

PALLIATIVE PERFORMANCE SCALE (PPS): A MULTI-FUNCTIONAL TOOL

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Today's workshop:

- Introduction of the Palliative Performance Scale
- The 'why' and 'when' of its creation
- Multiple functions of PPS
- Benefits for patients, families & clinicians
- South Canterbury pilot project, 2014
- Case studies and hands-on use of PPS

History:

- Originated at Victoria Hospice, Canada in 1986:
 - Changing needs for patients & families:
 - Increased # desiring home death
 - More care being delivered in community
 - Palliative care expansion:
 - Cancer formerly 98% of patients.
 - Inclusive of non-cancer diagnoses:
 - Heart Disease
 - Lung Disease
 - Stroke
 - Kidney Disease
 - Dementia, Frailty
 - Motor Neuron Disease
 - Need for assessment & rapid communication tool:
 - Larger teams with multiple people providing care

History (cont'd)

- Over 30 yrs, it has gradually gained acceptance & is now being used across Canada.
- Researched and validated. (Journal articles in later slide)
- Translated into 10 languages
- Not only in Hospice setting but also acute care & rest homes
- Since Jan 2014, used in Timaru community palliative care, Hospice South Canterbury, Pain Team and Nurse Maude in Christchurch

Inspired by KPS:

Score	Karnofsky Performance Scale (KPS)
100%	Normal; no complaints; no evidence of disease
90%	Able to carry on normal activity; minor signs or symptoms
80%	Normal activity with effort; some signs or symptoms of disease
70%	Cares for self; unable to carry on normal work or to do active work
60%	Requires occasional assistance but is able to care for most of his needs
50%	Requires considerable assistance and frequent medical care
40%	Disabled; requires special care and assistance
30%	Severely disabled; <u>hospitalization necessary</u> active supportive treatment is necessary
20%	Very sick; hospitalization necessary; active supportive treatment is necessary
10%	Moribund; fatal processes progressing rapidly
0%	Dead

Overview:

- PPS is a simple measurement tool:
 - pt function + illness + intake + LOC
- Both base-line and ongoing as you do additional assessments.
- Includes the main indicators of disease and pt function.
- Important to see the tool and understand how it works.

Palliative Performance Scale (PPSV2)

PPS	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
PPS 100%	Full	Normal Activity No Evidence of Disease	Full	Normal	Full
PPS 90%	Full	Normal Activity Some Disease	Full	Normal	Full
PPS 80%	Full	Normal Activity with Effort Some Disease	Full	Normal or Reduced	Full
PPS 70%	Reduced	Unable Normal Job/Work Some Disease	Full	Normal or Reduced	Full
PPS 60%	Reduced	Unable Hobby/House Work Significant Disease	Occasional Assistance	Normal or Reduced	Full +/- Confusion
PPS 50%	Mainly Sit/Lie	Unable to Do Any Work Extensive Disease	Considerable Assistance	Normal or Reduced	Full +/- Confusion
PPS 40%	Mainly in Bed	Unable to Do Any Work Extensive Disease	Mainly Assistance	Normal or Reduced	Full or Drowsy +/- Confusion
PPS 30%	Total Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Reduced	Full or Drowsy +/- Confusion
PPS 20%	Total Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Minimal Sips	Full or Drowsy +/- Confusion
PPS 10%	Total Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Mouth Care Only	Drowsy or Coma
PPS 0%	Death	x	x	x	x

How to Use PPS tool:

- 11 rows in increments of 10%-100%;
- no evidence of disease to PPS 0% dead.
- 5 columns describing function and abilities
- Predominantly read left to right.
- Remember that information on left holds the most weight.
 - Ambulation
 - Activity Level & Evidence of Disease

Palliative Performance Scale (PPSV2)

PPS	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal Activity No Evidence of Disease	Full	Normal	Full
90%	Full	Normal Activity Some Disease	Full	Normal	Full
80%	Full	Normal Activity with Effort Some Disease	Full	Normal or Reduced	Full
70%	Reduced	Unable Normal Job/Work Some Disease	Full	Normal or Reduced	Full
60%	Reduced	Unable Hobby/House Work Significant Disease	Occasional Assistance	Normal or Reduced	Full +/- Confusion
50%	Mainly Sit/Lie	Unable to Do Any Work Extensive Disease	Considerable Assistance	Normal or Reduced	Full +/- Confusion
40%	Mainly in Bed	Unable to Do Any Work Extensive Disease	Mainly Assistance	Normal or Reduced	Full or Drowsy +/- Confusion
30%	Total Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Reduced	Full or Drowsy +/- Confusion
20%	Total Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Minimal Sips	Full or Drowsy +/- Confusion
10%	Total Bed Bound	Unable to Do Any Work Extensive Disease	Total Care	Mouth Care Only	Drowsy or Coma
0%	Death	x	x	x	x

