The supportive and palliative care document

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The Botanical Gardens Birmingham June 2005

“Medical minds are obsessed with drugs
Nurses are also becoming obsessed with drugs”

Prof Martin Cowie

National Heart and Lung Institute

Living with heart failure

- TREATMENT AGENDA
  - Diagnosis
  - Expert management
  - Heart drugs
  - Up-titration
  - Fine tuning
  - Compliance
  - Exercise
  - Rehabilitation
  - Daily weight
  - Avoiding hospital
- SUPPORT AGENDA
  - Coordination
  - Communication
  - Information
  - Psychological support
  - Social support
  - Symptom management
  - Rehabilitation
  - Specialist support
  - Family/carer support

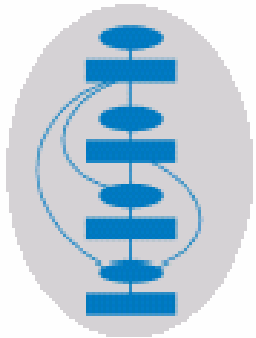
NHS

National Institute for Clinical Excellence

Guidance on Cancer Services

Improving Supportive and Palliative Care for Adults with Cancer

The Manual

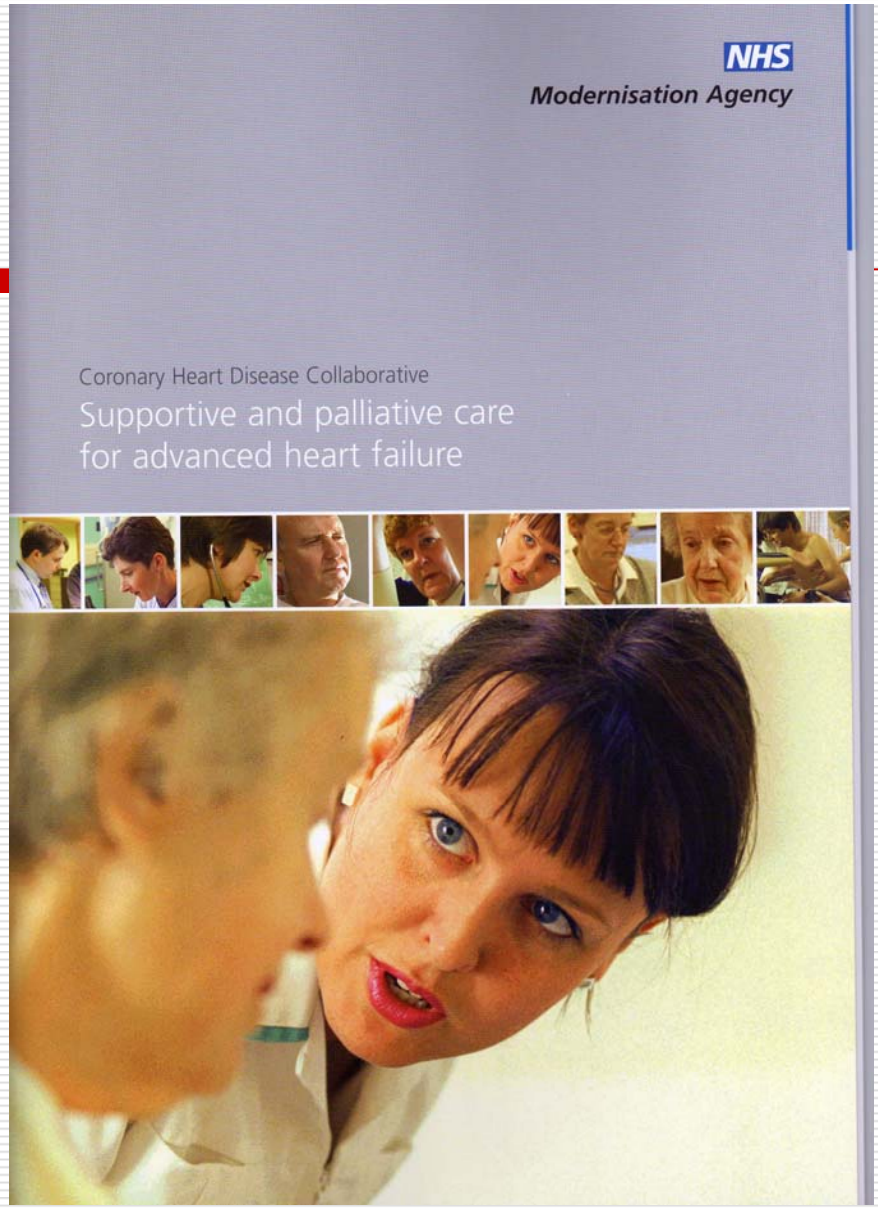


Changing ‘normal care’

