The Rehab Mindset in Palliative Care

Brian Phelan (brian.Phelan@teomanga.org.nz)

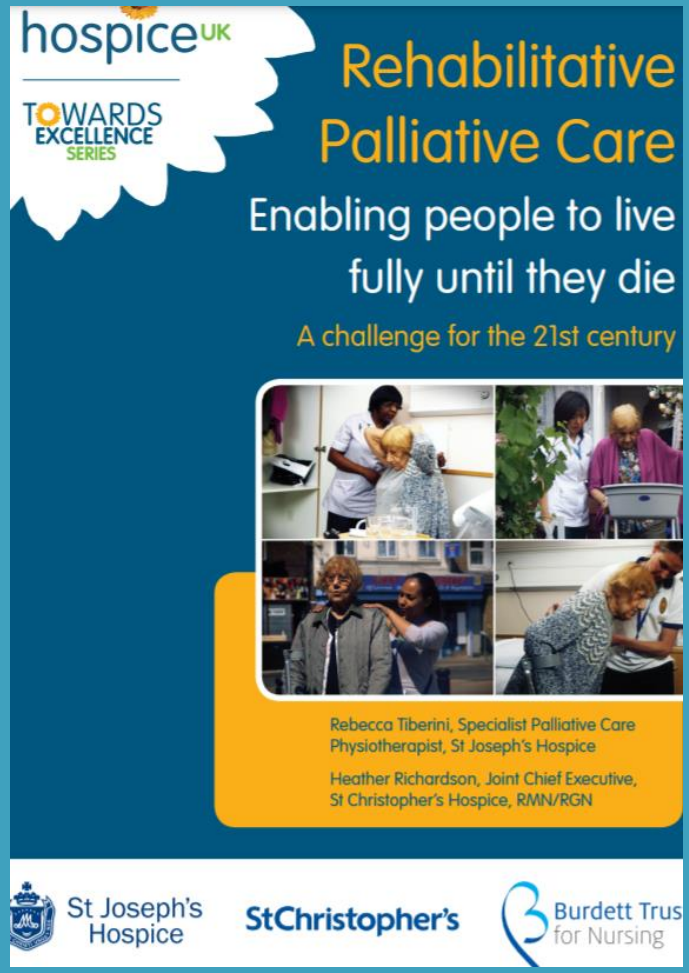
Te Omanga Hospice
Te Whare Manaaki Tangata

Overview

Rehabilitative Palliative Care – What, why, when

PT at Te Omanga Hospice – PC specific soft and hard skills

Charlotte – Resilience Strategies in relation to death and dying



Te Omanga Hospice
Te Whare Manaaki Tangata

Rate out of 10

- 1. How much do you understand the concept of ‘Palliative Care Rehabilitation’?
- 2. How confident are you in advocating for a rehabilitative approach to PC patients, whanau and the MDT?
- 3. How confident are you with intervening in common palliative care symptoms?
- 4. How confident are you in answering ‘difficult’ questions?
- 5. How satisfied are you that you understand the role of and options for managing work related grief?

The ambition of Rehabilitative Palliative Care is “the transformation of the dying into the living…the restoration of a patient to a person” (Derek Doyle, 2004).

Rehabilitative vs Trad PC

‘Dying well’
vs
Living well with dying

Medical vs Holistic
(Not just symptom management)

Care vs Enablement
(Optimise comfort yes but not the full story)

‘Traditional’ PC + Rehab = QOL

The PC Rehab Approach

An enabling approach designed to empower independence

Risk Confidence! (vs maximise safety)

Anticipate and cope constructively with losses resulting from deteriorating health

