



End of Life

BACCNA

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A man with a beard, wearing a light-colored sweater and dark pants, is standing in a library. He is holding a large, open book in front of him, reading it. The background is filled with bookshelves packed with books. The lighting is warm, and the overall atmosphere is quiet and studious.

What do we know?

Increasing Numbers

- Increasing age of death into adulthood
- Khairy P et al 2010 J Am Coll Cardiol
- ACHD growing epidemic
- Avila et al 2014 Canadian J Cardiol
- Lifetime Prevalence of Congenital Heart Disease in the General Population From 2000 to 2010.
Ariane J. Marelli
2014;130:749-756; June 18, Circulation

Life Expectancy

- Reduced in severe CHD
- Improving - ICDs CRT
- **1/3** deaths sudden, others gradual
- EOL life, resus, pts wishes need to be discussed
- Avoids distress re: treatment decisions at EOL

Care delayed/denied

- 48 patients, mean age 37yrs
- minority had EOL discussions prior to terminal admission
- most received aggressive treatment
- advanced palliative/EOL care should be developed to
 - reduce hospital therapies
 - improve death and dying

Call for early communication

- 200 ACHD pts + 48 CHD providers about EOL communication
- 2 patients had + 50% providers discussed EOL care
- 78% of patients wanted early discussion
- Drs discussions increase with complexity
- Early EOL discussion was favoured by 62% pts and 38% providers

Facilitators and Barriers to ACP

- Challenges of prognostication
- ACP not just for severely reduced life expectancy
- Most pts want this regardless of complexity of their disease
- Trusting relationship of pt and Dr in ACHD an excellent platform for these discussions

Knowledge and preference for ACP

- 200 pts
- 5% had completed, 56% never heard of them
- Infrequently completed in OPD
- HCP educate patients about advanced care directives
- Assist in preparing formal end of life planning
- Peoples wishes should be known and respected

A black and white lighthouse with a red band is situated on a rocky island. A massive, white-capped wave is crashing against the island, sending a huge plume of water high into the air. The sky is overcast and grey.

Avoid disaster

Discuss

Training

'How people die remains in the memory of those who live on'

*"You matter because you are you,
And you matter to the last moment of
your life.
We will do all we can, not only to help
you die peacefully, but also to live until
you die."*



~Dame Cicely Saunders



Dame Cicely Saunders (founder of the modern hospice movement)

What is palliative care?