- Normal for doctors/nurses to have had advanced communication skills training
- Normal for a ‘key worker’ to be allocated to patients with advanced disease
- Normal for nurses and doctors to assess anxiety and depression
- Normal for heart failure patients to have choice at the end of life

Changing ‘normal care’

- Normal to have psychologists, social workers and palliative care specialists to refer to
- Normal to use the Liverpool Care Pathway
- Normal to use the Gold Standards Framework
- Normal to use symptom control guidance
- Normal to audit the quality of care


NHS
Modernisation Agency
Coronary Heart Disease Collaborative
Supportive and palliative care
for advanced heart failure

What is this document?

- Translation of NICE guidance in cancer to heart failure
- Breaking down of supportive and palliative care into its constituent parts
- A collaboration between a cardiologist and a Macmillan nurse
- Perhaps one piece in a jigsaw

Face to face communication

- ‘Most people with heart failure do not understand the cause or prognosis of their disease and rarely discuss end of life issues with their professional carers.’

  Murray et al 2002

- Advanced communication skills training (SPIKES)
- Normal practice to proactively check understanding
- Competence and confidence to discuss end of life issues

Psychological support

- British and North American studies have found that the levels of psychological distress (in heart failure) are comparable to that of cancer.

  Addington-Hall 1995, Lynn et al 1997)

- Four level model of psychological support with heart failure nurses trained to work at level two
- Able to screen for psychological distress and assess the impact of heart failure on people's lives, moods, relationships and work.
- Able to work as a nurse in a therapeutic relationship with the patient. The patient or carer would be encouraged to apply their own solutions to their psychological concern. NICE 2004

General palliative care

Triggers for GSF in heart failure: two or more of the following

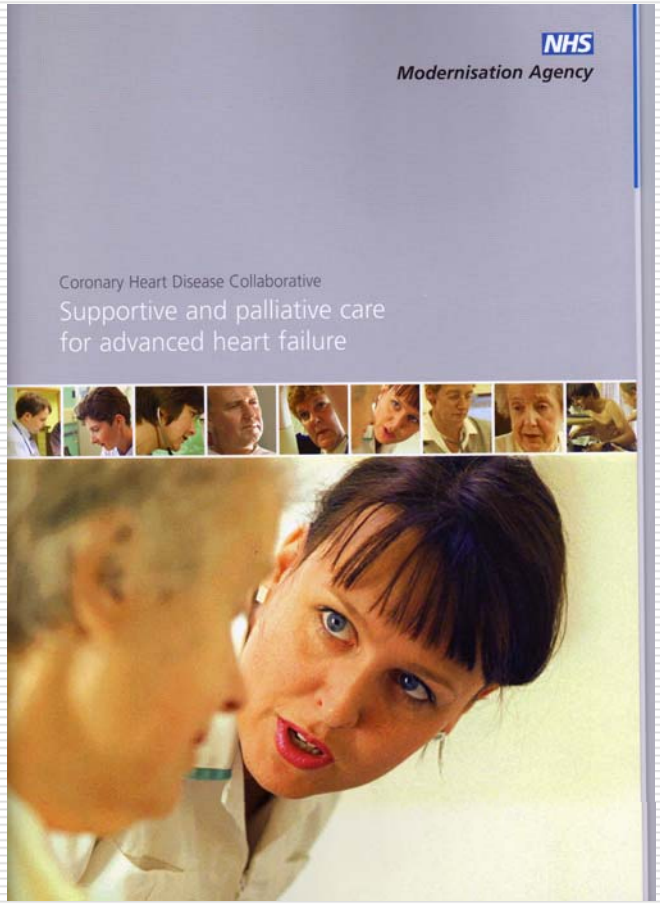
- NYHA III or IV
- Thought to be in the last year of life by the care team
- Repeated hospital admissions with symptoms of heart failure
- Difficult physical/psychological symptoms despite optimal tolerated therapy

