

# Joint advanced heart failure services

When should you bring in the  
specialists?

# Who provides the support?

**Families  
and  
informal  
carers**

## Generalists

- Primary care teams
- Hospital staff
- Nursing home staff

**Specialists**

# What some patients say about advanced heart failure

- Hope
- Spiritual strength
- Self esteem
- Humour

Baas 1997 CHF NYHA III & IV

- A belief that they could influence a more hopeful outcome for themselves

Martensson 1997 CHF NYHA II,III &IV

Despite significant symptom burden and poor prognosis

- High levels of satisfaction with their lives
- An ability to cope and adjust themselves

Baas 1997 CHF NHYA III & IV

# So who actually supports most of the patients with advanced heart failure?

Patients themselves

Families  
and informal  
carers

Generalists

- Primary care teams
- Hospital staff
- Nursing home staff

Specialists

# The overwhelmed patients

For some people heart failure creates a very difficult experience

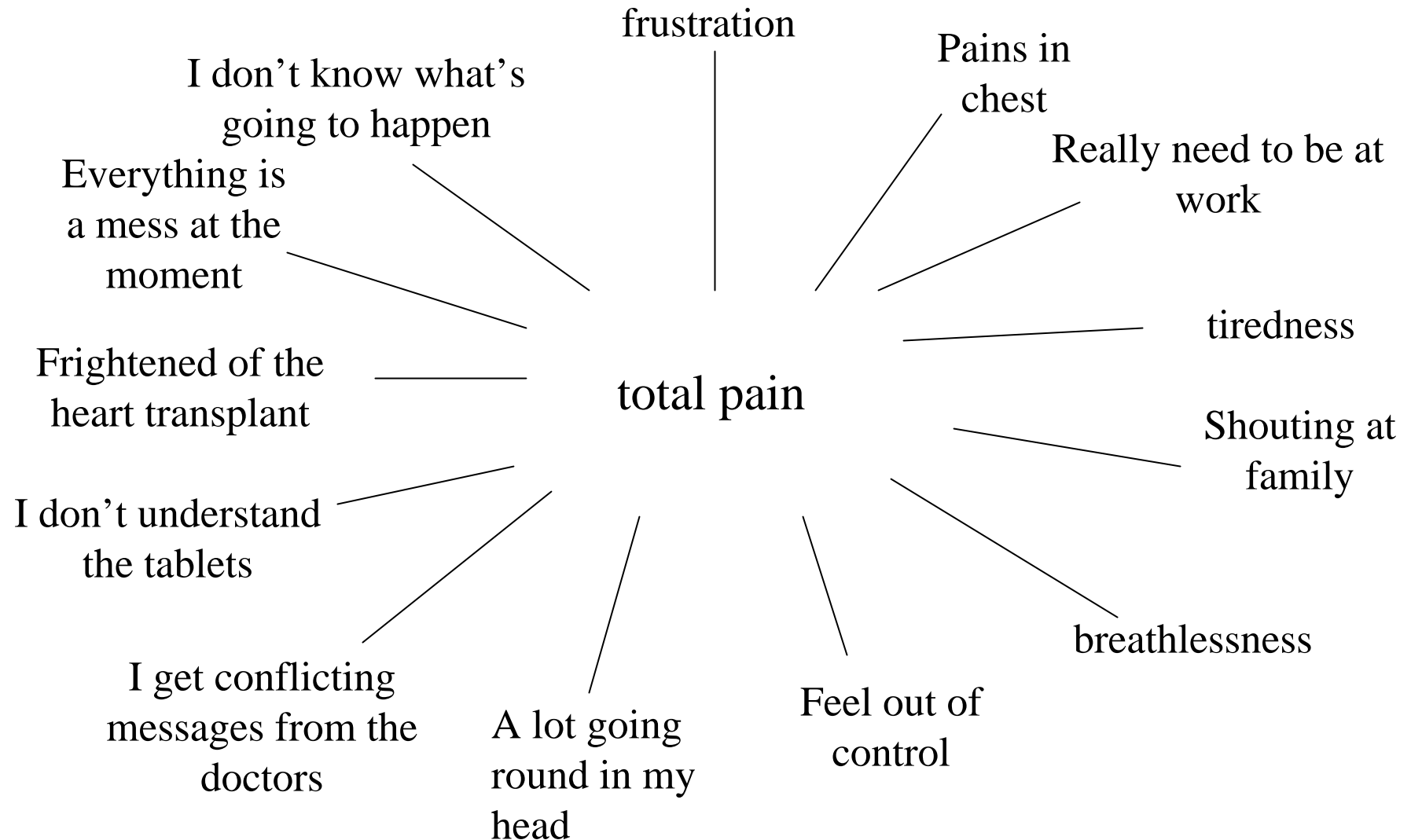
- Lack of physical and mental energy
- Anxiety and insecurity