Empower people to adapt to new state of being with dignity

Optimise function and wellbeing – personal goals and priorities

Support people to live fully until they die

The PC Rehab Mindset

Interdisciplinary approach - everyone needs to be on board

Collaboration between patients, carers, whānau and wider MDT

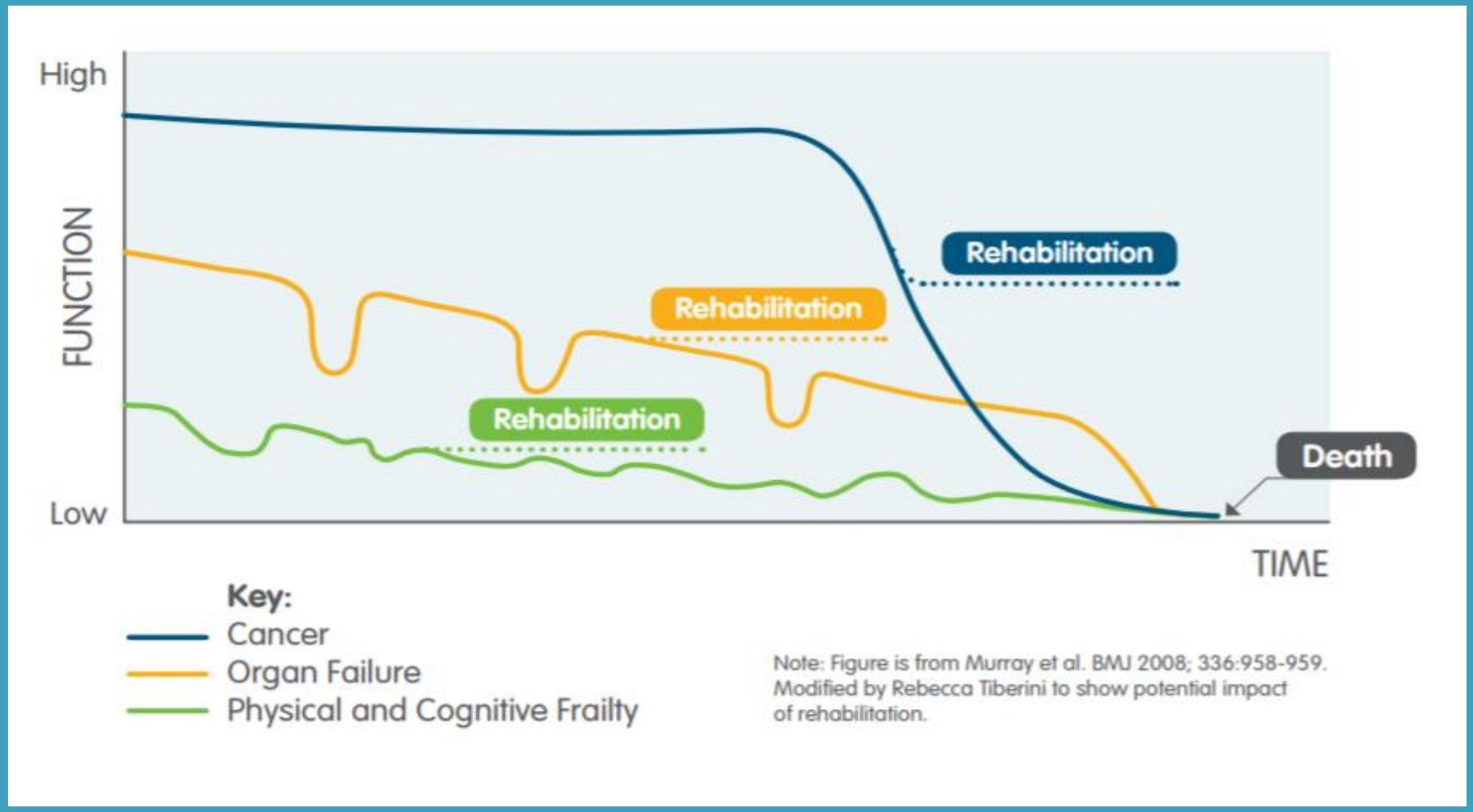
Organisational Mindset/Philosophy of Care

Rehab Mindset- Why?

- **Patient priorities and preferences** – Maintain normality, maintain function and independence,
- **Responding to Future Challenges** – Demography, increasingly chronic diseases, increasingly complex needs (36,300 NZ Deaths in 2023, 53,900 predicated in 2043 with biggest increase in aged care facilities)
- **Robust Evidence** – Rehab in advanced Cancer, advanced respiratory and Cardiovascular disease, advanced neurological conditions, older people and dementia
- **Economic benefits** – Reduce hospital admissions, earlier discharge from hospital/hospice, delay ARC admissions, decreased social care costs

Te Omanga Hospice
Te Whare Manaaki Tangata

Rehab Mindset - When?