Triggers for LCP in heart failure

- Multiprofessional team agrees that the patient is dying plus two of the following
- Bedbound
- Semicomatose
- Only able to take sips of fluid
- No longer able to take tablets

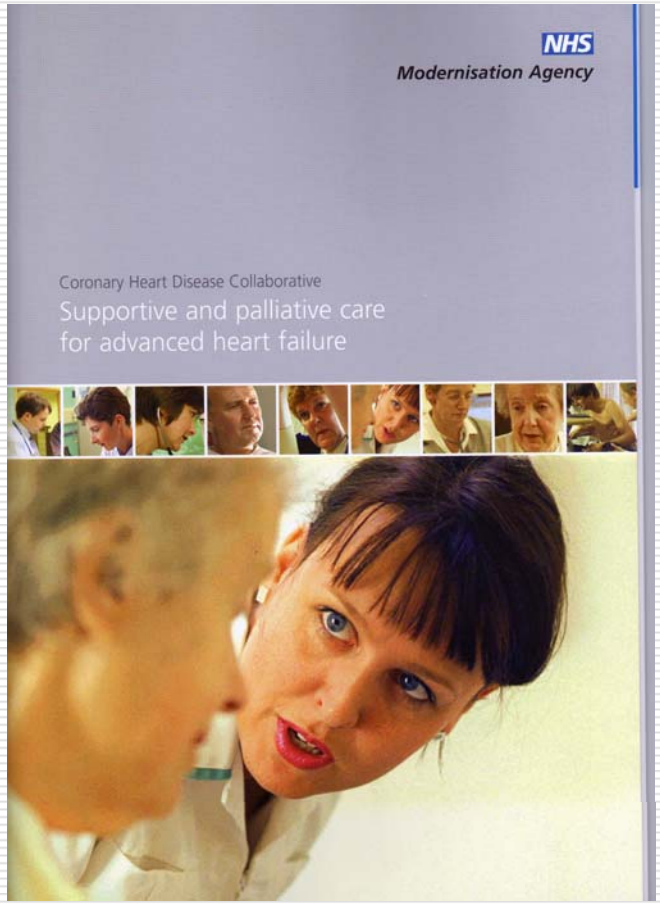
What I don't know about this document

- Whether anyone is using it
- Whether it clarifies anything



What we hope people will use it for?

- Encouragement to clinical staff
- Reference and evidence
- Structure to thoughts and plans at network level
- As a lever to influence policy makers



What I don’t know about supportive and palliative care in heart failure

- Why cardiology nurses and some doctors are so enthusiastic
- Why relatively few palliative care nurses and doctors seem to be enthusiastic

What else I don't know

- Whether we need to put any more effort into encouraging hospices to do more in non-malignant disease
- Whether we need to evangelise amongst the cardiologists
- Whether we are beating the drum too loudly or too quietly

