

Frailty Best Practice Conference – a hospice case study

Alison Stirton-Croft
Head of Community Services

Lea Van der Niet
Lead Nurse Hospice at Home

Introduction



- Palliative frailty and how its measured
- Complex patient case study
- Data
- Outcomes of hospice management
- Service user video

Palliative Frailty (in under 65's)



- **Understanding Palliative Frailty**

Palliative frailty in under 65s involves complex physical, psychological, and social decline requiring a shift from cure to comfort focused care. Frequently overlooked due to age and acceptance of palliative diagnosis.

- **Challenges in Care**

Younger adults face fluctuating health and difficulty accessing services designed for older or single-diagnosis patients. Delays in accessing services.

- **Hospice Support**

Hospices provide holistic, person-centered care improving symptom control, dignity, and reducing hospital admissions.

Recognizing unique challenges under 65 is vital to provide care that respects life stage and personal goals.

OACC framework

OACC - Phase of illness and AKPS

Phase of illness | Phase of illness allocation | AKPS Score | Aim & Objectives

What phase of illness is the patient in?

Phase of illness

☐ Is stable (XaIEF)

☐ Unstable status (XC0Cx)

☐ Patient's condition deteriorating (XM1UN)

☐ Imminent expected death (XaXPm)

☐ Patient died (XM01Y)

Stable - Patient's problems and symptoms are adequately controlled by established plan of care **and** further interventions to maintain symptom control and quality of life have been planned **and** family / carer situation is relatively stable and no new issue are apparent.

Unstable status - An urgent change in the plan of care or emergency treatment is required **because** the patient experiences a new problem that was not anticipated in the existing plan of care **and / or** the patient experiences a rapid increase in the severity of a current problem **and / or** family / carers circumstances change suddenly impacting on patient care

Deteriorating - The care plan is addressing anticipated needs, but requires periodic review, **because** the patient's overall functional status is declining **and** the patient experiences a gradual worsening of existing problem(s) **and / or** the patient experiences a new, but anticipated problem **and / or** the family / carer experience gradual worsening distress that impacts on the patient care

Dying - (imminent expected death) - Is death anticipated in a matter of days, requiring frequent, usually daily review with regular family/carers support

Deceased - The patient has died, bereavement support provided to family / carer's is documented in the deceased patient's clinical record

Patient's current functional status (Australia-modified Karnofsky performance status)
Used to measure how well the patient is overall and changes over time.

Karnofsky performance
Please select Karnofsky status from the drop down menu:
Please refer to reference table for guidance on Page 3

Patient's score

Australia-modified Karnofsky Performance Status scale %

N/A
100% - Normal, no complaints or evidence of disease
90% - Able to carry on normal activity, minor signs or symptoms of disease
80% - Normal activity with effort, some signs of disease
70% - Care for self, unable to carry on normal activity or do active work
60% - Able to care for most needs but requires occasional assistance
50% - Considerable assistance and frequent medical care required
40% - In bed for more than 50% of the time
30% - Almost bed bound
20% - Totally bed bound and requiring extensive nursing care by professionals and/or family
10% - Comatose or barely rouseable
0% - Dead

Complex patient case study

- 61y.o male
- Adenocarcinoma of rectum; Stoma in situ, mets to pelvic wall, attached to bladder, peritonium and lung .
- Long standing history of back pain , previous back surgery, repeated spinal root injections , used to high doses of opioids for pain management.
- Referred June 2024 – for symptom management. At point of referral on a syringe driver with Morphine 20mg, Buscopan 40mg, Haloperidol 2mg.
- “Swigging” from bottle of Oromorph.
- **What is important to the patient** – To get better and on with the remainder of my life Main issues Pain – abdominal and rectal
- Unable to tolerate NSAIDS or Gabapentin
- Socially – lives with wife, has 2 daughters locally. Previously landscaped gardener stopped 12yrs ago.

Under Isabel Hospice care:

10th June 2024 -16 September 2024

10 October 2024 – 10 July 2025

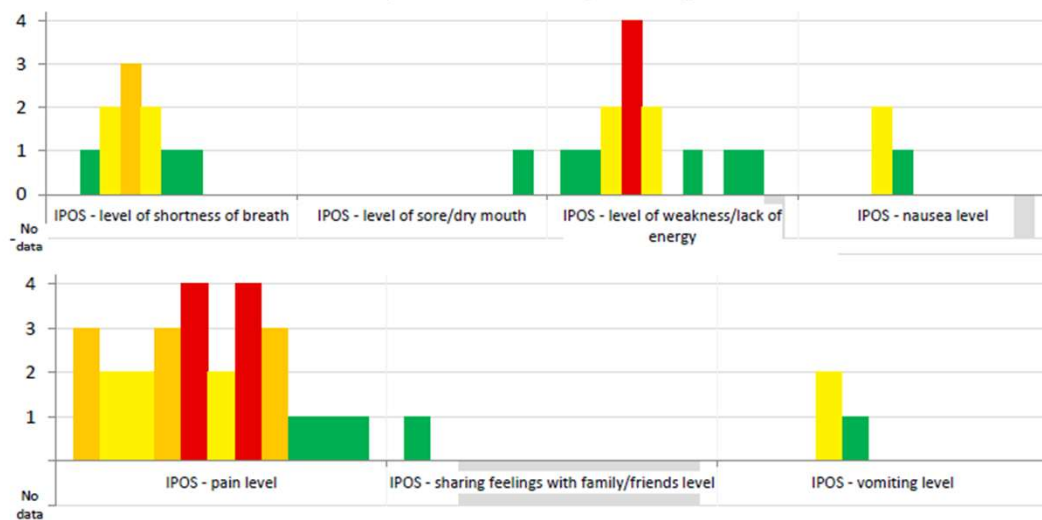
Admission to IPU 3 December 2024 – 20th December 2024

Services utilised Hospice at Home, Clinical Specialists, Palliative Doctors, HCA telephone caseload, Therapy Team, Family Support.

Physical Symptom Monitoring

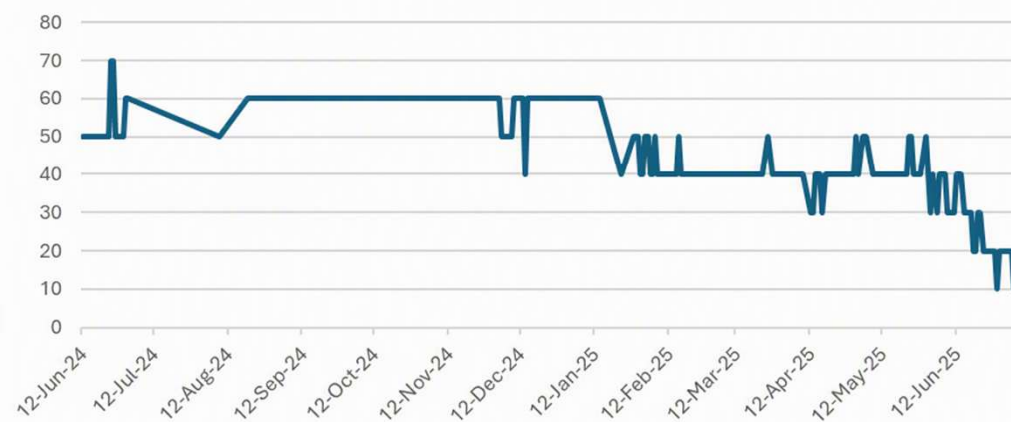


Patient responses to "How are you feeling over the last week"



Outcome measures showing symptom assessment and Changing AKPS over time.

AKPS



How did Hospice at Home support patient



Support offered

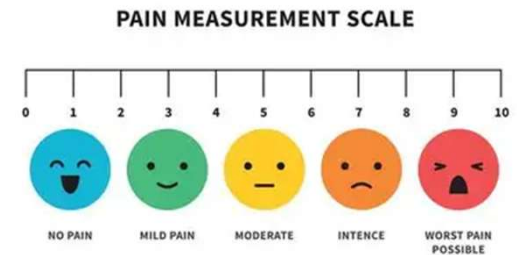
- To manage complex symptoms requiring frequent medication changes
- To provide psychological support
- To provide practical advice re diet, skincare, bowel care
- To provide advice and psychological support to wife and daughters
- To provide support at the end of life

Complex symptom control

Complex pain management :

Challenges

- Patient had different pains, pain changing as disease progressed
- Pain not fully opioid sensitive
- Patient allergic to gabapentanoid and amitriptyline not effective
- Patient developed fistula in bowel ? Absorption
- Patient had longstanding back pain and had been used to high dose medication



Challenges

- Complex medication regime
- Frequent changes in medication and doses
- Using Ketamine in community, site reactions and monitoring for adverse side effect and managing side effects
- Risk of opioid toxicity
- Ongoing management via syringe pump(s)
- High tolerance to medications
- High doses of medication via 2 syringe pumps



Other symptoms

Nausea and vomiting

Intermittent bowel obstruction

Frequent loose bowels from rectum causing burning rectal pain plus painful skin

Difficulty passing urine due to tumor being tethered problems with retention

Poor sleep due to frequent passing of loose motion via rectum with no control

Psychological distress, low mood

Other support

Support for wife to enable her to care for patient by:

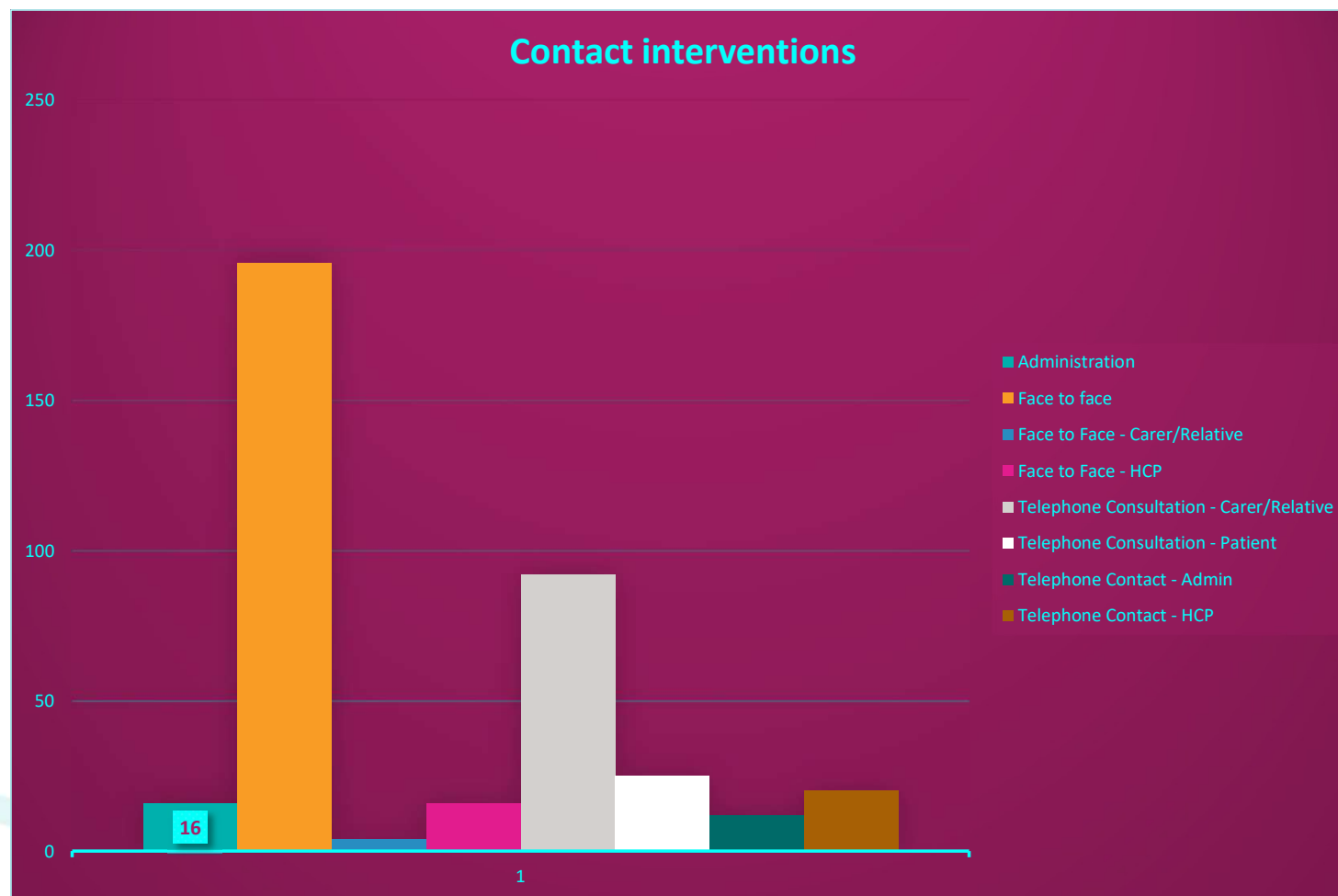
- Providing information re diet
- Re symptom control and medication management
- Practical advice re skin care
- Psychological support ongoing and throughout dying phase

Personal care

Supporting wife in last weeks of life.



Contact data



**196 Face to face home visits
from hospice team**

18 days in IPU

Is supporting the under 65's any different?

Supporting Autonomy

Maintaining Family Roles

Enhanced Symptom Control

Emotional Support and Security

Impact on families and carers



Education and Practical Guidance



Professional Support and Connection



Emotional and Psychological Care



Bereavement Support

The outcomes of Hospice management

**Reduced
Emergency
Admissions**

**Improved
Symptom
Control**

**Higher
Patient and
Family
Satisfaction**

**Support for
Staying at
Home**

- Complex Needs in Palliative Frailty
- Role of Community Hospice helps to provide holistic support
- Benefits of Early Recognition



*"How people die remains in the memory
of those who live on."*

Dame Cicely Saunders