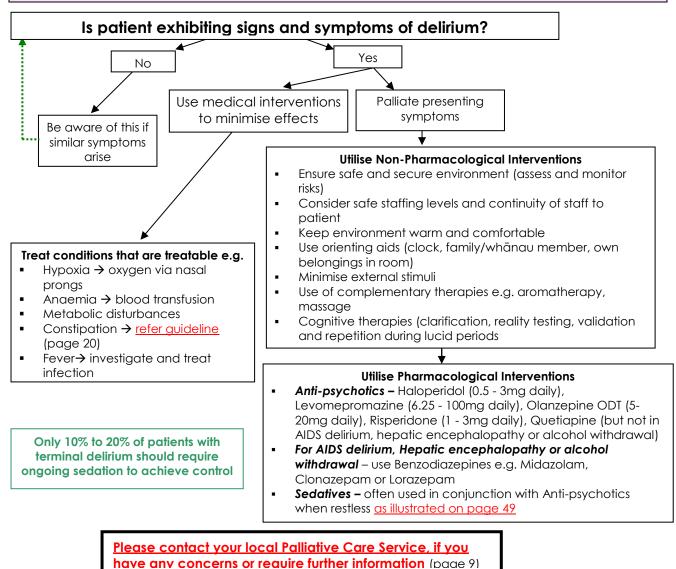
Symptoms include: disorientation, fear and dysphoria, memory impairment, reduced attention span, hyperactive, hypoactive, reversal of sleep-wake cycle, perceptual disturbances, disorganised thinking, dysgraphia, and sundowner effect

Causes: Drugs Severe Anaemia Cerebral Haemorrhage	Infection Metabolic disturbances Vitamin Deficiency Epilepsy – postictal	Organ Failure Hypoxia Cerebral Metastases
Aggravating factors: Dementia Fatigue Change of environment	Pain Urinary Retention Unfamiliar excessive stimuli	Constipation

Holistic Reflection

Emotional Considerations: How does this diagnosis affect the family/whānau? Is there any perception or understanding of this diagnosis?

Spiritual Considerations: How does this affect the person, their family/whānau and their lifestyle? Social Considerations: How does this diagnosis impacts on the remainder of their life? Physical Considerations: How can we make this person safe? How is this symptom affecting physical needs for this person?



Managing Social Issues

Discharge Planning

Discharge planning (or lack of) from one facility to another/home can be the difference between a smooth transition and a complicated one. Complicated transitions often increase the anxiety and stress for the patient and their families/ whānau as well as colleagues due to things often being left undone or not considered at all. Discharge planning involves **ALL** involved in someone's care and helps to ensure that all necessary requirements are in place at the time of discharge.

This includes:

- Communication between ALL providers involved in patient care (e.g. General Practitioners, District Nurses, Outreach Nurses) as well as the patient and their family/whānau
- The delivery of (or access to) necessary equipment
- The preparation of necessary scripts (ensuring that immediate medications are on hand if needed) and a decision on who is responsible for future scripts, ideally this should be the General Practitioner
- Information related to troubleshooting different situations which may arise, e.g. medication management for distressing symptoms, who to contact if/when

Equipment

Each of the Hospices has loan equipment that can be utilised when caring for palliative patients. For some pieces of equipment a hire fee may be charged and there may be a cost for delivery/retrieval. Phone your local specialist palliative care team for further information and to discuss your needs. Hospices of Northland Contacts (page 9).

Some of the equipment that is available is:

- Electric beds
- Pressure relief mattresses
- Alternating Air Pressure mattresses
- Syringe Drivers
- Wheelchairs
- Commodes, over toilet chairs
- Shower chairs

Home Help/Personal Care

The District Health Board contracts various local home support services to provide in home assistance with housework and personal care. <u>Please contact your local</u> <u>palliative care service</u> if this is required.

Long Term At-Home Support

For some families, long term care at home is a preferred option. This option is NOT provided by the District Health Board or Hospice. This type of care will need to be paid for privately by the patient or family/whānau. <u>Please contact your local</u> <u>palliative care service</u> if this is required.

Placement to a Long Term Facility

The process of placement of a palliative patient is one that requires assessment, co-ordination and communication. <u>Please contact your local palliative care</u> <u>service</u> if this is required.

Support for Family/Whānau/Carer

There is different pre-bereavement support for family/whānau within Northland depending on where people live. If you feel your patient and family/whānau could benefit from this type of support, please contact a member of the Specialist Team to discuss this further. <u>Please contact your local palliative care service</u> if this is required.

Volunteer Support

Volunteer support can be invaluable when caring for people during the palliative stage of their life. If you feel your patient and family/whānau could benefit from this type of support, please contact a member of the Specialist Team to discuss this further. <u>Please contact your local palliative care service</u> if this is required.

Nutritional Support

In palliative care it is rare that intravenous fluids and nasogastric tubes are required. Treatment centres on minimising discomfort from symptoms in an active and yet as free from medical technology and tubes as possible. Patients and their family/whānau must always be fully informed to make the decision that is right for them.

Pharmacist Support

North Haven Hospice contracts the services of a local Pharmacist to provide specialist pharmacist support. Should you have any concerns or queries of a pharmacological nature <u>please contact your local palliative care service</u>.

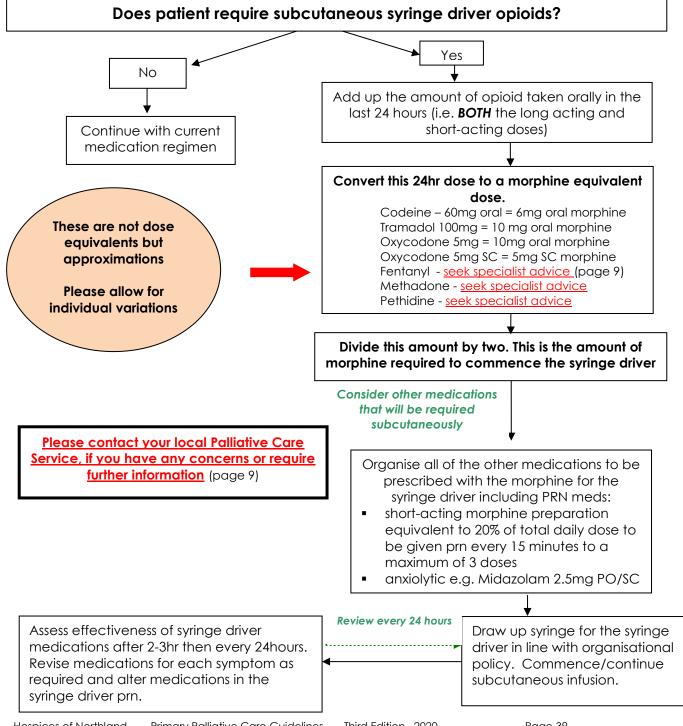
Syringe Driver Management

Commencing Subcutaneous Syringe Driver Medications

A Syringe Driver is a battery powered device that administers drugs subcutaneously over a chosen period of time. In Northland the T34 Syringe Driver is used. It is advisable that nurses and carers who are working with syringe drivers have gained competency after attending and updating their knowledge via the Hospice New Zealand syringe driver competency programme.

Details of training can be accessed via <u>www.northhavenhospice.org.nz</u> and <u>https://www.hospicemn.org.nz/</u>

The initial programme is 2-3 hours long and comprises of theory and practical training. Annually thereafter an hour update session is recommended to maintain competency.