Living with heart failure

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COORDINATION AND INVESTMENT

Integrated Care Pathway

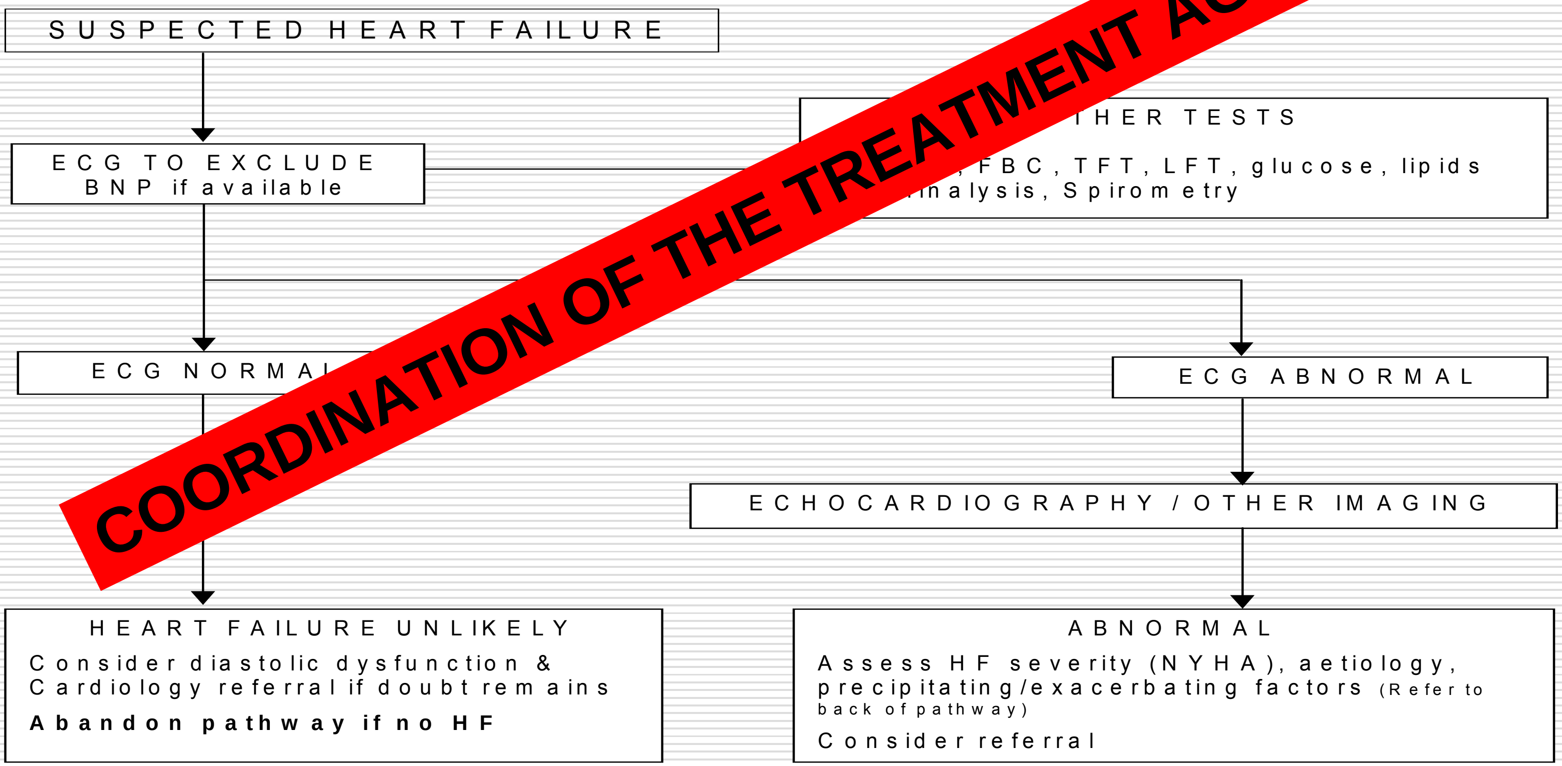
CHRONIC HEART FAILURE

Name… … … … … … … … … … … … … … … … … … .
U/R no… … … … … … … … Date of birth… … … … … …
Address… … … … … … … … … … … … … … … … … .
… … …. … … …. … … … … … … …. … … … … … M / F

USE THIS DOCUMENT IF SUSPECTED NEW ONSET, OR EXACERBATION, OF C[illegible] HF

Date commenced… … … … … … … … … … … … . Time… … … … … … . Doctor… … [illegible] … … … … ..