Rehab Mindset – Core Principles

- **Person-centred goal setting** – MDT support of patient priorities
- **Focus on Function (not just symptoms)** - MDT, holistic, comfort + function
- **Enable Independence** – MDT mindset geared towards empowering patients to maximise control and choice, optimal support level for safety/comfort + independence
- **Supportive self-management** – MDT encourages patients (and whanau) to play an active role in managing their illness and it's effects

- **PT 101 – job is to both apply to palliative patients ourselves and to engender in wider MDT, patient and whanau**

Te Omanga Hospice
Te Whare Manaaki Tangata

PC Rehab in Practice

Personal/Professional Confidence Barriers

Symptom/Problem Specific Tips and Tricks

Te Omanga Hospice
Te Whare Manaaki Tangata

Specialist Generalists

- Context Specialists, Skills Generalists
- Goal setting – Client directed, QOL focus, priorities, predicted deterioration
- Holistic – Large MDT + whanau - Physical, Psychosocial but also Spiritual and Cultural (TOH councilors, art therapy, music therapy, supportive therapies, spiritual adviser, Maori liaison officer)
- Pragmatic and practical problem solving – Risk Confidence!
- Palliative Care specific self-care (Charlotte)
- Communication skills
- Difficult Questions

Communication Tips

- Direct Language – say cancer, death, dying etc
- Short term ‘kindness’ can create downstream issues
- Open Q’s & The Power of Pauses
- The ‘How Long Left’ Question – Rule of thumb: Changes on monthly basis suggest months left, changes on a weekly basis suggest weeks left and daily changes suggest days left
- Big Q’s are evidence of high regard and trust (see it as a privilege!)
- Humor, positive energy – death is absurd and taboo therefore a great source of humor – PT’s uniquely well positioned for this

Te Omanga Hospice
Te Whare Manaaki Tangata

When are patients nearing EOL

Three triggers;

1. The Surprise Question: ‘ Would you be surprised if this patient were to die in the next few months, weeks, days?
2. General Indicators of decline – deterioration, increasing need, or choice for no further active care
3. Specific clinical indicators related to certain conditions

https://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf

Self Care = Professionalism

- Personal self-care – the usual suspects including exercise, sleep, diet, mindfulness, gratitude, journalling, talk therapies etc
- Professional self-care – supervision support, leadership, written reflections etc
- Palliative Care specific self-care (Charlotte) – sudden grief vs ‘bereavement creep’
- Philosophical/spiritual interest – death is what gives life meaning

Bread and Butter PC Physio

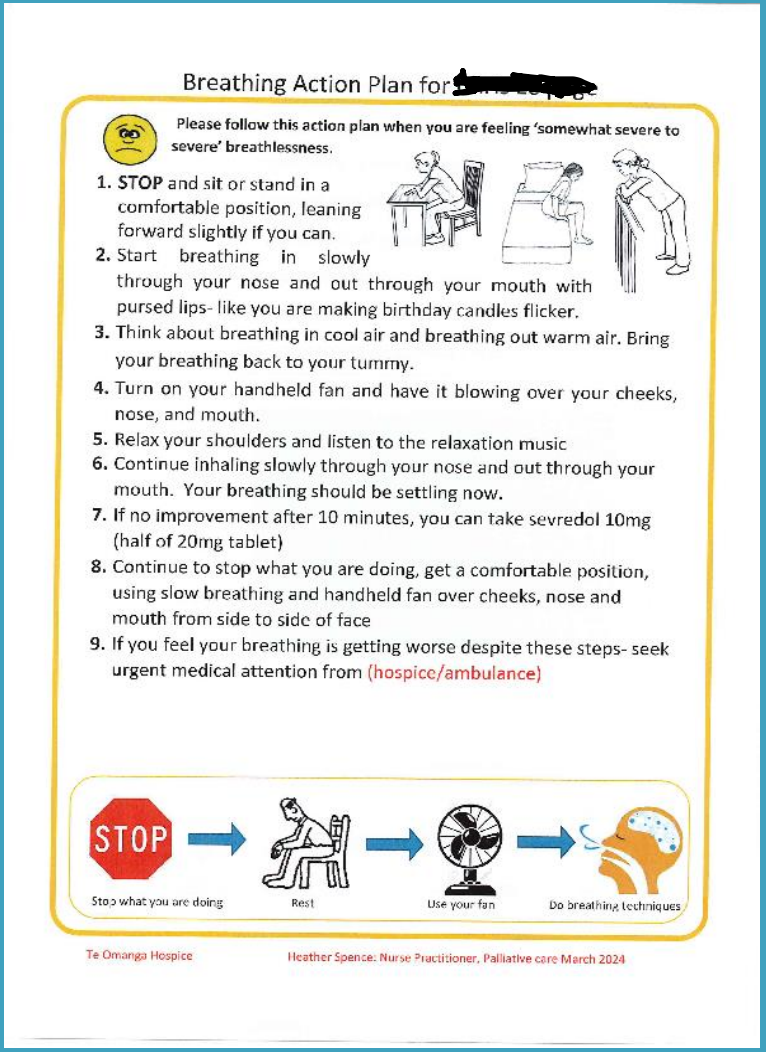
- Symptom Management – Pain, Dyspnoea, Fatigue, Anxiety, Breathlessness (Lymphoedema)
- *Proactive* Falls prevention
- *Proactive* Equipment provision
- *Proactive* manual handling advice/training for whanau/carers
- MDT Communication – Community/IPU/ Hospital (complexity management)
- Triage/Referrals