Choice of Drugs for Use in Syringe Drivers/Continues Subcutaneous Infusions (CSCI)

MORPHINE NOTE: Parenteral Morphine is 2x as strong as oral Morphine If pain not controlled on oral medication, consider increasing the oral dose by 30-50% when converting to subcutaneous and convert to a subcutaneous dose from this dose

DRUG - usual dose ranges quoted	USE	STAT DOSE	S/C DOSE OVER 24 HRS					
CYCLIZINE (Valoid™) (Antihistamine) 50mg/ml injection	Antiemetic, centrally acting on vomiting centre Good for nausea associated with bowel obstruction or increased intracranial pressure Dilute with water	50mg	100-150mg					
HALOPERIDOL (Serenace™) (Neuroleptic)	Antiemetic – good for chemically induced nausea	0.5 -1.5mg	1– 3mg					
5mg/ml injection	Delirium	0.5-1.5mg	1-3mg					
METOCLOPRAMIDE (Maxolon TM) 10mg in 2ml injection	Antiemetic (1) prokinetic (accelerates GI transit) (2) centrally acting on chemo-receptor trigger zone (CTZ), blocking transmission to vomiting centre.	10mg	30-60mg					
LEVOMEPROMAZINE (Nozinan™) 25mg/ml injection	NOTE: Don't use in combination with HYOSCINE Broad spectrum antiemetic, works on CTZ and vomiting centre (at lower doses)	5 - 6.25mg	5-25mg					
,	Delirium	12.5-25mg	12.5-200mg					
MIDAZOLAM (HypnovelTM) (Benzodiazepine) 15mg in 3ml	Sedative/anxiolytic (terminal agitation), anticonvulsant, muscle relaxant, controls myoclonus	2.5-10mg	5-60mg					
HYOSCINE BUTYLBROMIDE (Buscopan TM) (Antimuscarinic) 20mg /ml injection	Antisecretory and antispasmodic properties. Useful in reducing respiratory tract secretions Less sedating than HYOSCINE HYDROBROMIDE	20mg	40-100mg					
HYOSCINE HYDROBROMIDE (Hyoscine TM) (Antimuscarinic) 0.4mg/ml injection	Antisecretory and antispasmodic properties Useful in reducing respiratory tract secretions	400mcg	400mcg-2.4mg					

To see if the drugs you wish to give are compatible, check the <u>Syringe Driver</u> <u>Compatibility Chart</u> (Appendix Three page 60)

<u>Please contact your local Palliative Care Service, if you have any concerns or require</u> <u>further information</u> (page 9)

Managing Care at End of Life (Te Ara Whakapiri resources)

The same principles are applicable to the end of life care for **ALL** patients regardless if they are dying from cancer or a non-malignant disease/condition. End of Life/Terminal Cares begin when a diagnosis of dying is confirmed – preferably by a Multidisciplinary Team.

Recognise that Death is approaching

Patients entering the dying phase will manifest some if not all of the following:

- 1. Profound weakness usually bedbound
- 2. Drowsy or reduced cognition semi-comatose
- 3. Diminished intake of food and fluids only able to take sips of fluid
- 4. Difficulty in swallowing medication no longer able to take tablets

Treatment of Symptoms

The prime aim of all treatment at this stage is the control of symptoms current and potential while being aware of the patient and family/ whānau priorities. It is essential that all changes that you are observing in the patient and that are being considered medically are be communicated with the patient and family. Discussing what you think might occur is paramount in the family being prepared for this last phase. Taking into considerations different cultural norms, it important to inform the family that there is a belief that the patient is dying.

Please remember to treat each patient with individual consideration based on patient priorities and need. There is no one right "pathway" but there are common things to consider.

Don't forget basic care response to environment, positioning and elimination (a full bladder is very uncomfortable). It is important that this is done as a team, all agreeing that this is the most appropriate course in care. Avoid conflicting information being given to patient and families/whānau.

- **Discontinue** any medication which is not essential
 - e.g. anti-hypertensives long term antibiotics steroids replacement hormones vitamins and iron diuretics hypoglycaemics
- Prescribe medication necessary to control current distressing symptoms

• **PRNS** - All patients who are dying would benefit from having medication prescribed IN CASE distressing symptoms develop. Make sure that the PRN medication reflect what is being regularly administered

• **Route** - Consider the most appropriate route of delivery-subcutaneously, buccally, rectally etc.

• Review - All medication needs should be reviewed at least every 24hrs

<u>Note</u>: Not everyone who is dying requires a CSCI (Continuous Subcutaneous Infusion) but **if two or more doses of PRN medication have been required in 24 hours, then consider the use of a CSCI**.

End of Life Care for those with Dementia

Dementia is: a life limiting syndrome which affects the "brain resulting in global impairment of every aspect of the intellect, memory and personality without an alteration of consciousness."

(L. Badenhorst, n.d.)

Symptoms: Memory loss, difficulty performing familiar tasks, problems with language, disorientation to time and place, poor or decreased judgement, problems with abstract thinking, misplacing things, changes in mood and behaviour, changes in personality, loss of initiative. (Alzheimer's Association)

Causes include: nil concrete causes known

Holistic Reflection

Emotional Considerations: What does this condition mean for the family/whānau? **Spiritual Considerations**: Are there any considerations that need to be taken into account around this time? What things are left to do that need addressing at this time? Fluctuating levels of cognition can make issues difficult to deal with. Opportunities should be taken to clarify wishes, provide reassurance during these lucid times. How does this affect the person, their perception of self and their lifestyle?

Social Considerations: How does this symptom affect your relationship with family/whānau? How will they manage this condition?

Often patients may express symptoms in different ways such as:

- Vocal responses (crying, moaning, laughing)
- Adaptive behaviour (rubbing of the affected area, avoiding certain movements, keeping area still)
- Self-distracting behaviour (rocking, pacing, biting hand, gesturing)
- Facial expressions (grimacing)
- Withdrawal, low mood
- Refusing to eat or drink
- Sleep disturbance
- Hyperactive behaviour/ Self-injurious behaviour

Management Considerations

- Communication speak in clear, simple manner using gestures to supplement
- Do not argue with validity of delusions try to understand feelings being indirectly expressed
- The use of gentle touch and calming words to calm patient
- Distraction and diversion techniques as required
- Ensure patient environment is safe for them to be independent in/around
- Structure the environment to enhance familiarity (keep to a daily routine, use of labels for rooms/spaces/photos and memory (e.g. clocks, calendars)
- Use of music
- Pet therapy
- Aromatherapy (WDHB RACIP Guidelines, 2nd edition, 2012)
- Assess and treat pain refer to <u>guideline</u> (page 14)
- Confusion/ delirium- refer to guidelines on psychological issues (page 36)

End of Life Renal Failure

Renal Failure: occurs when the kidneys are no longer able to sustain their normal bodily functions

Symptoms: oedema (from sodium and water retention), restless legs, itch (from raised urea or phosphate), nausea and vomiting, confusion or delirium, (from increased toxins), fatigue (from anaemia), possibility of seizures

Causes include: chronic (multiple causes), acute (obstruction, drug induced)

Holistic Reflection

PQRSTU assessment: Consider this framework as a tool to assess the symptom holistically. <u>See PQRSTU guidelines (page 57)</u>

Emotional Considerations: What does this symptom mean for the family/whānau? **Spiritual Considerations**: Are there any considerations that need to be taken into account around this time? What things are left to do that need addressing at this time? Fluctuating levels of cognition can make issues difficult to deal with. Opportunities should be taken to clarify wishes, provide reassurance during these lucid times. How does this affect the person, their perception of self and their lifestyle?

Social Considerations: How does this symptom affect your relationship with family/whānau? How will they manage this symptom?

Management Considerations

- Nausea and Vomiting refer to guideline (page 27)
- Confusion/ delirium refer to guidelines on psychological issues (page 36)
- Breathlessness <u>refer to guideline</u> (page 28)
- Pain refer to pain guideline (page 14)

BUT remember:

- As the kidneys fail, the creatinine plasma concentrations will rise this is important for drugs whose metabolites are renally cleared. These drugs need to be reviewed, ceased or given at a smaller dose dependent on creatinine clearance The Palliative Care Handbook (McLeod, Vella-Brincat, MacLeod) p53.
- Morphine's metabolite is renally cleared so use methadone or fentanyl
 - instead
- NSAIDS increase sodium and water retention and are nephrotoxic and so if urea is raised there is an increased risk of GI bleed.
- Itch <u>refer to guideline</u> (page 32)

Note: Preparation and anticipation of possible issues reduces anxiety for the patient and family/whānau. Discuss the possible pathway with the level of information determined by patient and family/whānau.

End of Life Liver Failure

Liver Failure: occurs when the liver is no longer able to sustain its normal bodily function

Symptoms include: raised liver enzymes, jaundice, ascites, itch, encephalopathy, low albumin and raised INR

Causes include: liver metastases, previous raised alcohol intake, drugs, infections,

Holistic Reflection

Emotional Considerations: What does this symptom mean for the family/whānau? **Spiritual Considerations**: Are there any considerations that need to be taken into account around this time? What things are left to do that need addressing at this time? How does this affect the person, their perception of self and their lifestyle?