How to Use PPS tool:

- Determine ambulation ability then across to next and downwards until each column is determined.
- Look for the best horizontal fit. Each person is unique and may not entirely fit entirely in line.
- Definition of Terms is very important.
 - E.g PPS 60% occasional assistance to PPS 50% considerable assistance.

Instructions and Definitions

PPS level is determined by reading left to right to find a best horizontal fit. Begin at left column reading downwards until current ambulation is determined, then, read across to next and downwards until each column is determined. Thus, 'leftward' columns take precedence over 'rightward' columns. Also, see definitions of terms below.

Definition of Terms: Some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall 'best fit' using all five columns.

- 1. Ambulation** (Use term **Self-Care** to help decide the level)
 - **Full** — no restrictions, or assistance
 - **Reduced ambulation** — degree to which the patient can walk and transfer with occasional assistance
 - **Mainly sit/lie vs Mainly in bed** — the amount of time that the patient is able to sit up or needs to lie down
 - **Totally bed bound** — unable to get out of bed or do self-care
- 2. Activity & Evidence of Disease** (Use **Ambulation** to help decide the level)
 - **Activity** — Refers to normal activities linked to daily routines (ADL), house work and hobbies/leisure.
 - **Job/work** — Refers to normal activities linked to both paid and unpaid work, including homemaking and volunteer activities.
 - Both include cases in which patient continues the activity but may reduce either the time or effort involved.
- 3. Evidence of Disease**
 - **No evidence of disease** — Individual is normal and healthy with no physical or investigative evidence of disease.
 - **'Some,' 'significant,' and 'extensive' disease** — Refers to physical or investigative evidence which shows disease progression, sometimes despite active treatments.

Example 1: Breast cancer:
some = a local recurrence
significant = one or two metastases in the lung or bone
extensive = multiple metastases (lung, bone, liver or brain), hypercalcaemia or other complication

Example 2: AIDS:
some = may mean the shift from HIV to AIDS
significant = progression in physical decline, new or difficult symptoms and laboratory findings with low counts
extensive = one or more serious complications with or without continuation of active antiretrovirals, antibiotics, etc

- 3. Self-Care**
 - **Full** — Able to do all normal activities such as transfer out of bed, walk, wash, toilet and eat without assistance.
 - **Occasional assistance** — Requires minor assistance from several times a week to once every day, for the activities noted above.
 - **Considerable assistance** — Requires moderate assistance every day, for some of the activities noted above (getting to the bathroom, cutting up food, etc.)
 - **Mainly assistance** — Requires major assistance every day, for most of the activities noted above (getting up, washing face and shaving, etc.) Can usually eat with minimal or no help. This may fluctuate with level of fatigue.
 - **Total care** — Always requires assistance for all care. May or may not be able to chew and swallow food.
- 4. Intake**
 - **Normal** — eats normal amounts of food for the individual as when healthy
 - **Normal or reduced** — highly variable for the individual; 'reduced' means intake is less than normal amounts when healthy
 - **Minimal to sips** — very small amounts, usually pureed or liquid, and well below normal intake.
 - **Mouth care only** — no oral intake
- 5. Conscious Level**
 - **Full** — fully alert and oriented, with normal (for the patient) cognitive abilities (thinking, memory, etc.)
 - **Full or confusion** — level of consciousness is full or may be reduced; if reduced, confusion denotes delirium or dementia which may be mild, moderate or severe, with multiple possible etiologies.
 - **Full or drowsy +/- confusion** — level of consciousness is full or may be markedly reduced; sometimes included in the term **diplop**; implies fatigue, drug side effects, delirium or closeness to death.
 - **Drowsy or coma +/- confusion** — no response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period. Usually indicates imminent death

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Should PPS be calculated from 'observed' function or 'capable' of function?