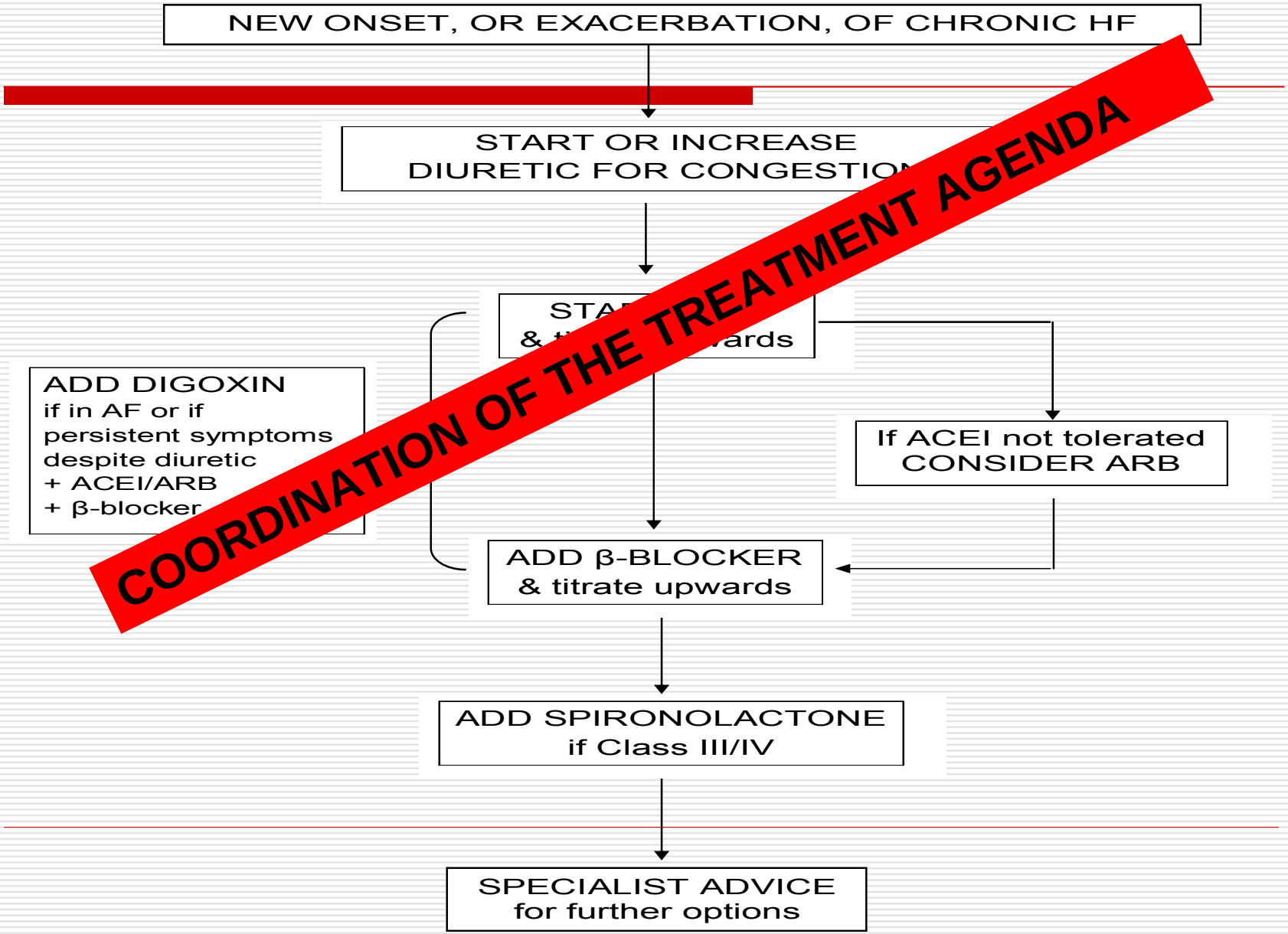
COORDINATION OF THE TREATMENT AGENDA



NYHA HEART FAILURE CLASSIFICATION

Class I	Impaired LV but no symptoms
Class II	Breathless on moderate exertion eg 2 flights of stairs, walking briskly, walking uphill
Class III	Breathless during everyday activities eg walking around the house
Class IV	Symptoms at rest eg unable to eat a meal comfortably without dyspnoea

