Symptom management in advanced heart failure

Dr Jason Ward

Consultant in Palliative Medicine

St Gemma's Hospice Leeds.

Jean 91 years old

1. HFpEF (ECHO Jan 2025 EF 60-65%, mild LVH, severely dilated LA).
2. Severe MR and mild MS.
3. DM II on insulin (Humulin M3).
4. Paroxysmal AF.

Jean 91 years old

Usually takes Furosemide 120mg and 80mg

Spironolactone 25mg OD, Dapagliflozin, Bisoprolol 2.5mg OM and Apixaban 2.5mg OD.

Hospital admission for iv diuretics June and Aug 2025

Sept	Cough and fever. Treated po amoxycillin for chest infection (CRP 251)
Oct	Worse, SOBoE, oedema to knees
	Increase weight
	Daughter asks if any alternative to hospital admission

Future wishes conversations

“I think it would be helpful to talk about what you would like to happen if you get *more unwell* again”

“I hope *you* will feel better with this treatment, but I’m worried at some point…. might it be a good idea to talk about that now?”

Useful opening questions

What's your understanding of where you are with your health/illness?

What are your fears and worries if your health worsens in the future?

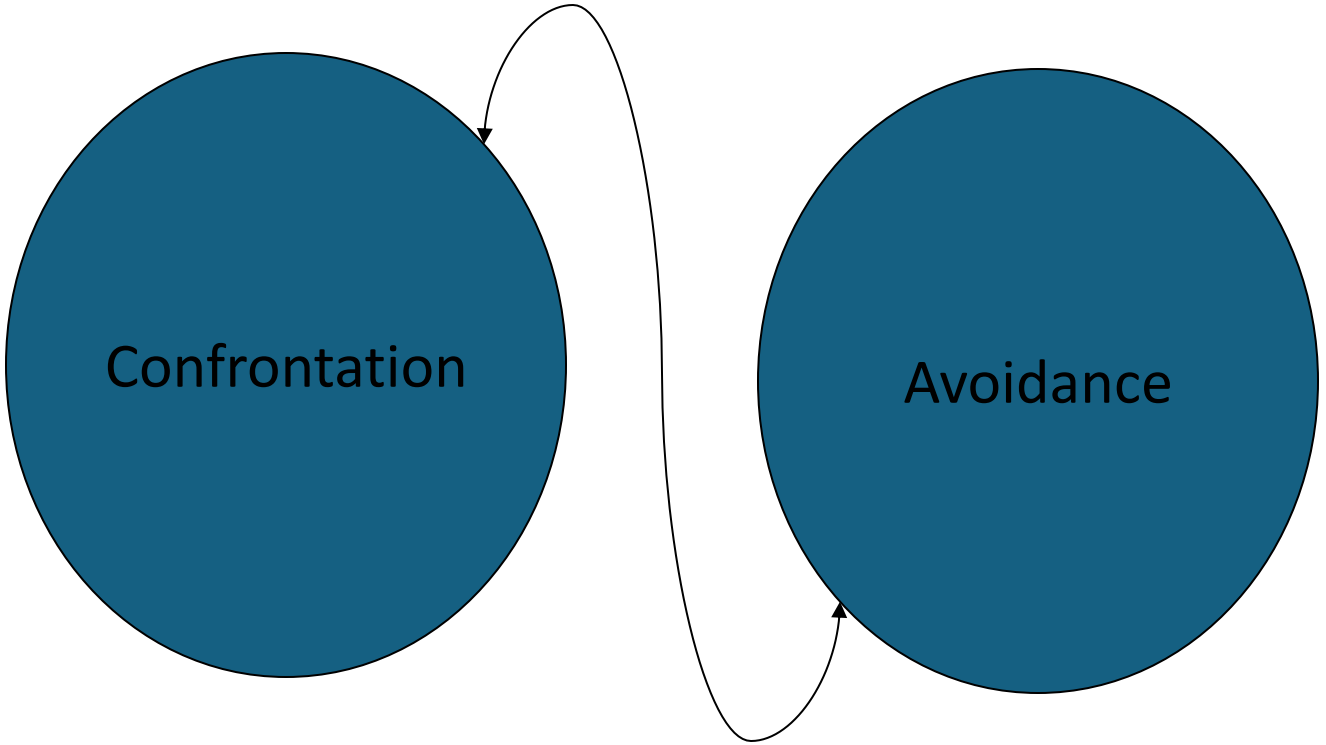
What are your goals/priorities if time is short?

What are you willing to go through (and not willing to go through) for the possibility of more time?

Who will make decisions if you can't?

Atul Gawande. How to talk end of life care with a dying patient

Pendulum of grief



Strobe M & Schut H. The dual process model of coping with bereavement. Death Studies 1999;23:197-224

DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION

Yorkshire & Humber Regional Form for Adults and Young People aged 16 and over

In the event of cardiac or respiratory arrest NO attempts at cardiopulmonary resuscitation (CPR) will be made. All other treatment should be given where appropriate.

NHS No	Hospital No	Next of Kin / Emergency Contact
Name		
Address		Relationship
Postcode	Date of Birth	Tel Number

Section 1 Reason for DNACPR: Select as appropriate from A - D (See reverse)

Details of all discussions, mental capacity assessments and MDT decisions must be recorded in the patient's notes.

