

Early engagement in supportive care for better symptom control & future planning

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Whistle stop tour

- Palliative Vs Supportive – clearing the confusion
- Enhanced supportive care – a model for cancer care?
- Transition to non malignant disease – Liver disease
- Establishing a supportive care clinic for ILD patients
- Preliminary data for ILD and outcome tool debates

Mind your language!

Definitions in palliative care are scarce... Euphemism and catchphrasing is rife

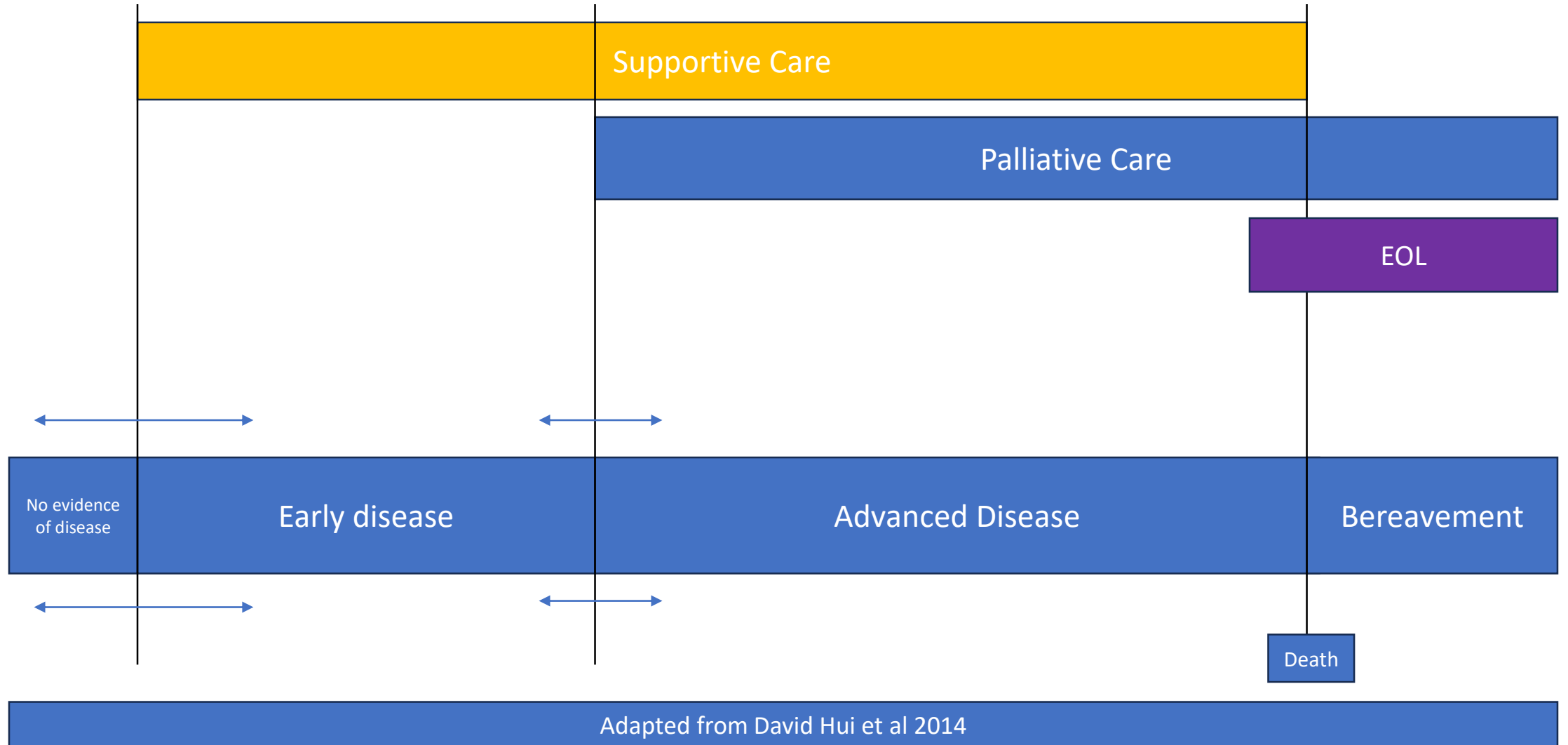
Euphemism has a Definition

A mild or indirect word or expression substituted for one considered to be too harsh or blunt when referring to something unpleasant or embarrassing.