DRUG THERAPY OF HEART FAILURE
Refer to guidelines on back page

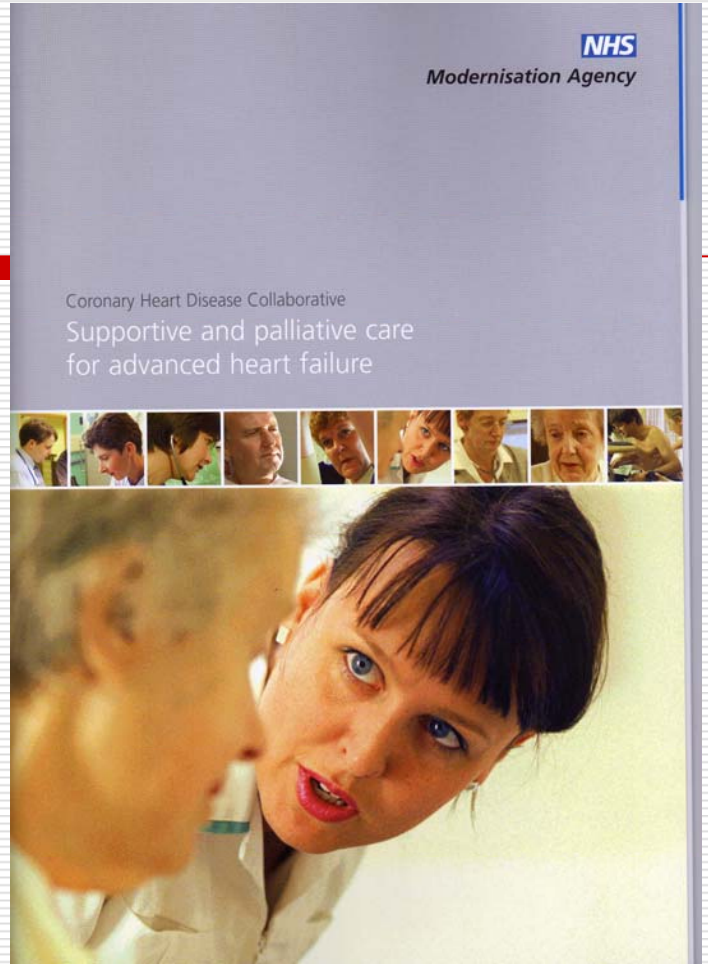


COORDINATION OF THE SUPPORT AGENDA

the gold standards framework

LCP LIVERPOOL Care Pathway

Promoting best practice for care of the dying



Responseline 0870 1555455

www.modern.nhs.uk/chd

Symptom management

Breathlessness:

- sublingual lorazepam 0.5mg -1mg prn to max 4g per day
- Diazepam 2mg po or buspirone 5mg as second line
- Low dose oral morphine 2.5mg 4hrly
- Rapid release may be more effective than sustained relief
- Even lower doses in renal impairment/failure or reduce frequency to bd or tds
- Laxatives
- Nebulised saline +/- bronchodilators

Pain

- Up to 78% in some studies
- WHO analgesic ladder
- Regular paracetamol
- Start morphine at lower doses 2.5mg 4hrly
- Diamorphine 1-2.5mg sc 4 to 6 hrly

Nausea and Vomiting

- Haloperidol 1.5 - 3mg po/sc nocte in renal impairment or renal failure

- If related to meals, early satiety, hepatomegaly metoclopramide 10mg po/sc tds
- Domperidone 10mg po tds
- Low dose levomepromazine 3-6mg od

Constipation

- Causes must be reduced food/fluid intake, diuretics, immobility, pain killers
- Sodium docusate 100-500mg daily in divided doses
- Plus a stimulant such as senna 2 tabs twice daily

Psychological issues

- **Anxiolytics:** lorazepam 0.5 – 1mg po/sl for panic or diazepam 2mg po tds for anxiety
- **Night sedation:** lorazepam 0.5 1mg po

  Lormetazepam 0.5 – 1mg po

  Temazepam 10-20mg po
- **Antidepressants**

  Sertraline 50mg daily or citalopram 10-20mg daily

  Mirtazepine 15-30mg nocte

Avoid

- NSAIDS
- CYCLIZINE
- TRICYCLIC ANTIDEPRESSANTS

Who gets referred to me?

- people with advanced heart failure
- complex mixture of physical, psychological, social and spiritual challenges
- people who have moved from coping to feeling overwhelmed
- panic, depression, anger, frustration, loss of hope, fear for the future, loss of control, loss of confidence