Social Considerations: How does this symptom affect your relationship with family/whānau? How will they manage this symptom?

Management Considerations

- Liver failure affects metabolism of drugs cleared from the body via the liver
- Decrease most metabolised drug doses by 25%
- For drugs that are highly dependent on the flow of blood; decrease drug dosage by 50%

e.g.

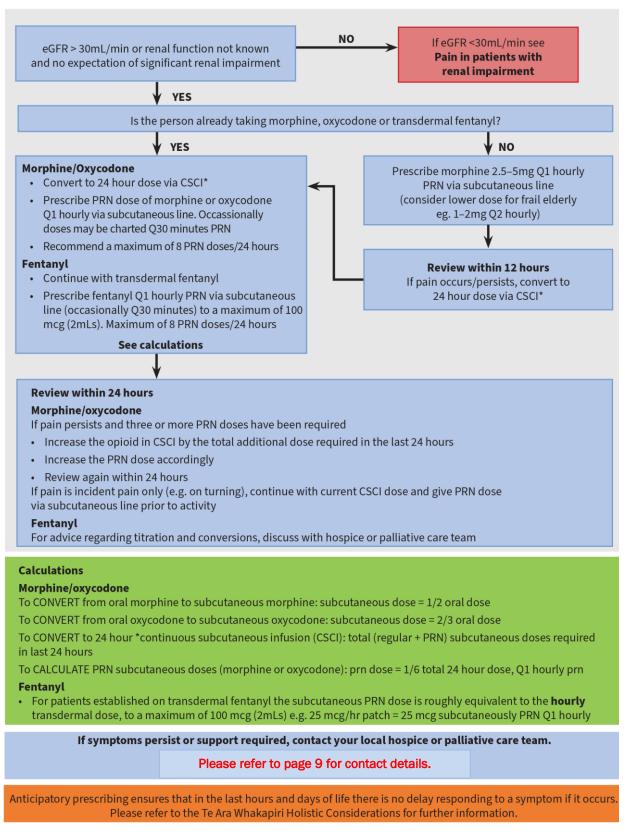
- Phenothiazines e.g. Prochlorperazine
- SSRI's e.g. Paroxetine
- Tricyclics e.g. Amitriptyline
- Some opioids e.g. morphine

(McLeod, Vella-Brincat, MacLeod, 2012, p54).

Pain in patients with no/limited prior pain

Anticipatory prescribing flow chart for the last days of life





Adapted from Te Ara Whakapiri, Principles and guidance for the last days of life (Ministry of Health, 2017) by the South Island Palliative Care Workstream South Island Alliance, May 2020. Review May 2022.

Pain in patients with renal impairment *Anticipatory prescribing flow chart for the last days of life*

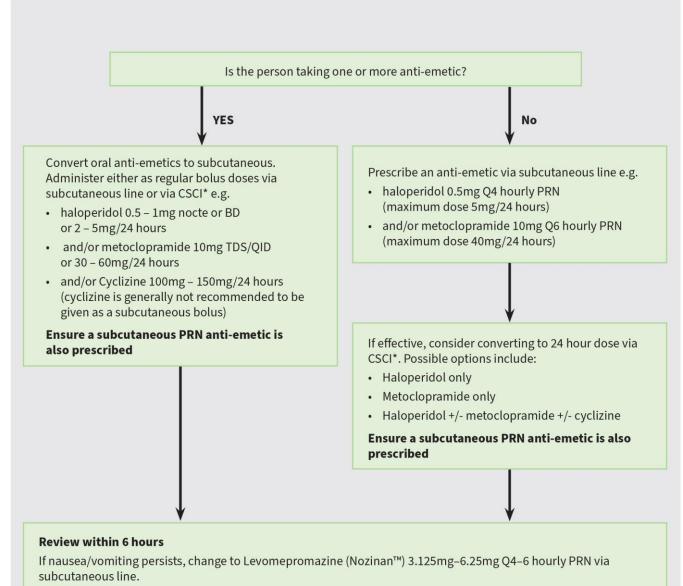


eGFR < 30mL/min YES	reason	>30mL/min (or there is no to expect significant renal nt) - refer to Pain in patients imited prior pain flowchart	
Is the person already ta	king an opioid for pain?		
YES	L.	NO	
If taking morphine or oxycodone contact your local hospice or palliative care team for guidance with conversions/calculations	PAIN PI	RESENT	
If on transdermal fentanyl , leave patch(es) in situ and prescribe PRN dose of fentanyl accordingly. See calculations	YES	NO	
If taking methadone keep dosing orally for as long as possible. Contact your local hospice or palliative care team if considering conversion to subcutaneous route	Give STAT dose of fentanyl 10–20mcg then Q1 hourly PRN via subcutaneous line Consider starting fentanyl 100–300 mcg via CSCI* over 24 hours	Prescribe fentanyl 10–20mcg Q1 hourly PRN via subcutaneous line Review within 12 hours If pain occurs/persists, consider starting	
Review within 24 hours		fentanyl 100-300mcg via CSCI* over 24 hours	
 If pain persists and/or three or more PRN doses required turning), increase the fentanyl in the continuous subcuta required in the last 24 hours An increase in the fentanyl PRN dose may be required (u 	aneous infusion* (CSCI) by the to	otal additional dose	
Intanyl calculations For patients established on transdermal fentanyl, the sub- transdermal dose, to a maximum of 100 mcg (2mLs) e.g. 2 For all other advice regarding titration and conversions, dis	5 mcg/hr patch = 25 mcg subcu	taneously PRN Q1 hourly	
If symptoms persist or support required, cont Please refer to page	act your local hospice or palli 9 for contact details.	ative care team.	
icipatory prescribing ensures that in the last hours and day			

Adapted from Te Ara Whakapiri, Principles and guidance for the last days of life (Ministry of Health, 2017) by the South Island Palliative Care Workstream. South Island Alliance, May 2020. Review May 2022.

Nausea/vomiting Anticipatory prescribing flow chart for the last days of life





- If effective convert to *continuous subcutaneous infusion (CSCI), max dose 25mg/24 hours
- Ensure subcutaneous PRN Levomepromazine (Nozinan™) is also prescribed

If symptoms persist or support required, contact your local hospice or palliative care team.

Please refer to page 9 for contact details.

Anticipatory prescribing ensures that in the last hours and days of life there is no delay responding to a symptom if it occurs. Please refer to the Te Ara Whakapiri Holistic Considerations for further information.

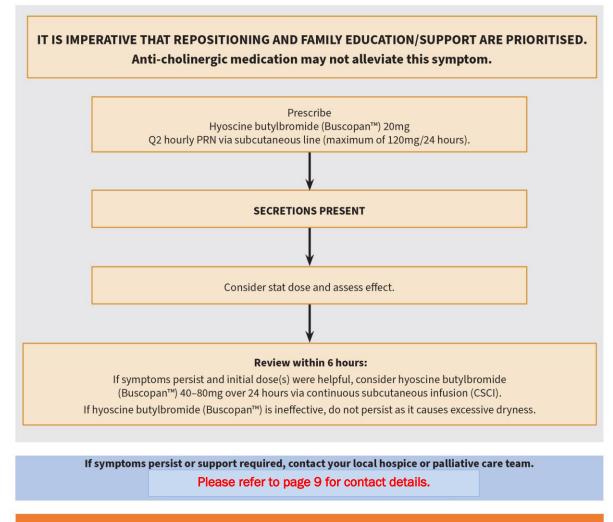
Adapted from Te Ara Whakapiri, Principles and guidance for the last days of life (Ministry of Health, 2017) by the South Island Palliative Care Workstream. South Island Alliance, May 2020. Review May 2022.