Most of the focus in the literature has been regarding the use of euphemism when talking about death and dying. I think the issue is broader...



Finding a definition



Blurred borders simplified

Three Questions – What can I do?

What can I do to ensure this person maintains their function for as long as possible, as this will impact their prognosis and quality of life

What can I do to ensure this person understands their life limiting condition? What is important for them now and how can I help to facilitate that?

What can I do to ensure this person dies peacefully in the place of their choosing?

Enhanced Supportive Care – malignant disease

- Cancer initiative developed by the team at the Christie.
- Commissioned by NHS England and multiple services funded for 1-2 years around the UK.
- Focus on early intervention by “Supportive Care” teams with careful collection of data.
- No set demands for team members or the way the service should be structured
- Outcomes demonstrated improved mean IPOS scores across all tumour groups and a reduction in secondary care usage – giving cost savings.
- Other papers have demonstrated reductions in length of stay and number of admissions.

> [Int J Palliat Nurs.](#) 2018 Oct 2;24(10):510-514. doi: 10.12968/ijpn.2018.24.10.510.

Multi-professional-delivered enhanced supportive care improves quality of life for patients with incurable cancer

Daniel Monnery ¹, Sinead Benson ², Ann Griffiths ², Claire Cadwallader ², Julian Hampton-Matthews ³, Alison Coackley ¹, Malcolm Cooper ², Amanda Watson ¹

Review > [Support Care Cancer.](#) 2020 Aug;28(8):3467-3475. doi: 10.1007/s00520-020-05447-4

Epub 2020 Apr 27.

Supportive care in cancer—a MASCC perspective

Ian Olver ¹, Dorothy Keefe ², Jörn Herrstedt ³, David Warr ⁴, Faust

Affiliations + expand

PMID: 32342221 DOI: 10.1007/s00520-020-05447-4

Review > [Crit Rev Oncol Hematol.](#) 2022 Aug;176:103728. doi: 10.1016/j.critrevonc.2022.103728.

Epub 2022 Jun 1.

Unmet supportive care needs of people with advanced cancer and their caregivers: A systematic scoping review

Randomized Controlled Trial > [N Engl J Med.](#) 2010 Aug 19;363(8):733-42.

doi: 10.1056/NEJMoa1000678.

Early palliative care for patients with metastatic non-small-cell lung cancer

Jennifer S Temel ¹, Joseph A Greer, Alona Muzikansky, Emily R Gallagher, Sonal Admane, Vicki A Jackson, Constance M Dahlin, Craig D Blinderman, Juliet Jacobsen, William F Pirl, J Andrew Billings, Thomas J Lynch

Observational Study > [Clin Oncol \(R Coll Radiol\).](#) 2023 Jun;35(6):e395-e403.

doi: 10.1016/j.clon.2023.03.002. Epub 2023 Mar 11.

Delivery Models and Health Economics of Supportive Care Services in England: A Multicentre Analysis

D Monnery ¹, K Tredgett ², D Hooper ³, G Barringer ³, A Munton ³, M Thomas ⁴, N Vijeratnam ⁵, N Godfrey ⁵, L Summerfield ⁶, K Hawkes ⁶, P Staley ⁶, K Holyhead ⁷, Y Liu ⁸, J Lockhart ⁸, S Bass ⁹, S Tavabie ¹⁰, N White ¹⁰, E Stewart ⁹, J Droney ¹¹, O Minton ⁹

ESC/ Supportive care in – Non malignant disease

Review > Am J Respir Crit Care Med. 2019 Jul 15;200(2):152-159.

doi: 10.1164/rccm.201903-0614PP.