- Most people cope with most things, most of the time

- Because they have to

But some people can become overwhemed

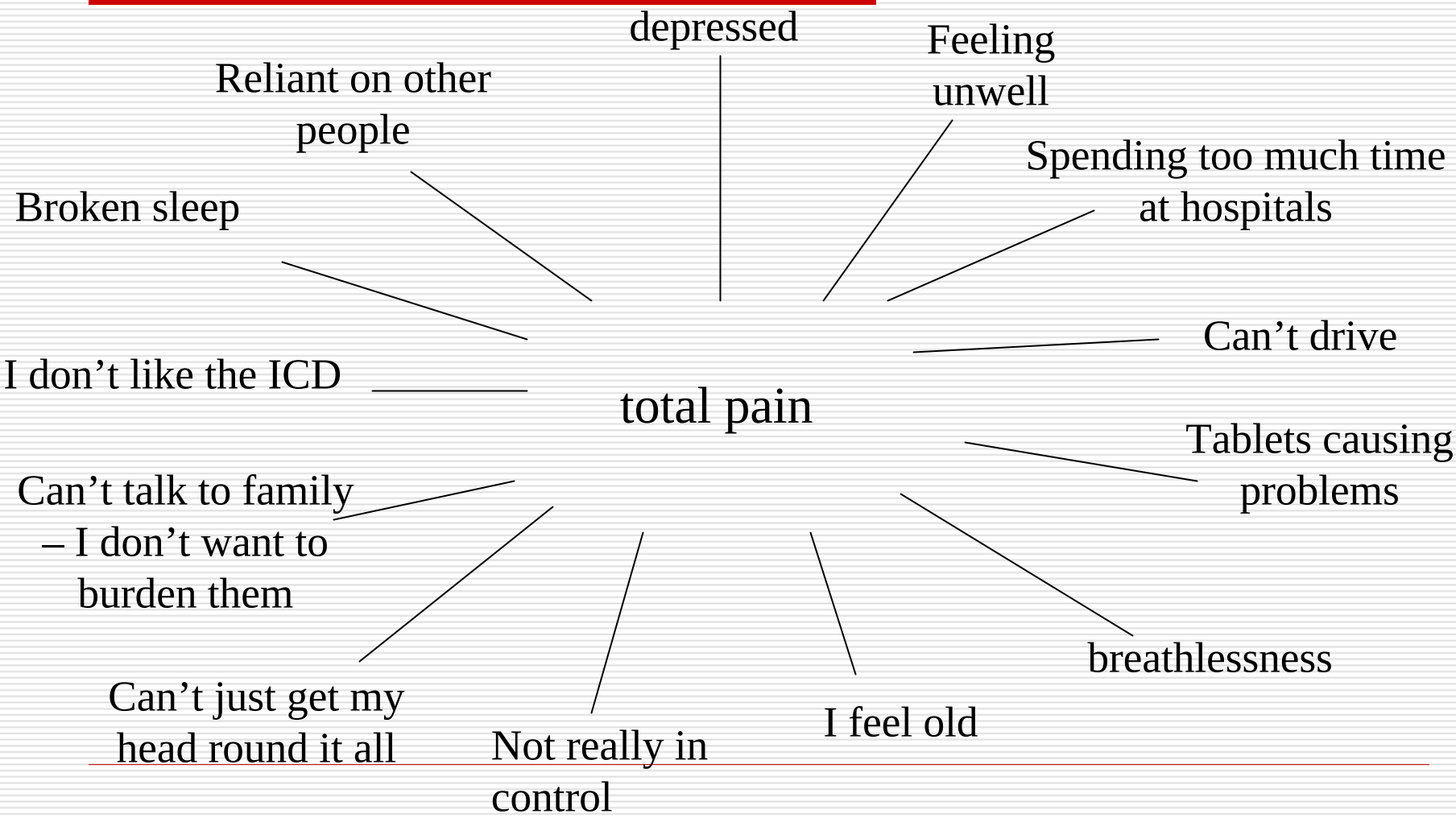
What can supportive care entail?

- Who were you before you were ill?
- What are your normal ways of coping?
- What are your current problems?
- What would help with those problems?
- What can you do yourself?
- What help do you want from other people?