A. ☐ CPR has been discussed with this patient. It is capacity to make this decision.

B. ☐ CPR is against the wishes of the patient as reco
The right to refuse CPR in an Advance Decision

C. ☐ The outcome of CPR would not be of overall be
i) They lack the capacity to make the decision
ii) They have declined to discuss the decision
This must be discussed with relevant
This has been discussed with ..... (n

D. ☐ CPR would be of no clinical benefit because of
.....
Even in situations in which CPR is
it is still good practice to explain to the patient and/
This has been discussed with the patient ☐
This has not been discussed with the patient because it w
This has been discussed with ..... (n

Section 2 Healthcare professionals co

Name & Designation	N
Organisation	O
Signature	Date S

Section 3 Review of DNACPR decision

This order is to be reviewed by: Date: .....

Review Date	Full Name and Designation	

AMBULANCE CREW

If Cardiopulmonary Arrest occurs, please do not attempt CP
Any other specific instructions: .....

ReSPECT

Recommended Summary Plan for Emergency Care and Treatment

1. This plan belongs to:

Preferred name	Full name
	Date of birth
	Address
Date completed	NHS/CHI/Health and care number

The ReSPECT process starts with conversations between a person and a healthcare professional. The ReSPECT form is a clinical record of agreed recommendations. It is not a legally binding document.

2. Shared understanding of my health and current condition

Summary of relevant information for this plan including diagnoses and relevant personal circumstances:

Details of other relevant care planning documents and where to find them (e.g. Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency plan for the carer):

I have a legal welfare proxy in place (e.g. registered welfare attorney, person with parental responsibility) - if yes provide details in Section 8 ☐ Yes ☐ No

3. What matters to me in decisions about my treatment and care in an emergency

Living as long as possible matters most to me	Quality of life and comfort matters most to me
What I most value:	What I most fear / wish to avoid:

4. Clinical recommendations for emergency care and treatment

Prioritise extending life	Balance extending life with comfort and valued outcomes	Prioritise comfort
clinician signature	clinician signature	clinician signature

Now provide clinical guidance on specific realistic interventions that may or may not be wanted or clinically appropriate (including being taken or admitted to hospital +/- receiving life support) and your reasoning for this guidance:

CPR attempts recommended Adult or child	For modified CPR **Child only, as detailed above**	CPR attempts **NOT** recommended Adult or child
clinician signature	clinician signature	clinician signature

www.respectprocess.org.uk

ReSPECT Version 3.0 © Resuscitation Council UK

Advance decision to refuse treatment (ADRT)

My name	If I become unconscious, these are the distinguishing features that could identify me:
Address	Date of birth: NHS no (if known): Hospital no (if known): Telephone number:

What is this document for?

This advance decision to refuse treatment has been written by me to specify **in advance** which treatments I don't want in future.

These are my decisions about my healthcare, **in the event that I have lost mental capacity and cannot consent to refuse treatment.**

This advance decision replaces any previous decision I have made.

Advice to the carer reading this document: Please check

- **Please do not assume that I have lost mental capacity before any actions are taken.** I might need help and time to communicate when the time comes to need to make a decision.
- If I have lost mental capacity for a particular decision **check that my advance decision is valid, and applicable to the circumstances that exist at the time.**
- If the professionals are satisfied that this advance decision is valid and applicable this decision becomes legally binding and must be followed, including checking that it is has not been varied or revoked by me either verbally or in writing since it was made.
  Please share this information with people who are involved in my treatment and need to know about it.
- **Please also check if I have made an advance statement about my preferences, wishes, beliefs, values and feeling that might be relevant to this advance decision.**

This advance decision does not refuse the offer or provision of basic care, support and comfort

What matters to me

Let staff know what matters to you – big or small.

It's important to be prepared to talk about what is important to you when you speak to someone about your health and wellbeing.

This helps them to support you better. Remember, you are the expert of your own health and experiences.

1. What matters to me?
For example:
- My religion / spiritual beliefs
- My pets
- Being in nature

2. Who are the most important people in my life?
For example:
- My family and friends
- My carer
- My community and faith group

3. What things do I do to keep well?
For example:
- Exercising
- Taking medication
- Eating well

4. Key things to think about for my future
For example:
- My goals and hopes
- My motivation

What matters to me

Use this space to write what matters to you.

Surprise question

"Would you be surprised if this patient died within the next 12 months?"

Overall accuracy %

White N et al. How accurate is the surprise question at identifying patients at the end of life. BMC Medicine 2017:15;153-

Surprise question

"Would you be surprised if this patient died within the next 12 months?"

Overall accuracy 72%

White N et al. How accurate is the surprise question at identifying patients at the end of life. BMC Medicine 2017:15;153-

Surprise question in HF

"Would you be surprised if this patient died within the next 12 months?"

Sensitivity 85%

Gonzalez-Jaramillo V et al. The surprise question in heart failure: a prospective Study. BMJ Supportive & Palliative Care 2024;14:68-75

St. Gemma's Hospice
Always caring

Sue Ryder Wheatfields Hospice

NHS

Leeds Community Healthcare NHS Trust and
The Leeds Teaching Hospitals NHS Trust

Supportive and Palliative Care Indicators Tool (SPICT)

Adapted from NHS Lothian 2011 v2 April 2013

1. Look for two or more general clinical indicators

- Two or more unplanned hospital admissions in the past 6 months.
- **Performance status deteriorating** (needs help with personal care, in bed or chair for 50% or more of the day).
- **Unplanned weight loss (5 - 10%) over the past 3 - 6 months and / or body mass index < 20.**
- A new event or diagnosis that is likely to reduce life expectancy to less than a year.
- Persistent symptoms despite optimal treatment of advanced illness.
- Lives in a nursing care home or NHS continuing care unit; or needs a care package at home.