Click to add text

Breathlessness

- Breathing mechanics – ‘nose, low and slow’
- Fatigue management and 4P’s of energy conservation
- Positions of ease, mobility aids
- Pursed lip breathing
- Handheld fans (have some in stock!)
- Breathlessness Action Plan - Meds plus day-to-day strategies

Breathlessness Action Plan



Breathing Action Plan for [redacted]

Please follow this action plan when you are feeling 'somewhat severe to severe' breathlessness.

1. **STOP** and sit or stand in a comfortable position, leaning forward slightly if you can.
2. Start breathing in slowly through your nose and out through your mouth with pursed lips- like you are making birthday candles flicker.
3. Think about breathing in cool air and breathing out warm air. Bring your breathing back to your tummy.
4. Turn on your handheld fan and have it blowing over your cheeks, nose, and mouth.
5. Relax your shoulders and listen to the relaxation music
6. Continue inhaling slowly through your nose and out through your mouth. Your breathing should be settling now.
7. If no improvement after 10 minutes, you can take sevredol 10mg (half of 20mg tablet)
8. Continue to stop what you are doing, get a comfortable position, using slow breathing and handheld fan over cheeks, nose and mouth from side to side of face
9. If you feel your breathing is getting worse despite these steps- seek urgent medical attention from (hospice/ambulance)

Te Omanga Hospice

Heather Spence: Nurse Practitioner, Palliative care March 2024

Breathing Action Plan for [redacted]

I have had this feeling before

I know it will go away soon

I am going to lean forward

I am going to use my fan

Focus on gently breathing out

I can do this- I am doing it now

I don't need to be frightened- I am ok

BORG BREATHING SCALE

0	NOTHING AT ALL
0.5	VERY, VERY SLIGHT (just noticeable)
1	VERY SLIGHT
2	SLIGHT
3	MODERATE
4	SOMEWHAT SEVERE
5	SEVERE
6	
7	VERY SEVERE
8	
9	VERY, VERY SEVERE (almost maximal)
10	MAXIMAL

Heather Spence: Nurse Practitioner, Palliative care March 2024

Te Omanga Hospice
Te Whare Manaaki Tangata

Acute ‘Panicky’ Breathlessness

- **Make your ‘Out Breath Longer’, ‘Out Breath Longer’, ‘Out breath longer’….**
- Use as a Mantra – on repeat
- Simplified and easy to remember in very acute situation
- Helps tame uncontrolled thoughts and uncontrolled breathing
- Harness ANS response to extended out breaths
- Teach to patient and carers – carers repeat same mantra – gives carers confidence which feeds into bigger picture

Neurological Disorders

- Management of ‘predicted’ (likely more complicated) deterioration
- Manual handling training for whanu and staff
- NB: The ‘Dexa journey’
- Steroid induced Proximal Myopathy
- Progressive neuromuscular disorders – Early Respiratory Intervention! (Breath stacking, Lung Volume Recruitment Bag (LVRB), manual cough assist, cough assist machine etc)
- Ataxias and inattention – implications for equip and manual handling etc
- All neuro patients to get early PT referral

Exercise Prescription

- For: Fatigue, QOL, self esteem, muscle mass, sleep, pain etc
- Individualized – fears vs capabilities vs hopes
- Goal setting – aim for incremental improvements with daily goal reset option
- ‘exercise session’ vs ’Little and often’
- Motivation (pushy?) vs Support (enable?)
- Prescribe and review vs general guidance

Te Omanga Hospice
Te Whare Manaaki Tangata

Key Take Homes

- Rehab Mindset in PC
  - Mindset/Philosophy change for entire MDT
  - Patient/Whanau focused goals not goals of MDT
  - Risk confidence vs safety at all costs
  - Enablement plus care
  - Living well with Dying vs Dying well
- Personal/Professional Confidence: Direct communication – Big Q's a privilege - Prognosis guidelines – self care
- Symptom Specifics – 'out breath mantra', early neuro planning, daily goal reset

Te Omanga Hospice
Te Whare Manaaki Tangata

Useful links and books

- https://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf
- https://hukstage-new-bucket.s3.eu-west-2.amazonaws.com/s3fs-public/2022-10/rehabilitative-palliative-care-enabling-people-to-live-fully-until-they-die.pdf
- Textbook: Potential and Possibility: Rehabilitation at end of life: Physiotherapy in Palliative Care
- Narrative Book: Kathryn Mannix – With the End in Mind

Thanks for listening !