Comprehensive Supportive Care for Patients with Fibrosing Interstitial Lung Disease

Marlies S Wijsenbeek¹, Anne E Holland^{2 3 4}, Jeffrey J Swigris⁵, Elisabetta A Renzoni⁶

Affiliations [+ expand](#)

PMID: 31051080 DOI: 10.1164/rccm.201903-0614PP

Review > Lancet Respir Med. 2017 Dec;5(12):968-980. doi: 10.1016/S2213-2600(17)30383-1.

Epub 2017 Oct 13.

Palliative care in interstitial lung disease: living well

Michael Kreuter¹, Elisabeth Bendstrup², Anne-Marie Russell³, Sabrina Bajwah⁴, Kathleen Lindell⁵, Yochai Adir⁶, Crystal E Brown⁷, Greg Calligaro⁸, Nicola Cassidy⁹, Tamera J Corte¹⁰, Klaus Geissler¹¹, Azza Adel Hassan¹², Kerri A Johansson¹³, Ronaldo Kairalla¹⁴, Martin Kolb¹⁵, Yasuhiro Kondoh¹⁶, Sylvia Quadrelli¹⁷, Jeff Swigris¹⁸, Zarir Udawadia¹⁹, Athol Wells²⁰, Marlies Wijsenbeek²¹

Review

> Am J Hosp Palliat Care. 2022 Jun;39(6):710-715. doi: 10.1177/10499091211040232.

9.

Supportive Care for the Interstitial Lung Disease Patient: A Must and Not Just a Need

James McCormick¹, Debra Gleason¹, Jessica M McFarlin¹

[Expand](#)

DOI: 10.1177/10499091211040232

Patel, K Porayko², Andrew E Scanga², Natasha J Schneider², E Wesley Ely², Jerome³, Mary Lynn Dear³, Douglas Conway³, Reagan Buie³, J Lindsell⁷, Gordon R Bernard⁸

Supportive Care Consultations for Patients With Liver Disease

Patel², Kara E Bischoff², Angela K Marks², Nwamaka Eneanya³, Steven Z Pantilat², Areej El-Jawahri⁶