Excessive respiratory tract secretions



PLACE YOUR LOGO HERE

Anticipatory prescribing flow chart for the last days of life



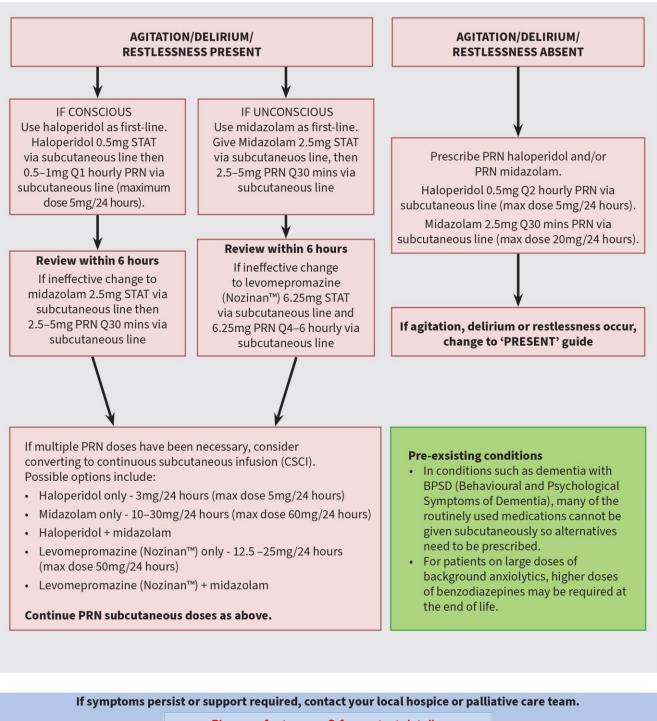
Anticipatory prescribing ensures that in the last hours and days of life there is no delay responding to a symptom if it occurs. Please refer to the Te Ara Whakapiri Holistic Considerations for further information.

Adapted from Te Ara Whakapiri, Principles and guidance for the last days of life (Ministry of Health, 2017) by the South Island Palliative Care Workstream. South Island Alliance, May 2020. Review May 2022.

Agitation, delirium and restlessness

Anticipatory prescribing flow chart for the last days of life





Please refer to page 9 for contact details.

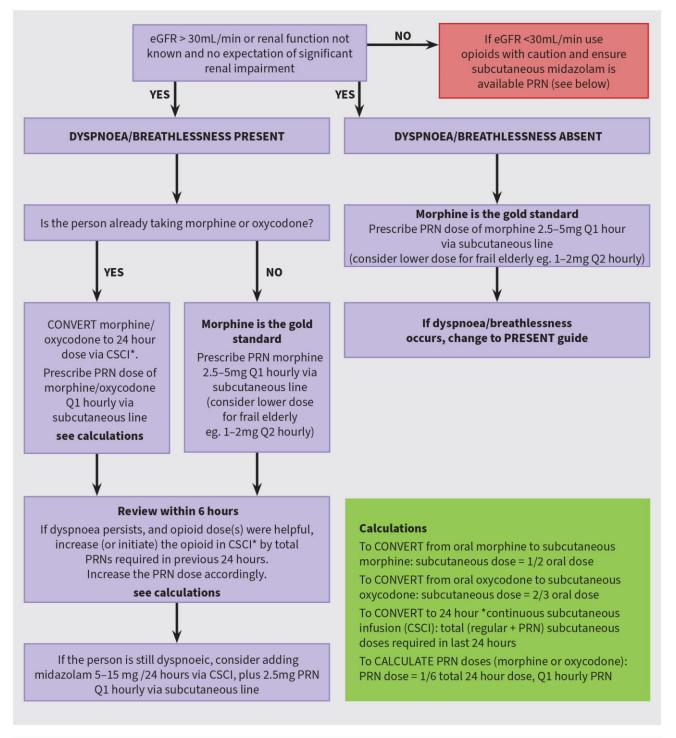
Anticipatory prescribing ensures that in the last hours and days of life there is no delay responding to a symptom if it occurs. Please refer to the Te Ara Whakapiri Holistic Considerations for further information.

Adapted from Te Ara Whakapiri, Principles and guidance for the last days of life (Ministry of Health, 2017) by the South Island Palliative Care Workstream. South Island Alliance, May 2020. Review May 2022.

Dyspnoea/breathlessness

Anticipatory prescribing flow chart for the last days of life





If symptoms persist or support required, contact your local hospice or palliative care team.

Please refer to page 9 for contact details.

Anticipatory prescribing ensures that in the last hours and days of life there is no delay responding to a symptom if it occurs. Please refer to the Te Ara Whakapiri Holistic Considerations for further information.

Adapted from Te Ara Whakapiri, Principles and guidance for the last days of life (Ministry of Health, 2017) by the South Island Palliative Care Workstream. South Island Alliance, May 2020. Review May 2022.

Care Considerations for End of Life Care

Patient and family will receive optimum care and wishes will be followed, to allow a respectful and comfortable death.

ISSUE	ACTION PLAN
Documentation	Medical history is completed (is required for death certificate) Details regarding burial/cremation and funeral plans are documented
Ensure essential family contact details are correct	Next of Kin/Family/Whānau details updated. Next of Kin/Enduring Power of Attorney/Family/Whānau are notified of current condition - if not present ASAP (within 30 minutes)
Assessment of dying patient	Review patient care and complete formal assessments as appropriate
Patient wishes are documented in Care Plan under Issue: End of Life Care	Patient wishes regarding care decisions are documented See section on Advance Care Planning (page12) and www.advancecareplanning.org.nz Enduring Power of Attorney is documented if known Preferred place of death is identified and documented
Review - Rationalisation of medication and interventions	Medication is reviewed and non-essential medications are discontinued Any PRN's (as required medications) are charted Any unnecessary interventions are discontinued e.g. blood sugar levels, blood pressure Any changes to medication/medical care are communicated and explained to family
Family/Whānau are informed and supported	 Family/Whānau are informed regarding: What is happening now What might happen- dying process and changes they may see Impending death and possible timeframes of events Family/Whānau have any issues/concerns documented
Cultural Needs are reviewed	Any specific cultural care requirements for patient/family/whānau are identified and documented
Spiritual Needs are reviewed	Any religious care requirements/traditions are identified and documented e.g. <u>Social/Emotional and Spiritual Assessment</u> Appendix Seven (page 69) Referral to Chaplain or Spiritual Care Support Worker.

ISSUE	DESIRED OUTCOME	ACTION PLAN
Physical Needs	Physical needs will be met to promote comfort during the dying process.	 PAIN Assess pain regularly and observe for subjective signs of pain e.g. frowning, wincing PRN medications for incident pain Positioning /splints/ pressure reliving mattress/monitor pressure areas Heat/wheatpack MANAGE BREATHING DIFFICULTIES Positioning Oxygen if indicated Normal saline via nebuliser Address increased secretions MANAGE SYMPTOMS OF NAUSEA/VOMITING Syringe driver prn Positioning Aromatherapy – ginger/spearmint Prescribe appropriate regular and prn medications and monitor effectiveness MANAGE ORAL CARES Routine/Preventative: Oral Care at least 2hrly as tolerated Mouth swabs/ice chips Mouth moisturiser Remove & soak dentures prn Lubricants to lips Topical analgesia prn HYGIENE AND ELIMINATION Attend to hygiene needs as required. Bed bath/ Hot towel sponge with essential oils/ Massage Ensure cleanliness and comfort by providing bowel cares and urinary cares as appropriate
Spiritual Needs	Spiritual support will be provided to patient and family/whānau	 Address spiritual needs, restlessness and agitation and expressed wishes Active, non-judgemental listening to beliefs, hopes and fears Time and privacy for spiritual practice and reflection, use of chapel/sacred space. Facilitation of religious practices Referral to Spiritual carer or own professional spiritual support Discussion of funeral planning – record specific detail in 'Planning for Future Care' Respect for specific practices including fasting and dietary requirements, devotional practices, respect for religious articles

Emotional Needs	Emotional support will be provided to patient and family/whānau	 Address emotional needs, restlessness and agitation Provide information and communication to patient and family/whānau Active listening, empathy, reassurance Recognition of family/carer role and acknowledgement of stressors Facilitate communication among patient & family Complementary therapies - Massage, relaxation, meditation, music Communication on the dying process Referral to counsellor/social worker
Cultural Needs	Cultural needs will be met	 Identify spokesperson Provide information to patient and family/ whānau and be guided by their cultural needs Maori Liaison / Spiritual Advisor e.g. Karakia, assistance with end-of-life Tikanga. Sensitivity and respectful inquiry – ask how we can help Recognition of concerns Respect & regard for cultural, social and spiritual practices, traditions, values and Use of professional interpreters as needed Written information in required languages Family meetings

Managing Palliative Emergencies

Palliative Care emergencies involve situations that can cause imminent death or result in extreme changes to the quality of the remainder of life for the patient and their family/whānau. Being aware of such emergencies and the symptoms of these possible emergencies results in proactive planning for the patient and their family/whānau.