Q&A

Te Omanga Hospice
Te Whare Manaaki Tangata

Self care-resilience strategies for dealing with death and dying

Charlotte Ferrick-
Aged residential care palliative care facilitator
Te Omanga Hospice

Te Omanga Hospice
Te Whare Manaaki Tangata

Independent allied health care workers

Allied health professionals provide a diverse range of interventions that prevent or slow the progression of conditions and empower older people to live full and active lives. Allied health interventions include assessment, diagnosis and therapies which enable people to maintain their level of mobility, hearing, sight, speech and swallowing, as well as nutrition.

Physiotherapists are employed to assess patient's mobility and to maintain their independence and attend facilities on a regular basis – usually twice a week for 3-4 hours at a time. They generally have a physio assistant with them to support their assessments.

This autonomous way of working has many benefits-to residents, their families and the facility but it can also be quite an isolating way of working, with minimal support.

Connecting dying and death with grieving for our relationship with a resident and their whānau

- Palliative care is provided by large MDT-

- Rest home level
- Hospital level

- When a resident begins to enter the dying phase-changes include
- Level of cognition
- Rapid or gradual physical decline
- Length of time spent with resident and intensity of interactions

- grieving for loss of unique relationship/connection

Recognising compassion fatigue

- Compassion fatigue can cause many different emotions;
- Anger, irritability, annoyance
- Cynical, embittered, resentful
- Mood swings, tearful and despair
- Anxiety and irrational fears
- Changes in cognitive functioning
- Physical fatigue/lack of concentration

Physical and psychological of Compassion fatigue

- Physical signs include;
- Headaches, migraines
- Nausea, vomiting ,diarrhoea
- High circulating cortisol levels- increase susceptibility to illness

- Psychological signs include;
- Anxiety, clinical depression
- Addictions- smoking.gambling,drugs,alcohol
- Eating disorders

Te Omanga Hospice
Te Whare Manaaki Tangata

Recognising emotional resilience in others and ourselves;

- Ability to self-calm
- Exercises self-care
- Ability to self-replenish
- Emotional expressiveness
- Nonjudgmental/self-supporting (lack of perfectionism)
- Optimism
- Hope
- Hardiness
- Sense of coherence
- Social support- in and out of workplace

Develop self-replenishing/self-care strategies:

- Acknowledge emotions and express them
- Practice self-care and assessment (exercise, sleep, follow a healthy diet)
- Reduce life stress outside work
- Recognise compassion fatigue and burnout across multidisciplinary teams
- Seek out mentorship. Recognising different colleagues providing support- male / male friendships important in largely female orientated area
- Talk with coworkers after particularly difficult patient and professional encounters
- Engage with counseling and behavioral resources as needed

Most importantly; self care =self talk=practicalities

- Self-care is a critical component of building resilience-requires intentional effort
- Changing the narrative to ourselves is important
- Being more forgiving-of our words/actions/thoughts-following frustrating situations
- Allow ourselves time to reflect/recover between resident visits
- Learning what helps us feel better-(for myself I have always found solace looking at being near the sea-both calm and volatile)
- Leave work on time

References

Mathieu F. The Compassion Fatigue Workbook: Creative Tools for Transforming Compassion Fatigue and Vicarious Traumatization New York. New York: Routledge; 2011. [Google Scholar] [Ref list]

Fighting Compassion Fatigue and Burnout by Building Emotional Resilience

December 2018 Vol 9, No 12

JaLisa Boyd, Gentry E, Narvarte K. A quantitative and qualitative quality-of-life evaluation of a large navigation team. Journal of Oncology Navigation & Survivorship. 2017;8(11):526.

Rate out of 10

- 1. How much do you understand the concept of ‘Palliative Care Rehabilitation’?
- 2. How confident are you in advocating for a rehabilitative approach to PC patients, whanau and the MDT?
- 3. How confident are you with intervening in common palliative care symptoms?
- 4. How confident are you in answering ‘difficult’ questions?
- 5. How satisfied are you that you understand the role of and options for managing work related grief?