2. Now look for two or more clinical indicators of advanced, progressive illness

Advanced heart / vascular disease

- NYHA Class IV heart failure, or coronary artery disease:
  - Breathless or chest pain at rest or on minimal exertion
- Severe, inoperable peripheral vascular disease

Advanced respiratory disease

- Severe chronic obstructive pulmonary disease (FEV1<30%) or severe pulmonary fibrosis:
  - Breathless at rest or on minimal exertion between exacerbations
- Has needed ventilation for respiratory failure

Advanced kidney disease

- Stage 5 chronic kidney disease (eGFR < 15ml/min)
- Kidney failure as a recent complication of another condition or treatment
- Stopping dialysis

Advanced liver disease

- Advanced cirrhosis with one or more complications in past year:
  - Diuretic resistant ascites
  - Hepatic encephalopathy
  - Hepatorenal syndrome
  - Bacterial peritonitis
  - Recurrent variceal bleeds
- Serum albumin < 25g/l, INR prolonged (INR > 2)
- Liver transplant is contraindicated

Advanced cancer

- Performance status deteriorating due to metastatic cancer and / or co-morbidities
- Persistent symptoms despite optimal palliative oncology treatment or too frail for oncology treatment

Advanced neurological disease

- Progressive deterioration in physical and / or cognitive function despite optimal therapy
- Speech problems with increasing difficulty communicating and / or progressive dysphagia
- Recurrent aspiration pneumonia; breathless or respiratory failure

Advanced dementia / frailty

- Unable to dress, walk or eat without help; unable to communicate meaningfully
- Needing assistance with feeding maintaining nutrition
- Recurrent febrile episodes or infections; aspiration pneumonia
- Urinary and faecal incontinence
- Fractured neck of femur

3. Is this patient at risk of dying in the next 6-12 months, or less? YES

4. Consider how to approach conversations about end of life care

5. Discuss inclusion of the patient on the Palliative Care Register with GP / members of the MDT

6. Assess needs and plan care:

- **Which services should be involved?**
- **Who is best placed to be the Key Worker?**

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Advanced lung disease

- Severe COPD (FEV1 <30%) or severe pulmonary fibrosis:
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- Has needed ventilation for respiratory failure

Advanced kidney disease

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Advanced liver disease

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Advanced neurological disease

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Advanced heart / vascular disease

- NYHA Class III / IV heart failure, or coronary artery disease:
  - Breathless or chest pain at rest or on minimal exertion
- Severe, inoperable peripheral vascular disease

Despite optimal medical therapy
(including ICD/CRT when indicated)

- Kidney failure as a recent complication of another condition or treatment
- Stopping dialysis

Advanced liver disease

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Poorer prognosis

- >1 admission or unplanned visit to HF clinic within last 12 months
- Intolerant to B-blocker or ACE-I/ARNI
- LVEF <20%
- Worsening RV function
- Worsening renal function
- Worsening liver function
- Ventricular arrhythmias/ICD shocks
- Need for escalating diuretic doses for persistent congestion
- SBP <90 mmHg and/or signs of peripheral hypoperfusion

McDonagh T.A., et al. 2021 ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure. *Eur. Heart J.* 2021:42;3599-3726

Estimating when a patient may die

v

Identify those at sufficient risk of deteriorating and dying that proactive assessment and care planning is appropriate