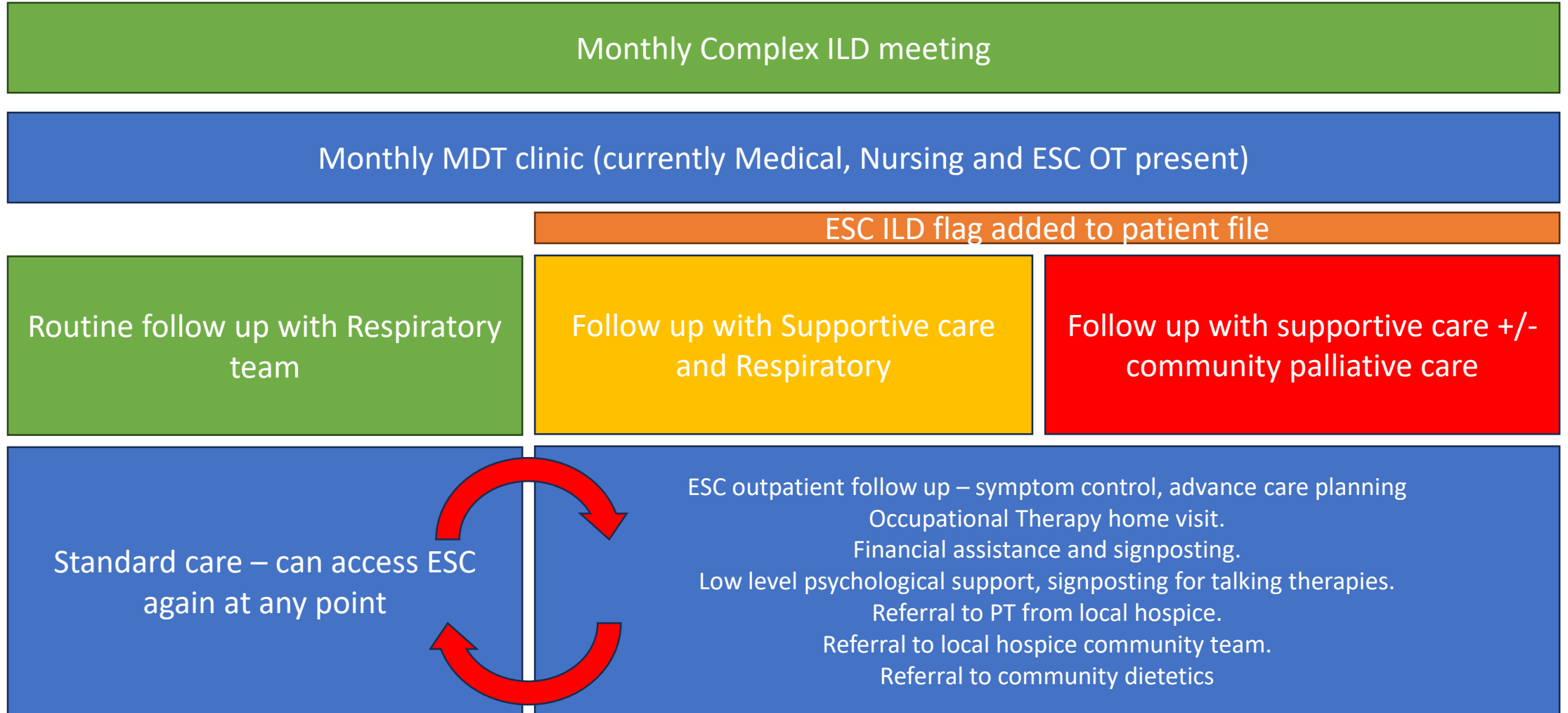
Evidence in summary

- Supportive/ early palliative care has been identified as beneficial in multiple conditions. Robust evidence is hard to collect but it is increasing.
- Evidence of improved survival in some instances.
- Better symptom control – as evidenced using outcome measures
- Reduced intervention and hospital admission at end of life
- Healthcare cost savings