Having the relevant drugs correctly charted and readily available for patients with the potential for an emergency will ensure any emergency is managed efficiently and effectively.

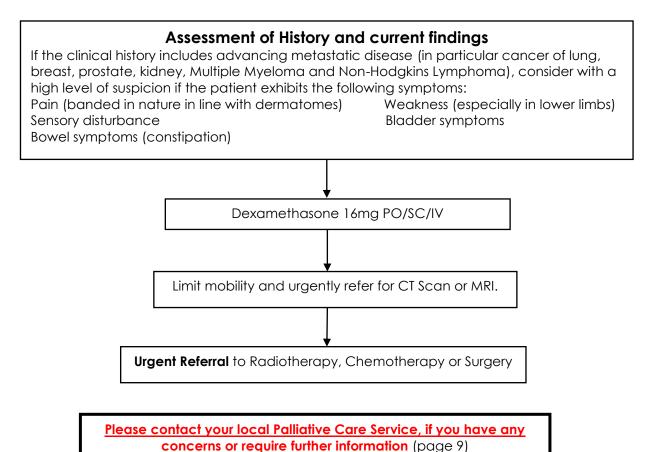
All emergencies should be considered as having a holistic impact on the patient and their family/whānau. Acting according to the advance care plan and treatment/care priorities is imperative to successful management of palliative emergencies.

Holistic Reflection

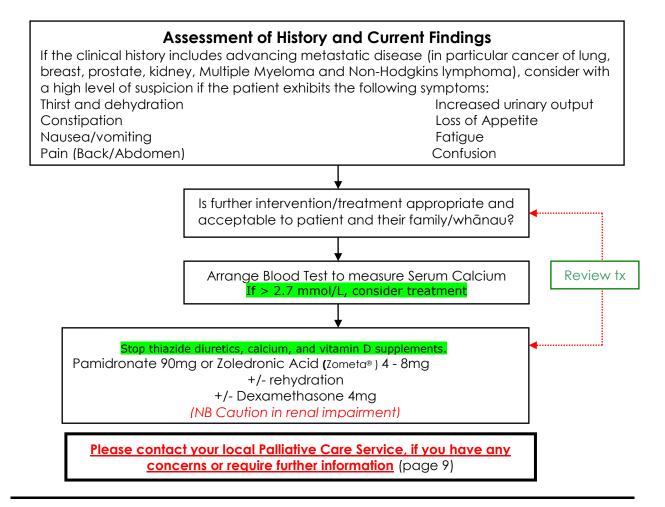
Emotional Considerations: How does this diagnosis affect the family/whānau? Is there any perception or understanding of this diagnosis?

Spiritual Considerations: How does this affect the person, their family/whānau and their lifestyle? Social Considerations: How does this diagnosis impacts on the remainder of their life? Physical Considerations: How can we make this person safe? How is this symptom affecting physical needs for this person?

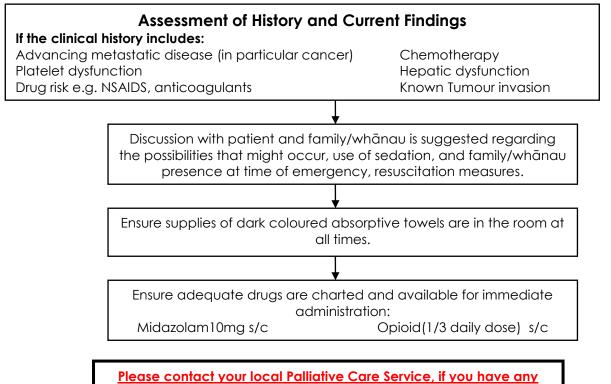
Spinal Cord Compression



Hypercalcaemia

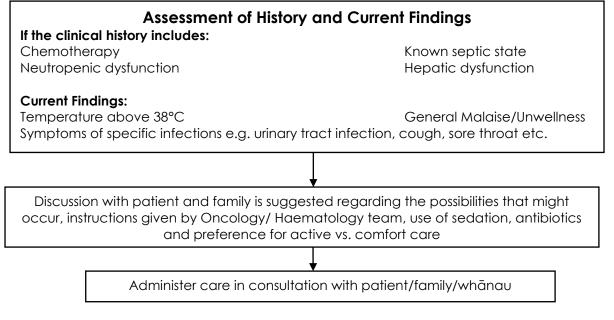


Massive Haemorrhage



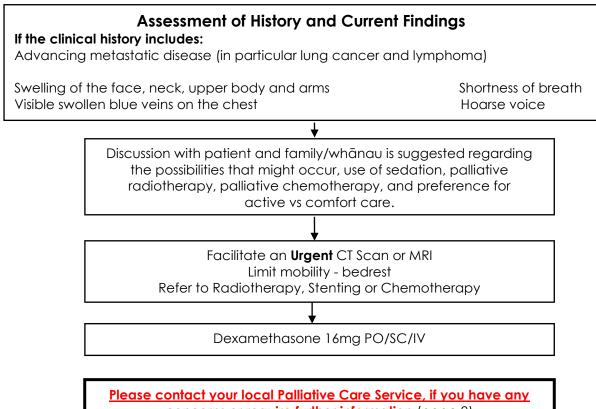
<u>concerns or require further information</u> (page 9)

Nutropenic Sepsis

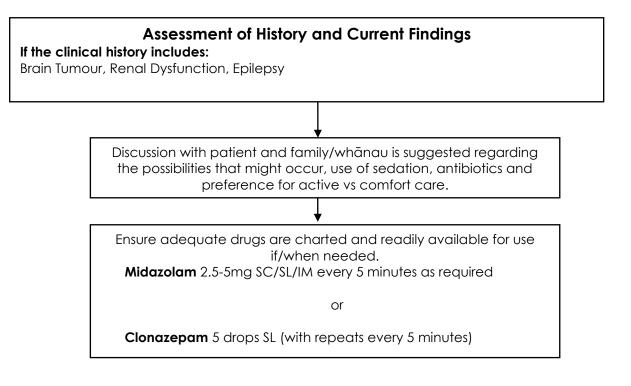


Follow the instructions given by or contact the Oncology/Haematology team at Whangarei Hospital.

Superior Vena Cava Obstruction



concerns or require further information (page 9)



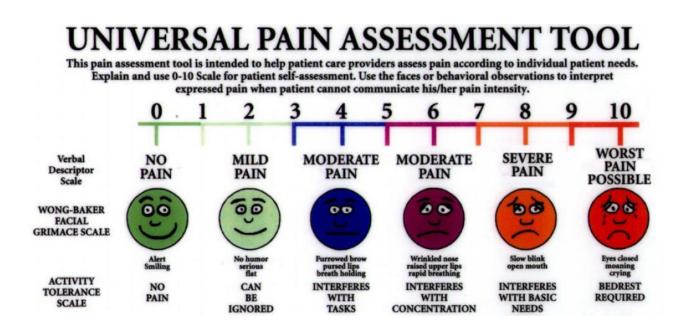
<u>Please contact your local Palliative Care Service, if you have any</u> <u>concerns or require further information</u> (page 9)

Appendix One - PQRSTU format

Consider the following assessing their pain using the PQRST format:

Ρ	Palliative factors Provoking factors	"What makes it better?" "What makes it worse?"
Q	Quality	"What is the symptom like? Give me some words that tell me about it."
R	Radiation	"Does the pain go any where else?"
S	Severity	"How severe is it?" Measured on numbered scale
T	Time	"Is this problem (with you) there all the time?" "Does it come and go at different times of the day?"
U	Understanding	"What does this symptom mean to/for you?" "How does this symptom affect your daily life?" "What do you believe is causing this symptom?" Does their pain have meaning?