palliative oncology treatment or too frail for oncology treatment

Advanced respiratory disease

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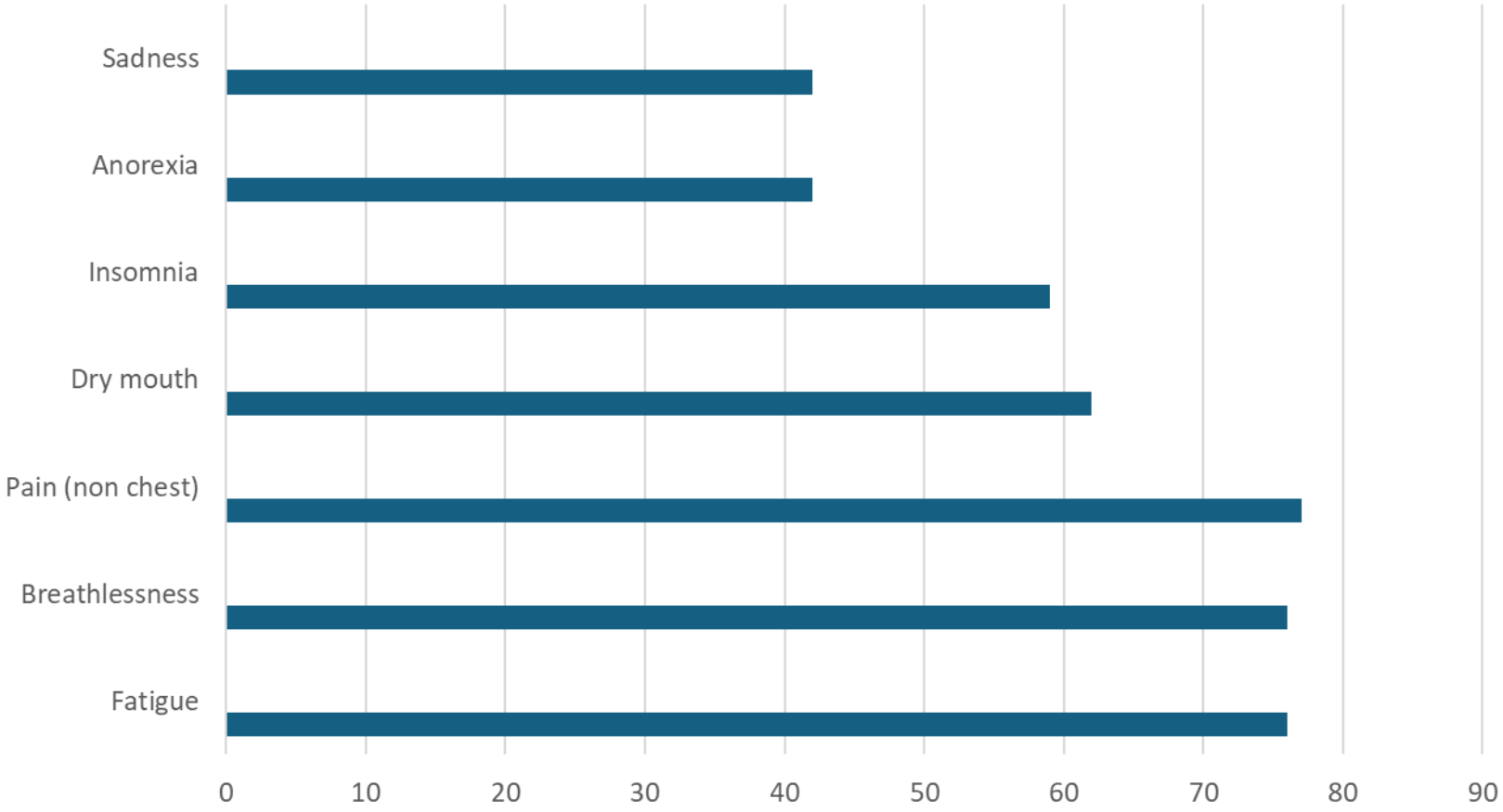
Symptom prevalence in patients in advanced HF

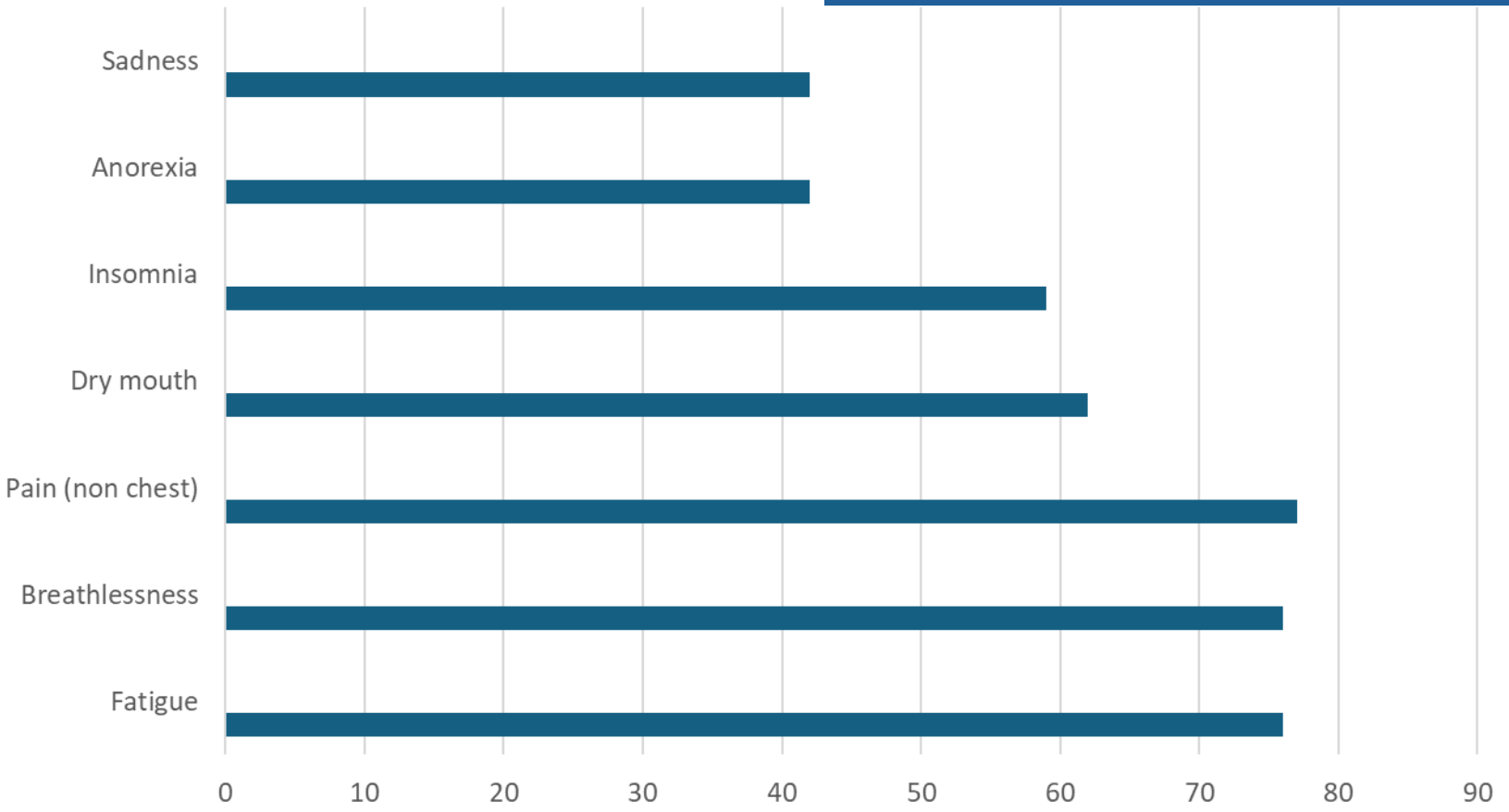
Symptom prevalence in patients in advanced HF