Martenson 1998 NYHA II,III&IV

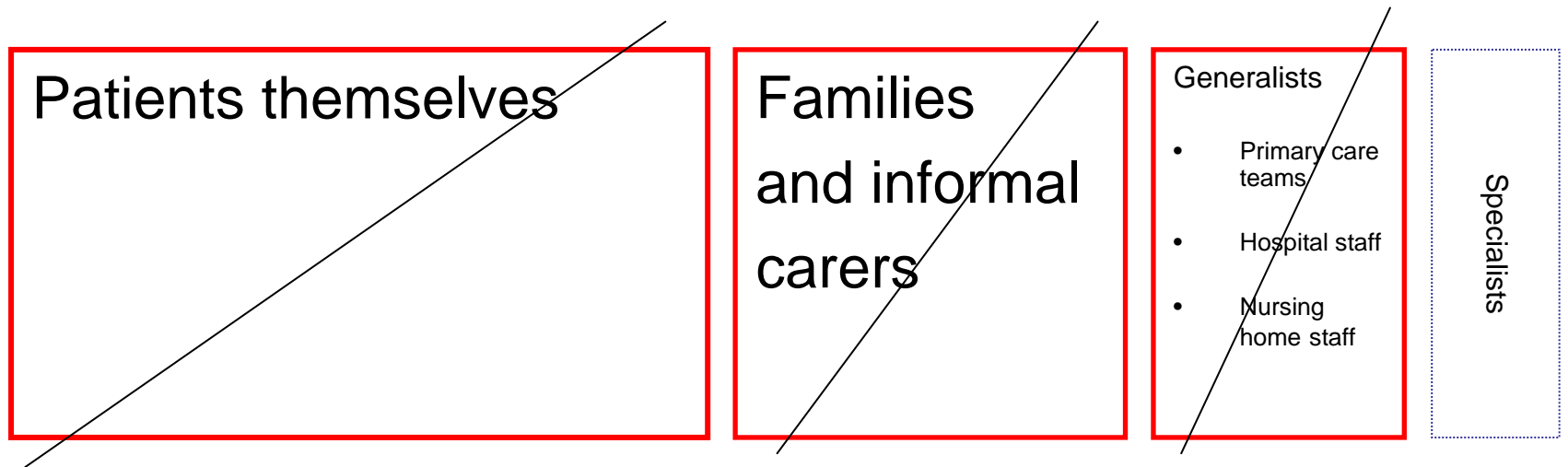
- Weak and out of control
- The hospitalised elderly found care to be
  - Confident but incomprehensible
  - Non-confident and incomprehensible

Eckman NYHA III&IV 1999

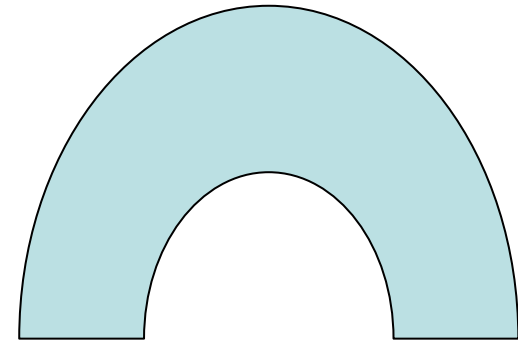
# Why do people become overwhelmed



# Where does the support system break down?



# Who will support the **overwhelmed** patient with advanced heart failure?



Patients  
themselves

Families  
and informal  
carers

## Generalists

- Primary care teams
- Hospital staff
- Nursing home staff

Specialists  
in the support  
of people with  
advanced  
illness

# What might the specialists in end of life care add?

Expertise in

- Psychological assessment and support
- Helping people with advanced disease to retain choice and control
- Communication about death and dying
- The masking of intractable symptoms
- The mobilisation of support services

# Choice at the end of life

Many patients choose life rather than death

- Patients were prepared to put up with more ill health than either their physicians or their informal carers thought they would

Califf 1998

Even though hospitals are confusing places where patients lose control

50 year old man NYHA IV

- Off transplant list – too ill
- Worsening renal function and worsening respiratory distress
- Little hope of improving renal function
- Symptomatic relief is the priority
- Speed of deterioration suggests life expectancy of hours and days rather than weeks
- Still for resuscitation and ICD still activated

No intention of 'giving up'

“Yes I want to be resuscitated.

Of course I want to be resuscitated”

# Dilemma

- We want to relieve his distress
- We want to avoid futile 'treatment'
- We want to avoid multiple ICD shocks
- We want him to have choice

BUT

- He wants to live, not to die
- He's been very close to death several times before

# Joint working between generalists and specialists in hospital

- His wife wanted no part in such a decision
- We put our dilemma to him
- Asked him to give us decision making powers
- “I want you to do what you think will help and I accept that you shouldn’t do what you don’t think will help”

# When should we involve specialist palliative care?

Patients themselves

Families and informal carers

Generalists

- Primary care teams
- Hospital staff
- Nursing home staff

Specialists in the support of people with advanced illness

# Finally

Where would I put new resources?

- Generalist care

What about the specialists?

- Fill fewer gaps by making experts of the generalists

- Thank you

- Describe a case
- David b heart failure nurse joint visit with comm mac
- End of life care chose hospital care
- Yes of course I want to be resuscitated
- Role of hospitals
- The pain is rarely neuropathic
- Learned that it is possible to discuss prognosis
- Patients want hospital care
- We know that generalists can be taught to discuss prognosis and to practice anticipatory care