Example of a Visual Analogue Scale



Appendix Two – Opioid Conversion Chart

Oral/Transdermal Opioids	Oral Morphine Equivalent Ratio		Administration and adjustment of opioid medication requires ongoing monitoring of symptoms and side effects in order to achieve optimum outcomes. There will be individual variation.								
Morphine (over 24hrs)	1:1	10mg	20mg	30mg	60mg	90mg	120mg	180mg	240mg		
Morphine Rescue Dose (4/24)		2.5mg	2.5 - 5mg	5mg	10mg	15mg	20mg	30mg	40mg		
Oxycodone(over 24 hrs)	1.5 : 1	7.5mg	15mg	20mg	40mg	60mg	80mg	120mg	160mg		
Oxycodone Rescue Dose (4/24)		2.5mg	2.5mg	2.5 - 5mg	5mg	10mg	10 – 15mg	20mg	25mg		
Fentanyl Patch (3 Days)		n/a	n/a	12mcg/hr	25mcg/hr	37mcg/hr	50mcg/hr	75mcg/hr	100mcg/hr		
Buprenorphine Patch (7 Days)		5mcg/hr	10mcg/hr	NB: 20mc	g/hr Bupren	orphine pat over 2	ch is equiva 4 hours	lent to 40m	g Morphine		
Tramadol	1:10	W	eak Opioids	s, but prior re	egular use s	hould be co	onsidered w	hen conside	ering		
Codeine	1:10			con	nmenceme	nt of strong	opioid				
Methadone	Variable	- 1 : 1 - 20	:1 ONLY C	OMMENCE A	AFTER CONS	ULTATION W	ITH PC CON	SULTANT as p	per page 18		
RESCUE DOSES 1/4 to 1/10, so c				ELY 1/6 OF T	HE TOTAL D	AILY DOSE O	F OPIOID T	his can be k	petween		
When changi	ng from one	opioid to o	another ther	e may be ir	complete c	cross toleran	ice and dos	e reduction	of 25% or		
more may be needed. After changing opioid, close assessment should follow and the dose altered as necessary											
	Opioid Con	version- Or	al to Subcu	taneous (N.	B. Subcutan	neous to Orc	al is reverse r	atio)			
Morphine	2:1					hine 20mg					
Oxycondone	2:1		e.g. Oxydone 20mg BD (40mg daily) = Oxycodone 20mg via CSCI over 24hr								
Methadone	2:1	e.g. Methadone 20mg BD (40mg daily) = Methadone 20mg via CSCI over 24hr									

Appendix Three – Syringe Driver Compatibility Chart

clonazepam clonazepam cyclizine dexamethasone dexamethasone dexamethasone dexamethasone haloperidol	hydromorphone
clonazepam - SI Y ? Y Y	?
cyclizine SI - SI SI Y Y	?
dexamethasone Y SI - ? SI	?
fentanyl ? SI ? - Y Y	-
glycopyrrolate Y Y ? Y - Y	Y
haloperidol Y Y SI Y Y -	Y
hydromorphone ? ? ? - Y Y	-
hyoscine butyl bromide (Buscopan [™]) Y SI Y Y ? Y	Y
hyoscine hydrobromide Y Y Y Y NA Y	Y
ketamine Y ? Y Y Y Y	?
methotrimeprazine/ levomepromazine (Nozinan™)YYYYYY	Y
methadone Y ? Y ? Y Y	?
metoclopramide Y Y Y Y Y Y	
midazolam Y SI SI Y Y Y	Y
morphine sulphate (normal strengths) Y Y Y ? Y Y	-
morphine tartrate (high strengths) Y Y Y ? ? SI	-
octreotide Y SI SI Y Y Y	?
ondansetron ? Y Y Y Y Y	?
oxycodone Y SI Y ? Y Y	-
phenobarbitone ? ? ? Y N ?	?

Combinations that have been used

Y = compatible	morphine+clonazepam+cyclizine (morphine sulphate and tartrate)
N = incompatible	morphine+clonazepam+dexamethasone (morphine sulphate and tartrate)
SI = sometimes incompatible (usually at higher concentrations)	morphine+clonazepam+haloperidol (morphine sulphate and tartrate)
NA = not usually used together	morphine+clonazepam+ketamine (morphine sulphate and tartrate)
? = unknown	morphine+clonazepam+metoclopramide (morphine sulphate Y, tartrate SI)

Info from:

The Palliative Care Handbook 7TH Edition 2014 – 24 hour syringe driver compatibility for subcutaneous administration table.
 Palliative Medicine Handbook on line at http://book.pallcare.info/index.php
 Compatibility of syringe driver admixtures for continuous subcutaneous infusions, Department of Pharmacy,

Diluent: water is recommended for all infusions except ketamine, octreotide, ondansetron and levomepromazine where sodium chloride 0.9% should be used although in combinations consider water.

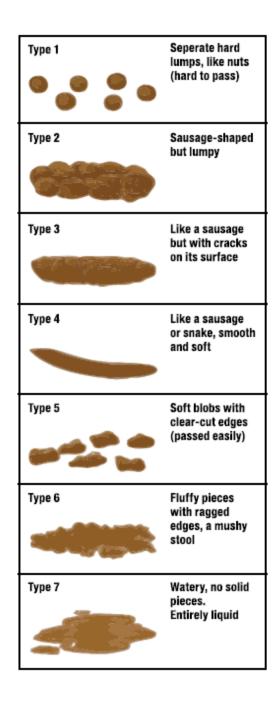
hyoscine butyl bromide(Buscopan TM)	hyoscine hydrobromide	ketamine	methotrimeprazine/ levomepromazine (Nozinan ^{™)})	methadone	metoclopramide	midazolam	morphine sulphate (normal strengths)	morphine tartrate (high strengths)	octreotide	ondansetron	oxycodone	phenobarbitone
Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	?	Y	?
SI	Y	?	Y	?	Y	SI	Y	Y	SI	Y	SI	?
Y	Y	Y	SI	Y	Y	SI	Y	Y	SI	Y	Y	?
Y	Y	Y	Y	?	Y	Y	?	?	Y	Y	?	Y
?	NA	Y	Y	Y	Y	Y	Y	?	Y	Y	Y	Ν
Y	Y	Y	Y	Y	Y	Y	Y	SI	Y	Y	Y	?
Y	Y	?	Y	?	-	Y	-	-	?	?	-	?
-	NA	Y	Y	?	Y	Y	Y	?	Y	Y	Y	?
NA	-	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	?
Y	Y	-	Y	?	Y	Y	Y	Y	Y	Y	Y	?
Y	Y	Y	-	Y	Y	Y	Y	Y	SI	Y	Y	?
?	Y	?	Y	-	Y	Y	?	?	?	?	?	N
Y	Y	Y	Y	Y	-	Y	Y	Y	Y	Y	Y	?
Y	Y	Y	Y	Y	Y	-	Y	Y	Y	Y	Y	?
Y	Y	Y	Y	?	Y	Y	-	NA	Y	Y	NA	?
?	Y	Y	Y	?	Y	Y	NA	-	?	Y	NA	Y
Y	Y	Y	SI	?	Y	Y	Y	?	-	Y	Y	?
Y	Y	Y	Y	?	Y	Y	Y	Y	Y	-	Y	?
Y	Y	Y	Y	?	Y	Y	NA	NA	Y	Y	-	?
?	?	?	?	N	?	?	?	Y	?	?	?	-

morphine+cyclizine+dexamethasone	morphine+dexamethasone+haloperidol
(morphine sulphate and tartrate)	(morphine sulphate and tartrate)
morphine+cyclizine+haloperidol	morphine+dexamethasone+hyoscine
(morphine sulphate and tartrate)	hydrobromide
morphine+cyclizine+hyoscine butyl bromide	morphine+dexamethasone+metoclopramide
(morphine sulphate, tartrate SI)	(morphine sulphate and tartrate)
morphine+cyclizine+metoclopramide	morphine+dexamethasone+midazolam
(morphine sulphate and tartrate)	(morphine sulphate SI, tartrate SI)
morphine+cyclizine+midazolam	morphine+dexamethasone+haloperidol
(morphine sulphate and tartrate)	(morphine sulphate and tartrate)

Auckland District Health Board 2002 4) Palliative Care Formulary on line at www.palliativedrugs.co.uk 5) Gardiner P R Compatibility of an injectable oxycodone formulation with typical diluents, syringes, tubings, infusion bags and drugs for potential co-administration. Hospital Pharmacist 2003; 10: 354-61

Appendix Four - Bristol Stool Chart

This chart is a good visual resource to "describe" faecal matter. This also gives a good indication of how long it has been in the bowel, i.e. type 1-3 have been in the bowel longer and therefore have less water content and may be harder to pass. This knowledge influences management.



http://www.nursingtimes.net/Journals/1/Files/2009/3/31/Stool%20Chart%20O4.pdf

Appendix Five – Assessment Tools

The AKPS measures the functional status of a patient and serves as a communication tool for quickly describing a patient's current functional level.