Blum M at al. Qual Life Res 32;2025:485-493

Symptom prevalence in patients in advanced HF

Median 9-13 symptoms



Blum M at al. Qual Life Res 32;2025:485-493

Leeds Palliative Care Network

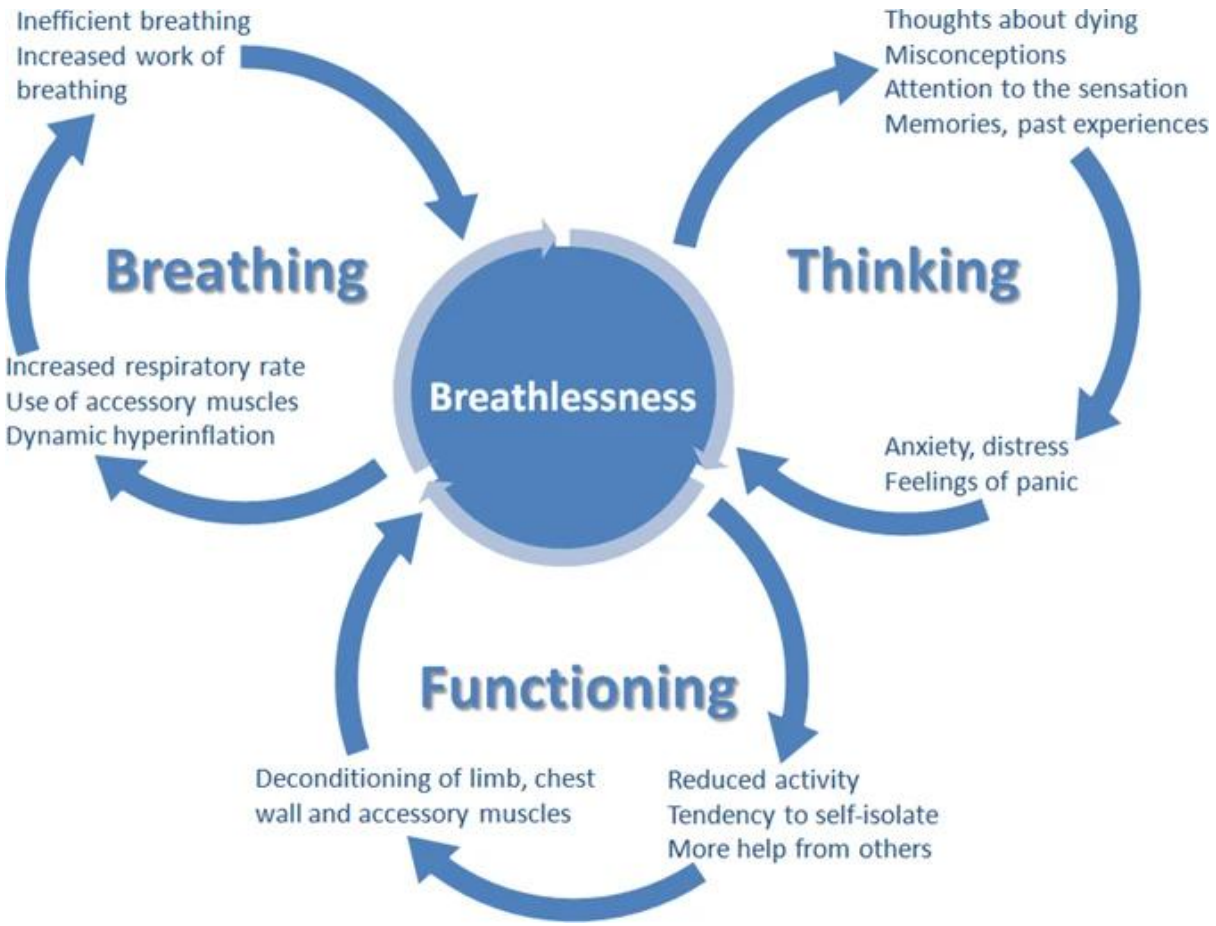
Symptom management guidelines for patients with advanced heart failure