- "One area which could affect reliability in use of PPS in residential settings where patients have less opportunity for independent functioning, regardless of whether they are capable of such activity" (Head and Ritchie).
 - Thus, raters should be instructed to ask appropriate questions about **what the patients is able to do**, rather than formulating the rating solely from observation

Head B, Ritchie CS, Smoot TM. Prognostication in hospice care: can the palliative performance scale help? *Journal of Palliative Medicine*. 2005;8(3):492-502

Improper use:

- Some staff not using PPS properly
 1. Not what pt **is** doing, but what **could** do
 - Eg. Mainly in bed
 2. PPS 30% often inaccurately used
 - Total bed bound
 - **Total** care

Why? Where's the value?

- Any good tool should:
 - Make your job easier
 - Help your understanding
 - Help improve care
- How can it help patients and caregivers?
 - What do they need now? How/who?
 - What support should we put in place for discharge?
 - What can they expect in the next few weeks?

One tool.....multiple functions



1. Assessment Tool:

- Gives initial 'snapshot' of the patient's condition/function within their disease trajectory
- Additional assessments ongoing, provide further information on patient's condition, rate of decline.
- Gives information about what patient might need:
 - Physical/emotional support /teaching
 - Equipment /medications
 - In Timaru, OT's use PPS to access equipment needs
 - When appropriate to have SC medications/syringe driver in the home?
 - In Canada, PPS 40% & below, all meds at no cost

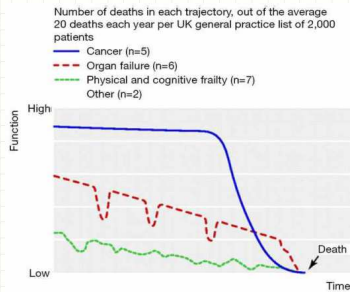
2. Communication tool:

- When giving report, asking for orders OR charting:
 - Efficient
 - Succinct
 - Simple but Informative
 - You can say a lot in a few words.
- Mr EF, Age 56, Dx Ca pancreas, PPS 50%
 - You have already given a large amount of information
 - Mainly sit/lie
 - Extensive disease
 - Needs considerable assistance

Communication (cont'd)

- Everyone has to speak/understand the same language.
- Once there is broad understanding and consistent use of the tool, exchange of information is more streamlined
 - "The pt is PPS 10%, groaning, appears in pain."
 - "The pt is PPS 80%, groaning, reports acute onset R abd pain 10/10 past 2 hrs."
- PPS has given the framework so whomever is receiving the information already knows the context of the situation.

How long? What can we expect?



3. Prognostication Tool:

- Valuable to understand how a patient is changing or declining.
- Working from baseline percentage, you can immediately enquire back:
 - E.g What were you doing 1 month ago?
- Ongoing ratings over days or weeks, then expands to create 'bigger picture'
- Anticipate ongoing needs, provide teaching, prepare pt's & families; prevent crises.

4. Evaluation Tool:

- Mr DM. Age 69. Ca colon with diffuse abd metastases. PPS 50%
- Rectal bleeding. Weak. Severe SOB/OE. Hgb 51
- Transfusion 4 units
- PPS gradually increased to 70%
- Scheduled for palliative RT

5. Teaching tool:

- Sometimes when family members are struggling with understanding what's going on, PPS can be a valuable visual tool.
 - Particularly in very rapid declines
 - "There are changes everyday.
 - "What's next?"
 - "We're overwhelmed."
 - Or very slow, stuttering trajectories.
 - "How long will this go on?"
 - "I don't know how much longer I can do this."

PPS	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal Activity & work No Evidence of Disease	Full	Normal	Full
90%	Full	This is a time of life-threatening crisis that creates high anxiety & ambiguity.	Occasional assistance	Normal or reduced	Full or confusion
80%	Full				
70%	Full				
60%	Reduced	Unable to do hobby/housework	Signif. Disease		
50%	Mainly sit or lie	Unable to do any work	Considerable assistance	Normal or reduced	Full or confusion
		Ext. disease			

PPS	Ambulation	"The Shift to Hospice Palliative Care"			
100%	Full				
90%	Full				
80%	Full				
60%-50%	Reduced	Change in focus ■ From managing the disease to managing one's life	Patient/family losses ■ Shrinking world ■ Reviewing one's life	Emotions ■ Ambivalence ■ Hope/denial ■ Fears re future	Communication ■ Protecting others ■ Loss of words
60%	Maint				
50%	Maint	Families ■ Feeling abandoned ■ New system	■ Roles alter ■ Reactions vary, resentments arise	■ Powerlessness ■ Fears re ability to manage	■ Differences increase ■ Indirect
40%	Total				
30%	Total				
20%	Total				
10%	Total				
0%	Death				