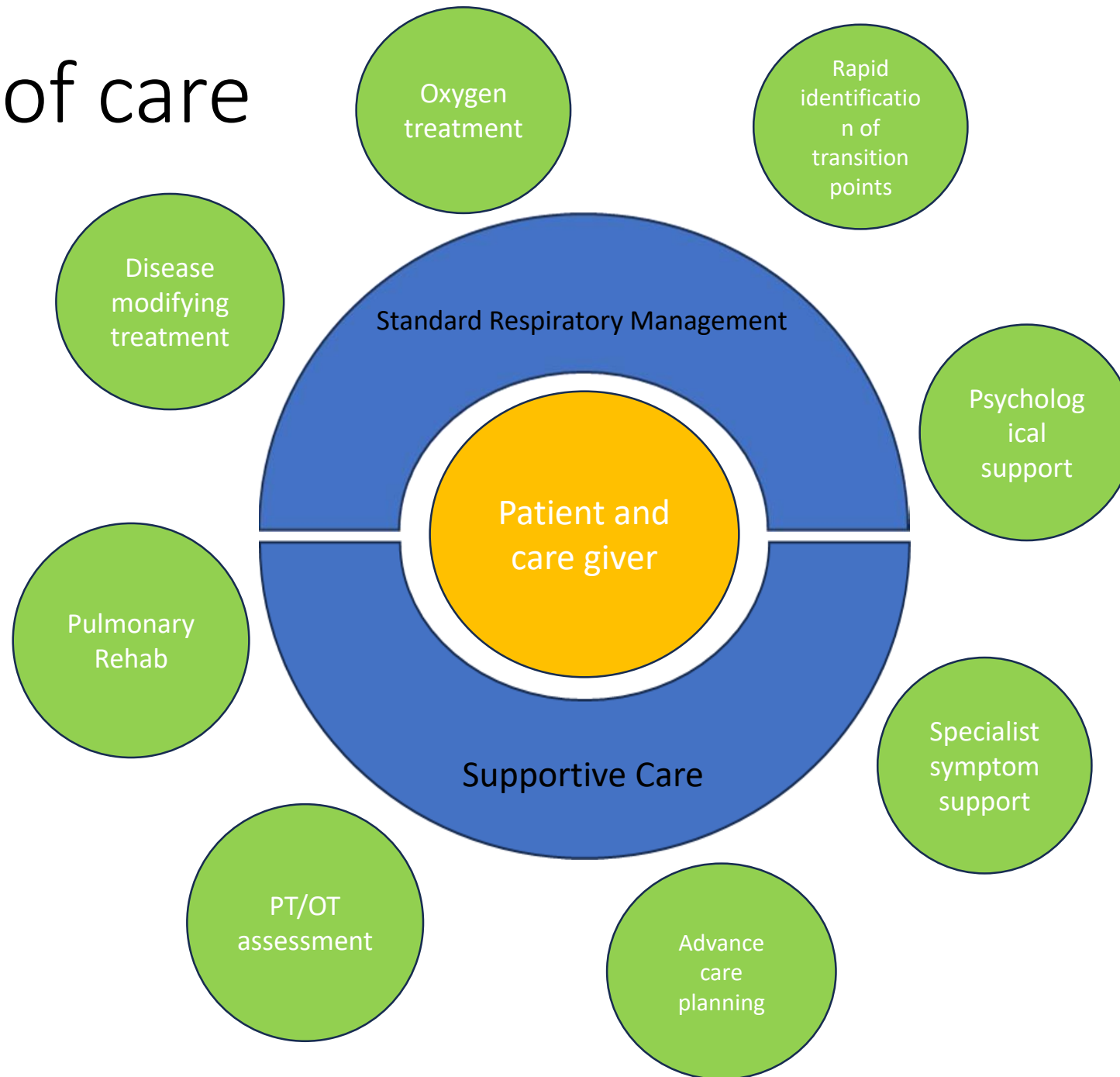
Setting up a Supportive ILD service

- Though the model for supportive care works on the idea of an MDT – sometimes you have to work with what you have!
- Clinic commenced as an addition to existing workload with a view to demonstrate QI.
- Used a trial and review model of service development.
- Utilised services already in existence to support patients once needs identified.

Where we are currently...



Model of care



Rapid identification of admission and transition points

- All patients have monitoring flags added to their hospital records
- Flags are searched daily – identifying anyone admitted who is known to the service.
- This allows for early review and improved continuity for patients
- Evidence from malignant disease groups demonstrates reduction of admission LOS average duration by 40%