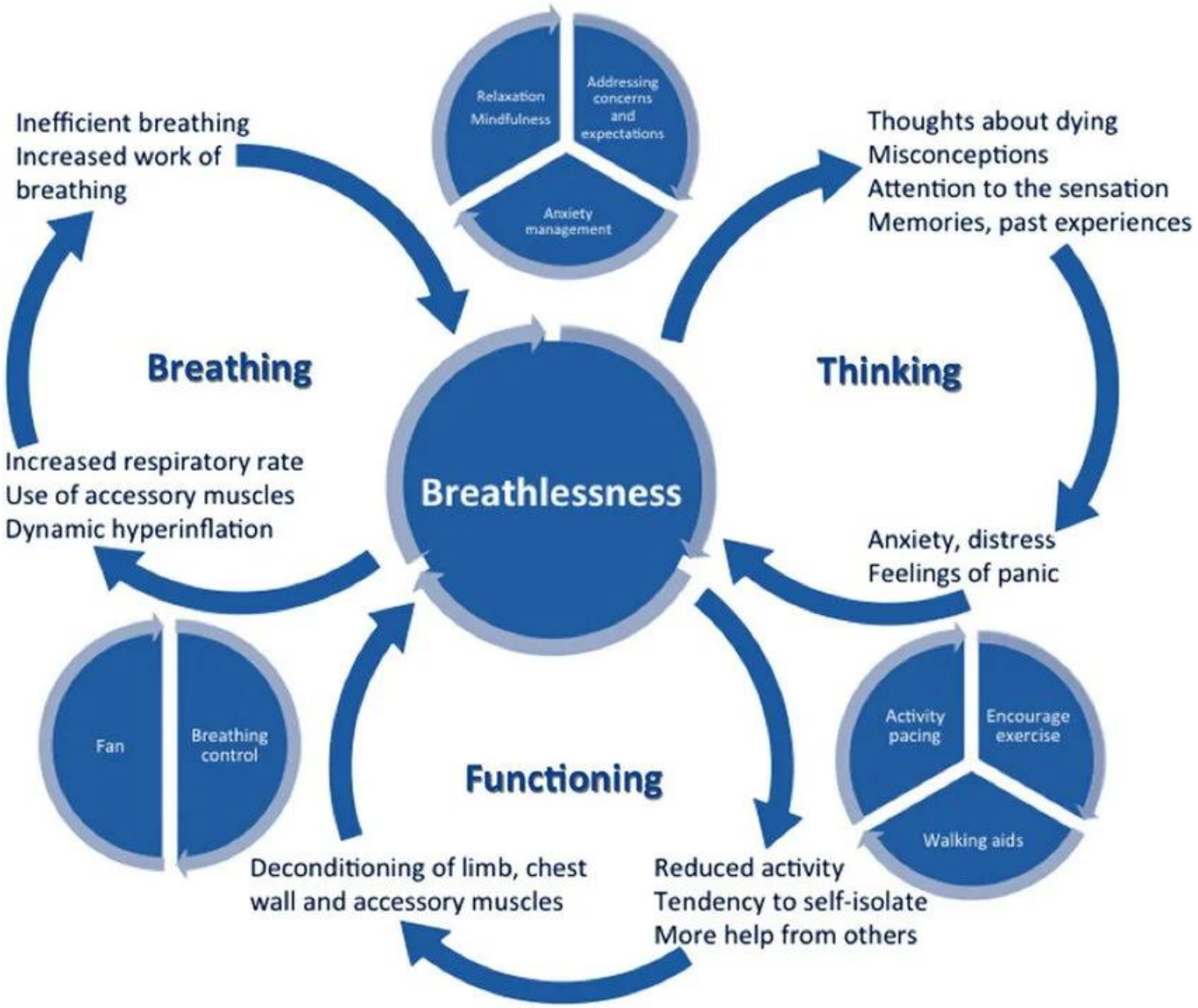
Management of refractory breathlessness

Management of the underlying illness has been maximised

- Drug free measures

- Drug measures


Inefficient breathing
Increased work of breathing
Thoughts about dying
Misconceptions
Attention to the sensation
Memories, past experiences
Breathing
Thinking
Breathlessness
Increased respiratory rate
Use of accessory muscles
Dynamic hyperinflation
Anxiety, distress
Feelings of panic
Functioning
Deconditioning of limb, chest wall and accessory muscles
Reduced activity
Tendency to self-isolate
More help from others


Relaxation
Mindfulness
Addressing concerns and expectations
Anxiety management
Inefficient breathing
Increased work of breathing
Thoughts about dying
Misconceptions
Attention to the sensation
Memories, past experiences
Breathing
Thinking
Breathlessness
Increased respiratory rate
Use of accessory muscles
Dynamic hyperinflation
Anxiety, distress
Feelings of panic
Fan
Breathing control
Activity pacing
Encourage exercise
Walking aids
Functioning
Deconditioning of limb, chest wall and accessory muscles
Reduced activity
Tendency to self-isolate
More help from others

Information Hub

Welcome to the St Gemma's Information Hub where patients can access a variety of information to help improve wellbeing and manage symptoms at home.

You can also find out about the range of services offered by St Gemma's and view a selection of our guides and leaflets for patients, families and carers.

Videos to help with breathlessness

Breathlessness is a common problem for those living with a life-limiting illness. Here are some videos to help you understand breathlessness, as well as learn breathing strategies, techniques. positioning and general management tips.

Watch videos →

Resources for patients

Coping with anxiety and panic

Strategies that may help you to feel more relaxed and improve your wellbeing.

Learn more →

Relaxation and mindfulness

Guided meditations and relaxations that you can access at any time.

Learn more →

Useful exercises

Seated exercise sessions demonstrated by our therapy team.