“The Shift to Hospice Palliative Care”

Psychosocial interventions

PPS	Ambu
100%	Full
90%	Full
80%	Full
60%-50%	
60%	Reduced
50%	Mainly
40%	Mainly
30%	Total
20%	Total
10%	Total
0%	Death

- Counsel patients regarding their grief, fears & the future
- Acknowledge and support expression of emotions
- Offer opportunities for life review
- Identify what's possible: hopes, choices, actions
- Counsel the family regarding the impact of the illness: strengths, struggles, supports, coping strategies
- Acknowledge and support difficult conversations; family differences

6. Workload tool:

- Patients require more physical assistance at PPS 40-50%.
 - If large # patients at this level, addition of workload to be considered.
- Patients 10-20% require less physical care, however families need much emotional support.

6. Data planning & surveillance:

- Health authorities need data to plan effectively
 - Workload needs
 - Length of stay
 - Demographics of dying

PPS Profile Comparison SCDHB Registry
Pall Registry Apr 10, 2014

PPS Level	Count
100%	0
90%	5
80%	12
70%	18
60%	16
50%	13
40%	5
30%	0
20%	0
10%	0
0%	2

PPS rollout in SCDHB:

- **PRE**-implementation Survey Jan
- PPS Training (**over 100 staff**) Jan-Feb
 - District nurses
 - Hospice nurses, staff
 - Pain Team
 - Hospital CNS, Mgrs, Soc Work, etc
 - Physicians
- Data collection
- **POST**-implementation Survey April
 - **** small preliminary data from 15 people**

When someone tells you or you read a PPS score, to what extent do you have a good picture of the patient's functional status?

Response	Chart	Percentage	Count
Always excellent picture		6.7%	1
Usually a good picture		80.0%	12
Mixed - sometimes good, other times not		13.3%	2
Often difficult to understand		0.0%	0
Almost always unable to get good picture		0.0%	0
Undecided		0.0%	0
Not applicable as I don't use PPS		0.0%	0
Total Responses			15

86.7%

To what extent do you find PPS of "practical value" in communication (verbal & documenting among your staff)?

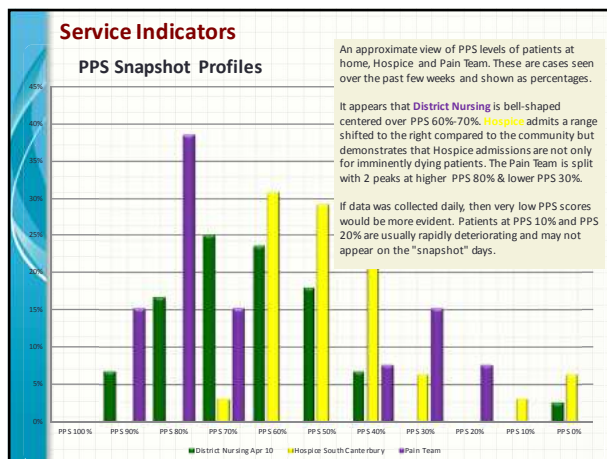
Response	Chart	Percentage	Count
No value		0.0%	0
Maybe a little value		6.7%	1
Some value		0.0%	0
Quite valuable		60.0%	9
Highly valuable		33.3%	5
Not sure/undecided/not applicable		0.0%	0
Total Responses			15

93.3%

To what extent do you think PPS should be used by all palliative services in SCDHB region?

Response	Chart	Percentage	Count
Not at all, waste of time		0.0%	0
Very skeptical but will if required		6.7%	1
Unsure but give it a try		0.0%	0
Probably useful so give it a try		13.3%	2
Very useful		40.0%	6
Very useful so should be mandated for all		40.0%	6
Undecided		0.0%	0
Total Responses			15

} 80.0%



- ### Case studies:
- Hands-on practice
 - Discussion
 - Questions?
 - Differences of opinion?
 - How might this help in your work setting?

Case 1

- Mrs. H. is a 68 year old woman whose main support persons are her husband and daughter. She had adenocarcinoma of the sigmoid colon 10 years ago, surgically resected, and was disease free until last year, now has metastases to her lungs. The oncologist is recommending chemotherapy which she is thinking about but quite hesitant. She resides at home and with the help of home support worker and home care nurse. She does her own personal care after a caregiver helps her to the bathroom. She moves slowly but is steady on her feet. At night, she uses a commode at the bedside. She spends much of the day sitting in a lazy-boy chair in the living room and falls asleep. She frequently nods off but awakens readily when roused.
- She has only one good meal a day and finishes at best, about 30% of that. She experiences pain in her right chest and lower abdomen, helped with regular analgesics. She complains of hesitancy with urination and occasional diarrhea and has periods of profuse sweating. Her left leg is edematous and her abdomen distended.