In your prime

- Hard working – independent
- Self reliant – practical
- Honest – loyal
- Family is very important
- Like to meet new people
- Happy with your own company
- Good at solving problems
- Tend to protect other people from your worries

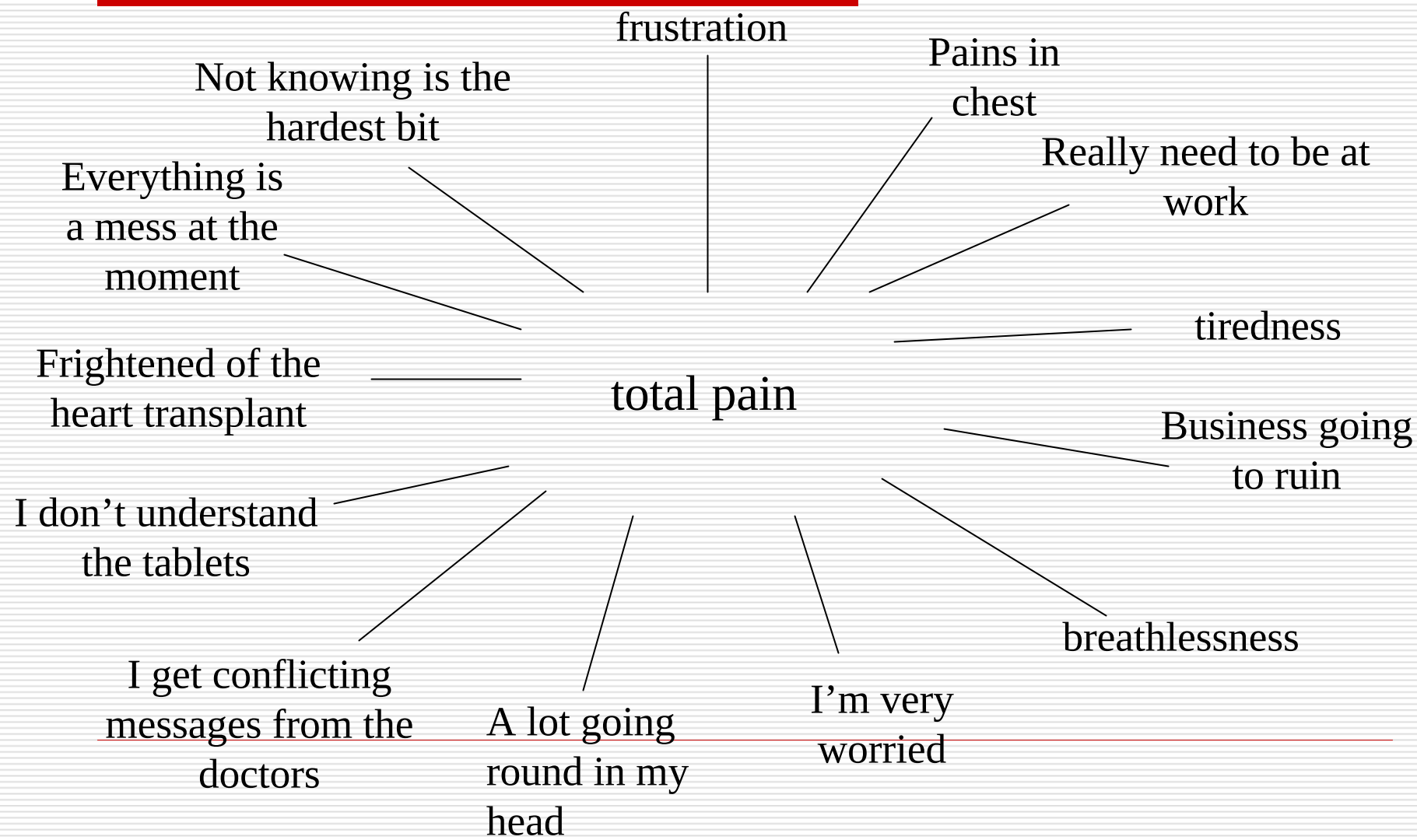
Tell me everything that concerns you at the moment



So what would help?

- Walking the dog helps
- Getting better would help
- I need reassurance not a kick up the backside
- I need to talk to the consultant about why I’m still out of breath
- I need to work out how to stop Jane from pressing the buttons which ignite my anger and make me feel guilty

Tell me everything that concerns you at the moment



Living with heart failure

- Living with much reduced energy
- looking good and feeling like ****
- 65year old with the mind of a 40 year old and the heart of a 90 year old
- learning to see the wood for the trees
- seeing the size of the problem
- solving your own problems again

- List of strengths and achievements
- list of problems and concerns
- so tell me what helps you cope with all of this?
- Tell me everything that does or could make any one of these problems any easier.
- Create a list of things that would help
- Finally, what would you like me to do?

Thank you