Learn more →

More information for patients

Systemic, low dose, opioids

Alter the sensation of breathlessness in the brain without causing reductions in oxygen levels

Systemic, low dose, opioids

Meta-analysis did not show any significant benefit of opioid therapy on management of breathlessness in patients with HF

Gaertner J et al. Effect of opioids for breathlessness in HF: a systematic review and Meta-analysis. Heart 2023;109:1064-1071

Systemic, low dose, opioids

143 participants, 5-10mg BD MST

No evidence that morphine improves worst breathlessness intensity

Johnson M, Williams B, Keerie C et al. Morphine for chronic breathlessness (MABEL) in the UK: a multi-site, parallel-group, dose titration, double-blind, randomised, placebo-controlled trial The Lancet Respiratory Medicine, 2025; 13, 967-977

Systemic, low dose, opioids

- Regular modified release opioid
  - v immediate release

    MST 5mg BD

- Regular laxative e.g. senna 7.5-15mg ON

- Titrated upward, preferably once weekly, balancing beneficial and adverse effects

    Max 30mg daily

Systemic, low dose, opioids

eGFR < 20-30

- Oxycodone MR 5mg -10mg BD
- IR oxycodone liquid 1-2mg PRN/QDS

Other drugs

- Benzodiazepines
  - Lorazepam 0.5mg – 2mg /day
  - Diazepam 2mg – 5mg nocte
- Nebulised saline
  - if difficulty expectorating
- Antidepressants
  - only if depression

Simon ST et al. Benzodiazepines for the relief of breathlessness in advanced diseases in adults. *Cochrane Database of Systematic Reviews* 2016

Oxygen and palliation of breathlessness

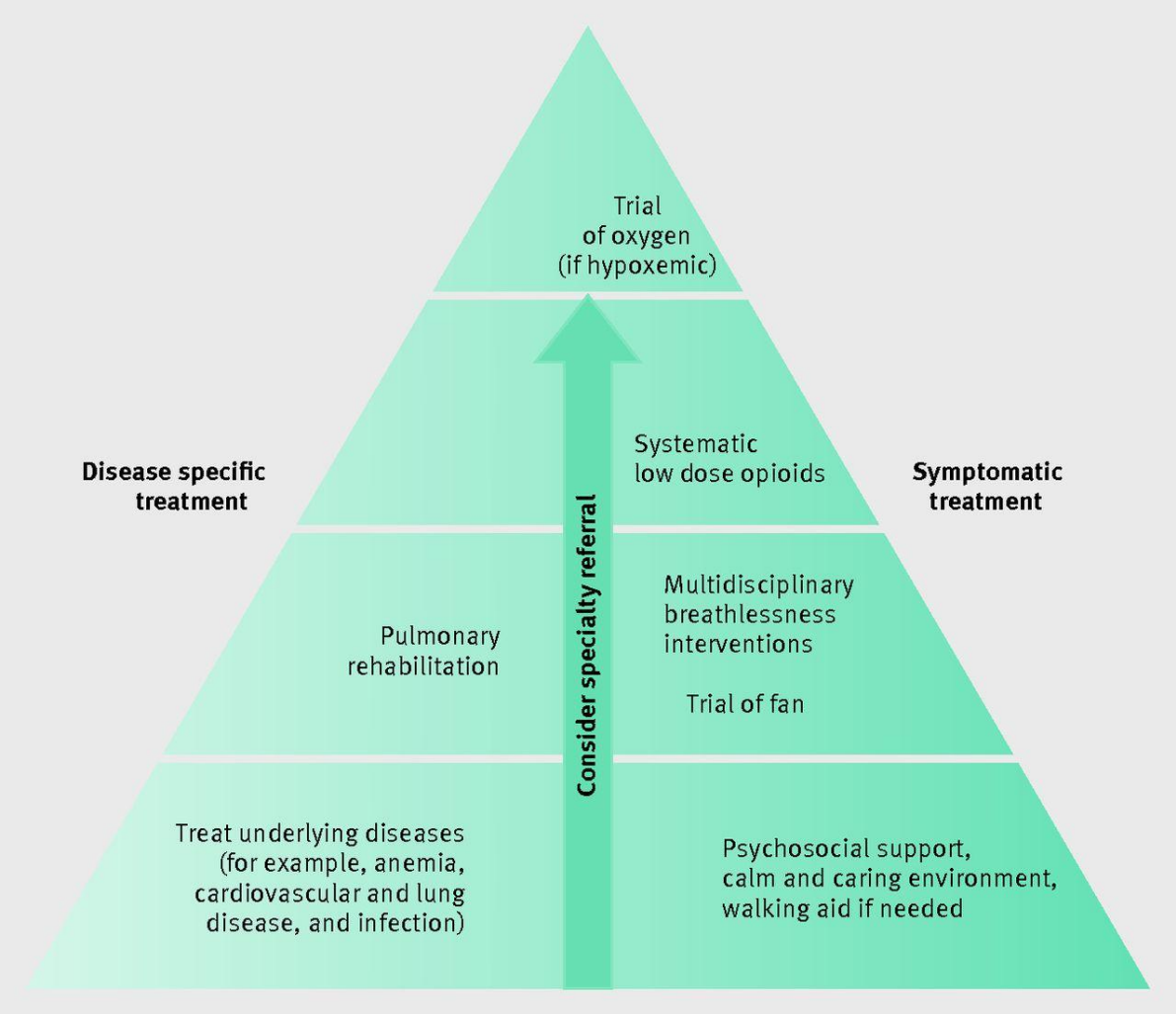
- O_2 is not consistently beneficial
  - even in patients with hypoxic

- Facial cooling may be as beneficial e.g. fan

- Do not offer long-term home oxygen therapy for advanced heart failure

NICE. Chronic Heart Failure in Adults: Diagnosis and Management 2018 Sep. (Guideline, No. 106.)