How to assess AKPS

- 1. Use the AKPS definitions to determine the initial score at the start of an episode of care.
- 2. Assess routinely. PCOC recommends a minimum of daily for inpatients and at each contact (phone or inperson) for community patients or in hospital consultative patients.
- 3. Assess whenever there is a phase change.
- 4. Assess at episode end when a patient is discharged.
- 5. Assessment may be conducted in-person or over the phone (except for initial assessment).

AKPS ASSESSMENT CRITERIA	SCORE
Normal; no complaints; no evidence of disease	100
Able to carry on normal activity; minor sign of symptoms of disease	90
Normal activity with effort; some signs or symptoms of disease	80
Cares for self; unable to carry on normal activity or to do active work	70
Able to care for most needs; but requires occasional assistance	60
Considerable assistance and frequent medical care required	50
In bed more than 50% of the time	40
Almost completely bedfast	30
Totally bedfast and requiring extensive nursing care by professionals and/or family	20
Comatose or barely rousable	10
Dead	0

Po	tential actions following AKPS assessment
Point on AKPS Scale	Recommended Action
Patient has AKPS of 90, 80 or 70 at	Consider completing an advance care planning discussion with the
episode start	patient and their substitute decision-makers.
Patient has AKPS of 60	Consider referral to allied health if patient has been in active work and
	is no longer able to work.
Patient has AKPS of 50	Consider discussion at multidisciplinary team meeting and review care
	plan
	Provide appropriate equipment as required
	Consider referrals for community packages
	Complete a caregiver assessment.
Patient has AKPS of 40 or 30	Consider discussion at multidisciplinary team meeting and review care
	plan – patient may be commencing deterioration and further supports
	may be required.
	Consider pressure area care.
	Provide appropriate equipment as required (for example, alternating
	pressure mattress).
	For community patients – consider impact of care on family caregiver.
	Complete a caregiver assessment.
Patient has AKPS of 20 or 10	Commence end of life care planning
	If death is likely in days, change to Terminal Phase.

IPOS Patient Version



Patient name	:
Date (dd/mm/yyyy)	:
Patient number	: (for staff use)

Q1. What have been your main problems or concerns over the past 3 days?

1	
2	
3	

Q2. Below is a list of symptoms, which you may or may not have experienced. For each symptom, please tick <u>one box</u> that best describes how it has <u>affected</u> you <u>over the past 3</u> <u>days</u>.

	Not at all	Slightly	Moderately	Severely	Over- whelmingly			
Pain	0	1	2	3	4			
Shortness of breath	0	1	2	3	4			
Weakness or lack of energy	0	1	2	3	4			
Nausea (feeling like you are going to be sick)	0	1	2	3	4			
Vomiting (being sick)	0	1	2	3	4			
Poor appetite	0	1	2	3	4			
Constipation	0	1	2	3	4			
Sore or dry mouth	0	1	2	3	4			
Drowsiness	0	1	2	3	4			
Poor mobility	0	1	2	3	4			
	Please list any <u>other</u> symptoms not mentioned above, and tick <u>one box</u> to show how they have <u>affected</u> you <u>over the past 3 days</u> .							
1.	0	1	2	3	4			
2.	0	1	2	3	4			
3.	ο	1	2	3	4			

	Not at all	Occasionally	Sometimes	Most of the time	Always		
Q3. Have you been feeling anxious or worried about your illness or treatment?	0	1	2	3	4		
Q4. Have any of your family or friends been anxious or worried about you?	0	1	2	3	4		
Q5. Have you been feeling depressed?	0	1	2	3	4		
	Always	Most of the time	Sometimes	Occasionally	Not at all		
Q6. Have you felt at peace?	o	1	2	3	4		
Q7. Have you been able to share how you are feeling with your family or friends as much as you wanted?	0	1	2	3	4		
Q8. Have you had as much information as you wanted?	0	1	2	3	4		
	Problems addressed/ No problems	Problems mostly addressed	Problems partly addressed	Problems hardly addressed	Problems not addressed		
Q9. Have any practical problems resulting from your illness been addressed? (such as financial or personal)	о 🗔	1	2	3	4		
	On my own	With help	With help from a member of staff				
Q10. How did you complete this questionnaire?							

If you are worried about any of the issues raised on this questionnaire then please speak to your doctor or nurse The IPOS (Integrated Palliative Outcome Scale) tool is designed to assist in the assessment of what is important to the patient, the 10 common physical symptoms (pain, shortness of breath, lack of energy, nausea, vomiting, poor appetite, constipation, sore mouth, drowsiness, and poor mobility), a rating of the emotional and spiritual wellbeing as well as highlighting practical needs.

The severity **at the time of assessment or over the previous 3 days** of each item is rated (Not at all to Overwhelming)).

It is the **patient's opinion of the severity of the symptoms** that is the "gold standard" for the assessment.

If the patient cannot do it independently but still able to provide input (e.g. when mildly cognitively impaired) the IPOS is completed with the help of family/whānau, friends or health care professionals. If the patient cannot participate at all or refuses to do so it is completed by the health professional alone. The symptoms are assed as objectively as possible.

Here are some examples of objective indicators: Pain – grimacing, guarding against painful manoeuvre Tiredness – increased amount of time spent resting Drowsiness – decreased level of alertness Nausea – retching or vomiting Appetite – quantity of food intake Shortness of breath – increased respiratory rate or effort that appears to causing distress to the patient Depression – tearfulness, flat affect, withdrawal from social interactions, irritability, decreased concentration and/or memory, disturbed sleep pattern Anxiety – agitation, flushing, restlessness, shortness of breath Wellbeing – how the patient appears overall

The IPOS provides a clinical profile of symptom severity over time and a context within which symptoms can begin to be understood. However, it is not a complete symptom assessment in itself. For good symptom management to be attained the IPOS must be used as just one part of a holistic clinical assessment.

Appendix Six – Referral Criteria for Specialist Palliative Care

Following *initial referral meeting* or any *subsequent review of service* applicability the patient is assessed against the following criteria before being admitted to the service or continuing to receive service from The Specialist Palliative Care Team

General Criteria must meet ALL of these criteria				
Must be resident within the catchment area				
Progressive incurable disease or the patient has refused treatment if competent to do so				
Presence of <i>unstable complex symptoms or psychosocial issues</i> that are important to				
the patient that are unable to be managed by the current care team				
The patient agrees to referral if competent to do so (or an advocate for them)				

PLUS

General Indicators					
 must have at least one of the following 					
Progressive deterioration in performance scale or					
Dependence in three of more activities of daily living					
Multiple co-morbidities					
Symptoms that cannot be alleviated by treating underlying disease					
Signs of malnutrition due to illness – cachexia, albumin <25g/l					
Severe documented progression of illness over recent months.					