Case 2

- Mrs. JB was an 82 years old lady, admitted with Alzheimer's disease of 7 years duration. Her family felt she was getting worse and they could not manage any more at home.
- She has been bed-bound for the past 6 months. She required constant care, and has to be fed small amount of food at a time, and occasionally has aspirated. Two days ago, she started to have a low grade fever and became very drowsy.
- She responds with a grunting sound when turned or repositioned by the nursing staff. The nurse is able to give small amounts of clear fluid by syringe without causing coughing or aspiration

Case 3

- Mrs. MK is a 93 year old lady was brought to the hospital in a acute respiratory distress, chronic atrial fibrillation and left leg stasis ulcer, and was admitted overnight with a diagnosis of end stage heart disease. Her other medical problems include chronic pain syndrome with abdominal pain, pulmonary hypertension and chronic heart failure, overactive bladder, osteoporosis, macular degeneration, depression, hypertension and mild cognitive impairment.
- She was very short of breath on admission, especially on exertion, and was using oxygen at 4 l/min. She has a productive cough, with thick yellow phlegm. With significant bilateral leg edema, she requires a lot of help to walk and doesn't want to get out of bed. She has problems swallowing and suffers from GERD. Her food has been minced and required a nurse to feed her.

Case 4

- Mr. T. is a 81 year old married man living at home with his elderly wife. He was only diagnosed with cancer in the right lung three months ago and has been managing fairly well at home with the support of his wife, son who lives in town, home care nurse and home support worker. Mr. T. has been in bed and unable to do much care for himself. The home support worker has shaved and sponged him daily. The family has taken turns giving him mouth care to keep his lips and teeth moistened. Requires 2 people to turn him in the bed.
- Mr. T. sleeps most of the time but awakens when roused. His concentration is limited and he does tend to fall back asleep easily. When awake, Mr. T. can make his needs known with a few words and brief responses. He voids in the urinal during the day and wears absorbent pads at night.
- Mr. T. is tolerating full fluids some days but does experience nausea occasionally. He has had some difficulty swallowing his pills and his medications have been simplified to include only oral Morphine, lorazepam, and laxative; those necessary for comfort. He is still able to take these medications orally. Metoclopramide has just been ordered for the nausea.
- The family feel that Mr. T. has been declining over the past few weeks since admission. They think that the pain in his lower back has been escalating and they have had to increase his opioid by 50%.

Case 5

- Miss O. is a single 63 year old woman living alone in her own home, supported by close friends and home care nurse. Two years ago a subcutaneous mass on her right chest wall was discovered and squamous cell carcinoma was confirmed with unknown primary. She received radiation and chemotherapy treatments.
- She is mobile and does her personal grooming and self care. Her energy level is OK for some household activities but somewhat reduced by shortness of breath on exertion when vacuuming or scrubbing the bathtub. Friends help out with grocery shopping and a cleaning lady now does her house work. She usually sleeps well at night unless wakened by pain. Her appetite is good, and enjoys a wide variety of foods and reported no weight lost recently. She has occasional heartburn, relieved by Maalox.
- She recently gave up driving. She is alert and oriented. She has some mild bilateral lower leg edema. Pulse is strong at 80/min and her colour is pink. She continues to smoke approximately ten cigarettes a day with occasional cough. At night she sleeps with oxygen on. She has some chest wall pain and is taking oral Morphine. Recent chest x-rays showed several tumors in both lungs. She declined further treatment.

Case 6

- Mr. FS is a 41 year old man with a large rectal cancer. He is brought to the physician's office in a wheelchair. He has a history of chronic diarrhea for 15-20 years, with 5-6 bowel movement per day, and more frequently last 3-4 months, with abdominal bloating and pelvic pressure and numbness in right anterior thigh. He has difficulty in sensing fullness of bladder, difficulty passing his bowel movement with gradual increase in constipation. Blood in stools were noted since a month ago. He has weakness in right leg for which he now needs to use a cane when walking. He has also stopped fishing on his boat. Food intake is poor over the past week due to recurrent vomiting after eating. He is a smoker for 20 years, and weighs over 300 lbs.
- On examination, Mr. FS can get up and off examination table with assistance. He looks sick. No clubbing, jaundice, cyanosis or pallor detected. His chest, CVS, abdomen are all normal. Rectal examination showed an extremely large pelvic mass situated mostly anterior and onto the right side of pelvis. He and his wife want all treatments possible. He is referred for surgical consult as to developing bowel obstruction and to oncology for probable rectal radiotherapy.