Principles of breathlessness management



Ekstrom MP et al The management of chronic breathlessness in patients with advanced and terminal illness. BMJ 2015;350:27-30

Pain

- Chest pain
  - Cardiac vs non-cardiac (oesophageal, mood disorder)
- Hepatic pain
- Abdominal distension
- Oedema
- Gout

Pain

3. Strong opioid

Oramorph 2.5-5mg PRN

MST 10-20mg bd

2. Weak opioid

1. Paracetamol 1gm QDS

Pain

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Oramorph 2.5-5mg PRN

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Caution with

NSAIDs

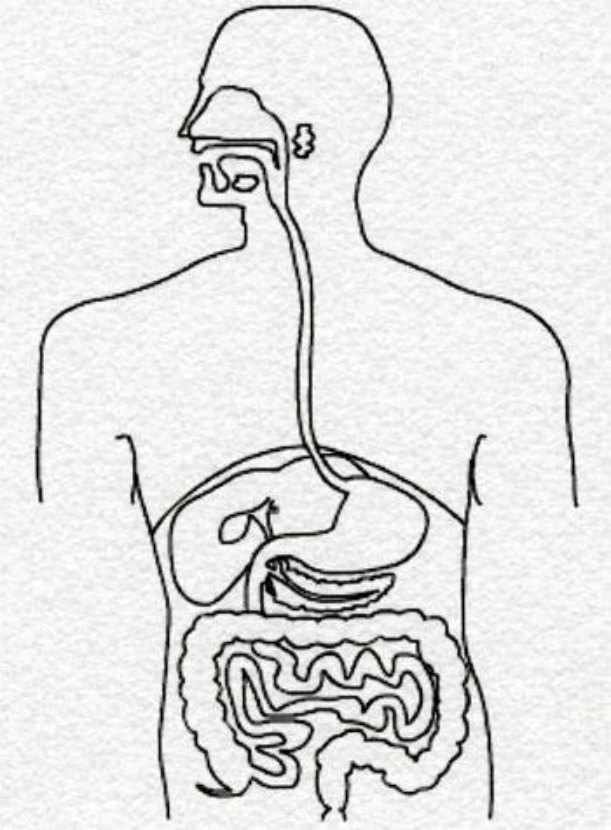
Amitriptyline

Gabapentin/Pregabalin

Anorexia

Taste abnormalities
Denture problems
Candidosis
Xerostomia

Infection



Emotions

Early satiety,
nausea

Constipation

Nutritional supplements

- What is the goal?
- Unlikely to reverse weight loss/ cachexia in advanced stages
- Complan shakes, build up soups…

Nausea and vomiting

Cause	Common symptoms	First Line Drug Stat Dose	24-hour range
Gastric stasis e.g. ascites, engorged liver	Early satiety Large volume vomit Hiccups		
Chemical e.g. medication uraemia	Constant nausea Small volume frequent vomits		
2nd line or multifactorial			

Nausea and vomiting

Cause	Common symptoms	First Line Drug Stat Dose	24-hour range
Gastric stasis e.g. ascites, engorged liver	Early satiety Large volume vomit Hiccups	Metoclopramide 10mg PO/SC Domperidone 10mg PO	30mg PO 30-60mg PO/SC
Chemical e.g. medication uraemia			
2nd line or multifactorial			

Nausea and vomiting

Cause	Common symptoms	First Line Drug Stat Dose	24-hour range
Gastric stasis e.g. ascites, engorged liver	Early satiety Large volume vomit Hiccups	Domperidone 10mg PO Metoclopramide 10mg PO/SC	30mg PO 30-60mg PO/SC
Chemical e.g. medication uraemia	Constant nausea Small volume frequent vomits	Haloperidol 500mcg PO/SC	1-5mg PO/SC
2nd line or multifactorial		Levomepromazine 2.5-6.25mg PO/SC	6.25-12.5mg PO/SC

Itch

- Localised causes
- Dry skin
- Hyperphosphataemia
- Iron deficiency anaemia
- Medication changes

Itch

- Localised causes
- Dry skin
- Hyperphosphataemia
- Iron deficiency anaemia
- Medication changes

- Emollients
- Hyperphosphataemia
  - oral phosphate binder
- Ureamia
  - gabapentin 50-100mg ON
- Idiopathic
  - Sedating antihistamine, e.g. chlorphenamine 4mg ON (4mg QDS)
  - Sertraline 50-100mg OD

Depression v sadness

Citalopram 10mg OD increasing to 20mg after 1 week

Sertraline 50mg OD increasing to 100mg after 4 weeks

Mirtazapine 15-30 mg ON especially if nausea or poor appetite or poor sleep

Anxiety

- Have you always been a worrier?
- Generalised anxiety disorder v specific trigger
  - Consider antidepressant
    - e.g. sertraline 25-50mg OD, max 100mg daily
- Remember drugs, nicotine and alcohol withdrawal

Insomnia

- Drug free measures
- Diuretics, ISMN
- Zopiclone 3.75-7.5mg ON
- Mirtazapine 15mg ON

Fatigue

- ‘Validate’ the patient’s experience
- Information
- Reverse the reversible
- Exercise and energy expenditure planning

Scottish Palliative Care Guidelines: weakness and fatigue 2014

Questions?

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