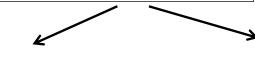
PLUS

Presence of Various Disease Specific Indicators

_		-		_		_			_	F.	_	-	 -	1
	(pleas	se	deta	ails	whi	ch	ind	icat	ors	ap	lqq	V)		

CANCER	CARDIAC	PULMONARY	RENAL	NEUROLOGICAL	STROKE	LIVER DISEASE	DEMENTIA	OTHER





Complex palliative care not able to be confirmed. Patient referred back to appropriate primary provider. Patient & Family/Whānau Informed Complex palliative care need confirmed - patient admitted to Specialist Palliative Care Service

DISEASE SPECIFIC INDICATORS

CANOED							DEMENTIA	ATUER
CANCER	CARDIAC	PULMONARY	RENAL	NEUROLOGICAL	STROKE	LIVER DISEASE	DEMENTIA	OTHER
At least one of the following is present:	At least one of the following is present:	At least one of the following is present:	Not willing or able to undergo dialysis or transplant PLUS at least one of the following	Significant progressive decline in function PLUS at least one of the following:	At least one of the following is present:	At least one of the following is present:	At least one of the following is present:	Other situations might include
CA1 Incurable metastatic disease	CD1 Advanced heart failure	PU1 Shortness of breath at rest	RE1 Patient wishes to stop dialysis	NE1 Inability to walk	ST1 Persistent vegetative state	LI1 Ascites despite maximum diuretics, spontaneous peritonitis	DE1 Inability to dress or walk without assistance	OT1 Multiple co- morbidities with no primary diagnosis
CA2 Inoperable disease	CD2 Three or more admissions to hospital within the last 12 months with symptoms of heart failure	PU2 Documented progressive disease	RE2 Signs of renal failure are present (severe nausea, pruritus, restlessness, altered consciousness)	NE2 Dependence on assistance for activities of daily life	ST2 Severe dysphagia	LI2 Jaundice; hepatorenal syndrome	DE2 Urinary or faecal incontinence	OT2 Patient medically unfit for surgery for life-threatening disease
CA3 Complex symptoms	CD3 Physical symptoms despite optimal tolerated therapy	PU3 Symptomatic right heart failure	RE3 Intractable fluid overload	NE3 Barely intelligible speech, difficulty in communication	ST3 Post stroke dementia	LI3 PTT> five seconds above control	DE3 No consistent meaningful verbal communicati on: PLUS at least one of the following	OT3 Failure to respond to Intensive Care (in ICU, CCU, SCBU, PICU)and death therefore inevitable
CA4 Complex psychosocia l issues	CD4 Psychological symptoms despite optimal tolerated therapy	PU4 Cachexia	RE4 Rapid deterioration anticipated by Renal Team	NE4 Cachexia; difficulty eating and drinking and declines feeding tube	ST4 Poor nutritional status	LI4 Encephalopa thy	DE4 Difficulty swallowing/e ating; >10% weight loss over the last 6 months	
	CD5 Symptomatic arrhythmias resistant to treatment			NE5 Significant dyspnoea and/or requires oxygen at rest and declines assisted ventilation		LI5 Recurrent variceal bleeding if further treatment inappropriate	DE5 Recurrent urinary and/or respiratory infections	
	CD6 Physical damage (e.g. stroke) following resuscitation for cardiac arrest.						DE6 Multiple Staff III or IV decubitus ulcers	
							DE7 Symptoms causing distress	

Adapted for North Haven Hospice from Specialist Palliative Care Referral and Referral Criteria East Cheshire.

Appendix Seven – Social/ Emotional/ Spiritual Assessment

1. Awareness of Diagnosis/Illness:

Issues: circumstances, unexpected, untimely, traumatic, concurrent "What happened when you were given your diagnosis?"

2. Concurrent crises and past issues:

Issues: other crises e.g. financial, residential, care issues, other losses "What other things are going on at the same time as the illness?" "Have you had other losses to deal with?" "How have you dealt with these losses?"

3. Relationships

Issues: Patient's role in the family, patient's age, blended family, isolation of nuclear family

"Can you tell me a little about your family?"

4. Social Supports

Issues: family and social supports, level of support, grief reactions, depression, anxiety "How have things been with your family and friends?"

5. Patient's Wishes & Goals

Issues: Where the patient wants to be cared for, what level of support would be required, the family's ability to provide care, patient's/family's need of financial support and services available

"Where would you like to be cared for?" "How could this happen?"

6. Spiritual Beliefs

Issues: meaning, purpose, spiritual isolation, loss of connection with faith in God "How are your spiritual needs met?"

7. Are there any specific cultural/religious/spiritual needs?

8. Expectation of Palliative Support Services

"What do you expect from the Hospice Support Services?" "Is there anything you can think of that you want/don't want?"

Appendix Eight – Alternative to CSCI use

CSCI (Syringe Driver) MEDICATION If on	BUCCAL/SL option Extreme caution in unconscious patients	PR option	TRANSDERMAL option	<u>SC Bolus</u> option
MORPHINE SC:Rectal = 1:2 SC:Oral = 1:2 Oral:Rectal = 1:1	RA-morph elixir 5mg/ml and 10mg/ml formulations Divide into q4h doses	Arrow Morphine LA tabs Use tablets rectally BD	Fentanyl patch See table below*	
METHADONE SC:Oral = 1:1 SC:Oral = 1:1 Oral:Rectal= 1:1	Methadone Use 10mg/ml formulation Total daily SC dose as total daily buccal dose (Divide and give either BD or TDS)	Methadone Use 5mg tabs rectally Total daily SC dose as total daily rectal dose (Divide and give either BD or TDS)		
FENTANYL			Fentanyl patch See table below*	
BUSCOPAN (for secretions)	Atropine drops 1 drop up to QID, consult palliative care team if needing increased dose		Hyoscine hydrobromide patch 1.5mg/patch = Buscopan 30mg	
HALOPERIDOL	Olanzapine dispersible 5mg tab 5mg = Haloperidol 2mg	Haloperidol tabs 0.5mg, 1.5mg and 5mg give same total dose in divided amounts BD PR (SC:Rectal= 1:1)		Haloperidol 5mg/ml inj Divide CSCI dose by 2 and give BD
LEVOMEPROMAZINE SC:Rectal = 1:1	Olanzapine dispersible 5mg tab 5mg = Levomepromazine 12.5mg	Levomepromazine 25mg tab		
MIDAZOLAM	Clonazepam drops (1 drop=0.1mg) 5-10 drop BD =15mg Midazolam Lorazepam tabs 2mg QID = 15mg Midazolam	Diazepam (Stesolid 5 and 10mg) Given BD or TDS 20-30mg = 15mg Midazolam		

Moving away from <u>CSCI (Syringe Driver)</u> towards alternative routes of administering <u>REGULAR medications</u> to maximise patient/family independence at end-of-life KEY: FIRST LINE, SECOND LINE, THIRD LINE

Fentanyl patch	Fentanyl dose	Oral morphine
(mcg/hour)	(mcg/day)	(mg/24H)
1⁄2 12.5	150mcg/day	<30
12.5	300mcg/day	30-59
25	600mcg/day	60-134
50	1200mcg/day	135-224
75	1800mcg/day	225-314
100	2400mcg/day	315-404

*<mark>PO morphine:TD/SC fentanyl = 150:1</mark>

*When cutting a fentanyl patch cut diagonally across the backing join from corner to corner NOT parallel to it

Moving away from <u>SC PRNs</u> towards alternative routes of administering <u>PRN</u> medications to maximise patient/family independence at end-of-life

SC MEDICATION	BUCCAL option	PR option	TRANSDERMAL	SC PRN
	Extreme caution in		option	BOLUS
If on	unconscious			
	patients			
MORPHINE	RA-morph elixir	Sevredol 10 and		SC Morphine
SC:0ral = 1:2	5mg/ml and	20mg tabs		
	10mg/ml			
	formulations			-
METHADONE	°	one for PRN pain relief ple	ease discuss with Pall	iative Care Team
FENTANYL	Fentanyl injection			
	100mcg/2ml			
	25mcg (0.5ml) =			
DUCCODAN	2.5mg morphine			
BUSCOPAN	Atropine drops			SC Buscopan
	1 drop up to QID,			
	consult palliative			
	care team if			
	needing increased dose			
HALOPERIDOL	Olanzapine wafers	Haloperidol tab		SC Haloperidol
HALOFERIDOL	5 mg and 10 mg	0.5mg and 1.5mg		Schalopendoi
	wafers available	tabs available		
LEVOMEPROMAZINE	Olanzapine 5mg	Levomepromazine		SC Levo-
SC:Buccal = 1:1	dispersible tab	25mg tab		mepromazine
SC:Rectal = 1:1	5mg= 12.5mg			
	Levomepromazine			
	Levomepromazine			
	injection 25mg/ml			
MIDAZOLAM	**Midazolam spray			
SC:Buccal 1:1	1 spray = 0.5mg			
	Midazolam			

**Midazolam spray

5 ampules of 15mg/3ml into 1 bottle

75mg/bottle = 500mcg (0.5mg)/puff

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Te Ara Whakapiri: Toolkit https://www.health.govt.nz/system/files/documents/publications/te-ara-whakapiritoolkit-apr17.pdf

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