Case 7

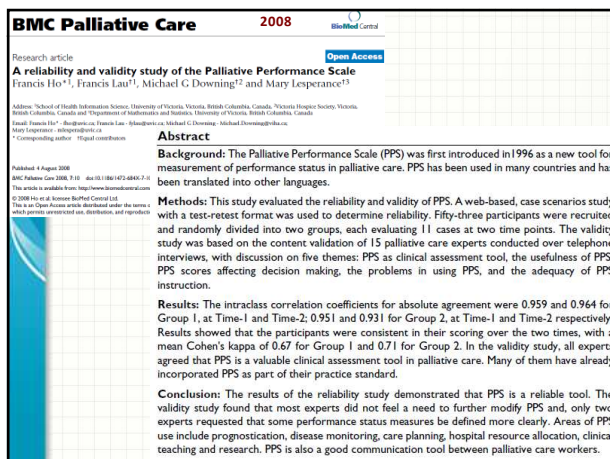
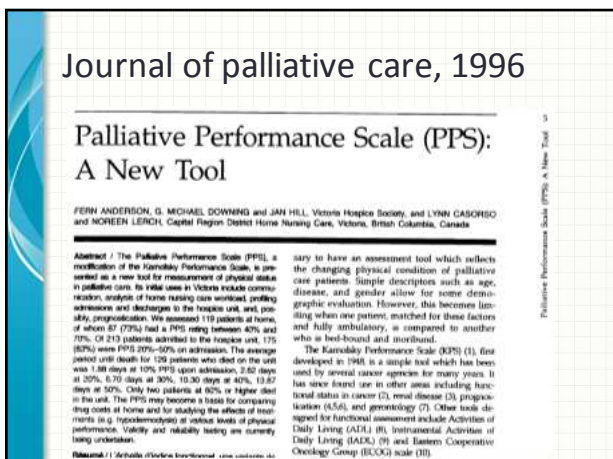
- Mrs GH is a 44 year old woman with unresectable papillary serous ovarian CA. She has had 2 courses of chemotherapy, and has felt well for a few months. She is on opioid for pain relief. Mrs. GH continues to garden but is finding it increasingly difficult in the last two weeks to finish the job. She drives her teenagers to soccer practices.
- A week ago, she developed increased abdominal pain, a tight band across abdomen, and was not wanting to take deep breath or cough. Fentanyl was increased to 500 microgram q72h. She was admitted from home, put on methadone conversion with good success in pain control. Her abdomen pain decreased. She did not think she needs further support.
- She is looking forward to be discharged home. She recognized that some drowsiness can be a side effect of her medication, and discussed that with her physician. She also experienced some fatigue and raised the question of whether she could drive. Her physician cautiously reassured her that she can continue to drive only if she does not feel drowsy, but also suggested that perhaps a mother soccer mom could pick her kids up. She sleeps well in own room.

Case 8

- Miss. M is a 70 year old single woman. She has been in the residential palliative care unit for one month. Her primary diagnosis of ductal carcinoma of the right breast 2 years ago has metastasized to her ribs, lumbar spine and liver. Mastectomy and radiation therapy were performed at the time of diagnosis.
- She is in bed all the time with staff doing her personal care. She requires frequent mouth care, turned approximately every two hours, with a Foley catheter for urine collection and bowel care with suppository or enema. She is unable to swallow and her medications have to be administered by a butterfly port, and she is not able to take in any food or fluids for the past four days.
- She is very thin and cachectic. Her skin colour and temperature of her extremities has been cool. Her breathing is shallow with intermittent apneic periods lasting for upwards of 20-45 seconds. Her breathing is also congested with an occasional harsh loose cough. Her pulse is 128 and thready. She is primarily in a continuous sleeping state and opens her eyes only when turned. She is non-responsive verbally but did frown and resist mouth care earlier this morning. Since then, the staff have not noted any further such reactions.

Thank you!

- Please see journal articles and references following.
- Contact information:
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 - tdowning@scdhb.health.nz



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