Outcome measures

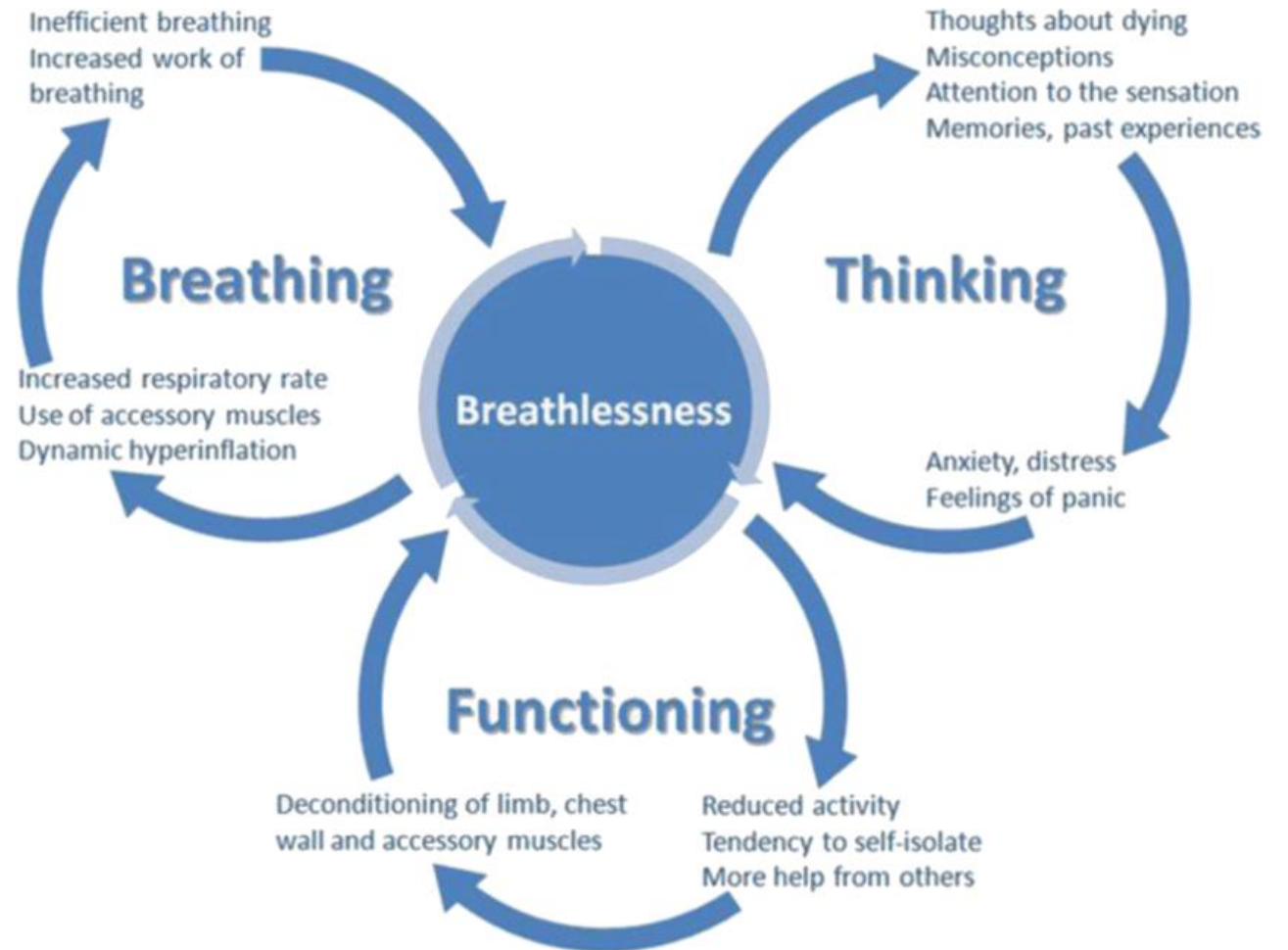
- Measuring success in supportive and palliative care is difficult.
- What is the definition of a success? What is a positive outcome?
- Multiple measures have been proposed to try and capture the 'value' of supportive care
- [download.ashx \(st-margarets-hospice.org.uk\)](#)
- [MYMOP® - Meaningful Measures - The home of MYCaW® and MYMOP®](#)

Data we collect currently

Measure	How
Symptoms	MyMOP Exeter clinic used IPOS
TEP	Team documentation
Unplanned hospital admissions – last year of life	Via BI team
Length of hospital admission - last year of life	Via BI team
PPOC/ PPOD	Team documentation
Place of death	Notes

Symptom burden

- Breathlessness
- Cough
- Anxiety
- Sputum
- Depression
- Fatigue
- Diarrhoea
- Appetite
- Running nose
- Pain



Early impact of the ILD service

- Symptom burden reduced on average by 1.3 points on self scoring
- Improvements in activity of 0.6 points on self scoring
- General wellbeing scores improved by 0.75 points on self scoring

Conclusion

- Palliative and supportive care can be difficult to define, with the former being misunderstood by patients and other clinicians. The focus is on ensuring the patient lives as well as they can.
- There is a known and documented supportive care need for patients with ILD.
- Supportive care has been utilised successfully for both malignant and non malignant disease.
- Outcome measurements are difficult but not impossible to gather.
- Blurring boundaries between community and hospital services leads to greater continuity for patients
- Early evidence demonstrates an impact on patient's symptom burden with our current intervention. Data on admissions and advance care planning will follow. There is no reason to think they will not mirror the liver and malignant disease work.

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