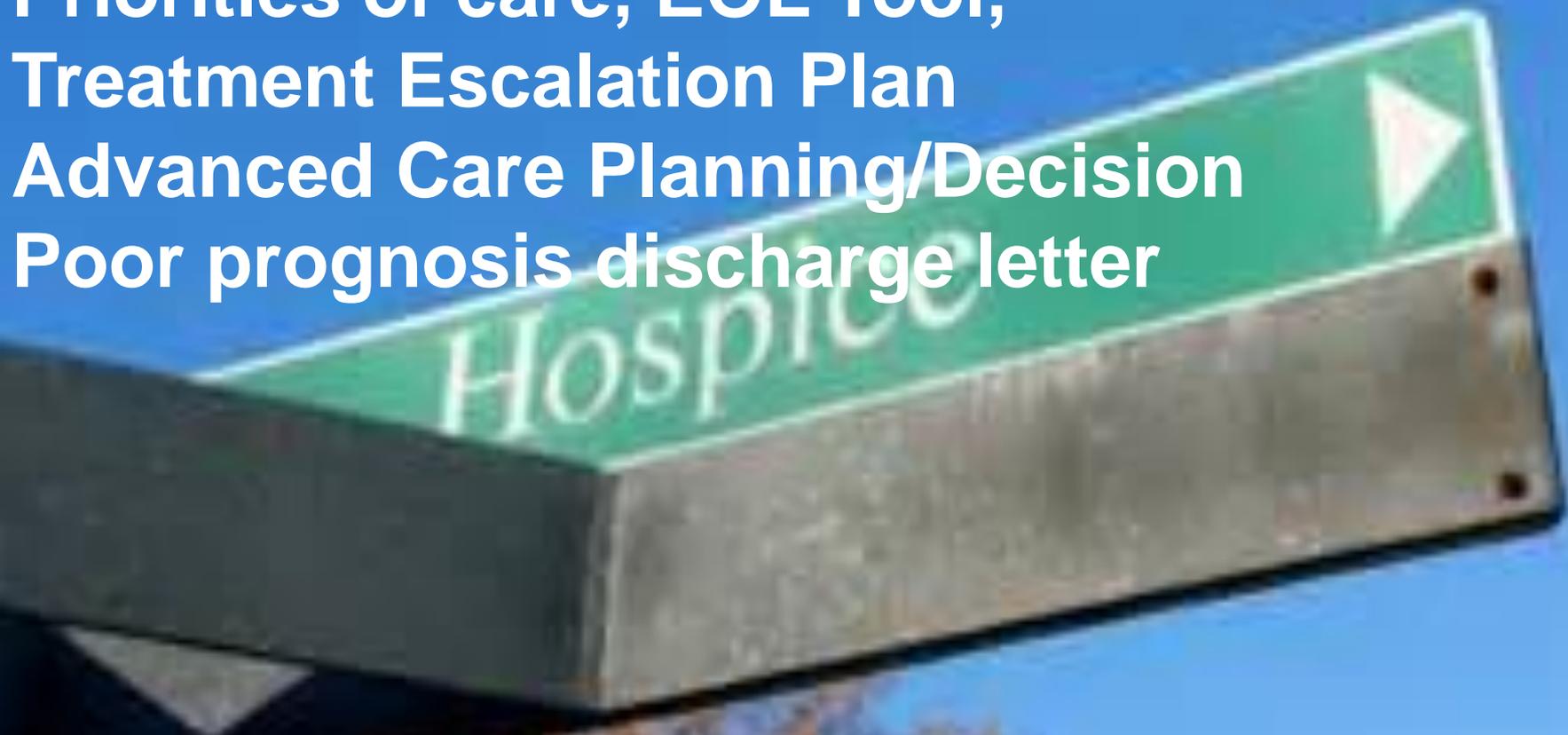
- Talking about death doesn't bring death closer. It's about planning for life.
- Without communication and understanding, death and terminal illness can be a lonely and stressful experience, both for the person who is dying and for their friends and family.



Dying
Matters

*'Let's talk
about it'*

Discussion patient and family EOL
Community HF team
Palliative care referral
Priorities of care, EOL Tool,
Treatment Escalation Plan
Advanced Care Planning/Decision
Poor prognosis discharge letter



Mental capacity

LPA

Help



Planning for your future care

A GUIDE

Preferred Priorities for Care

(Easy read)



Help



Written in with the
National Council of
Palliative Care

Aims to support those
caring for people affected
by heart failure

To open up conversations
about end of life wishes
and preferences



- The GSF Prognostic Indicator Guidance
- For clinicians to support earlier recognition of patients nearing the end of life
- The surprise question
- Next few months, weeks or days?

Symptoms in EOL Cardiac disease

- Breathlessness, may need home O₂
- Anxiety, may need benzodiazepines, opiates, treat depression
- Anorexia
- Cachexia
- Profound lethargy
- Syncope (treatable rhythm disturbances)
- Refractory oedema (IV medication)
- Abdominal distention

Cases

- K.A. 44 yrs post artificial heart
- M.B. 32yr old OOH
- R.B. 39yrs Welsh ICD
- A.L. 22yrs plus family
- A.D. 44yrs mild L/D
- S.H. 21yrs, PH palliative care



'Frightening'

*The scale of support required for congenital patients is significant, challenging and expensive, (medically, emotionally, and physically) putting other cardiac patients into the shade, and potentially just gaining them **a few extra years.***

*Being the parent of a sick child (Whatever age they are!) is **isolating and frightening,** you and your colleagues have made it bearable.*

Involve family

Despite aiming, through transition into adult services, to make young people more independent and responsible for their own health – if they have a complex condition there will have been years of family support, with the ‘child’, parents and hospital staff working as a triangulation team, and the family working hard to enable the young person to access normal age appropriate activities at home. Together they will express valid opinions, remember key points and decisions made, and offer a holistic view. The stress of writing out the parent had a significant negative impact, her emotional wellbeing and her health.

Parents

*Increase family involvement and create opportunities to have a planned reduction of **parental support, driven by the patient** at a pace that works for them and their health. **Opportunities for parents to continue to ask key questions** of the medics – in majority of case the patients will continue to be living within the family home, require parental support, and consideration needs to be given to this.*

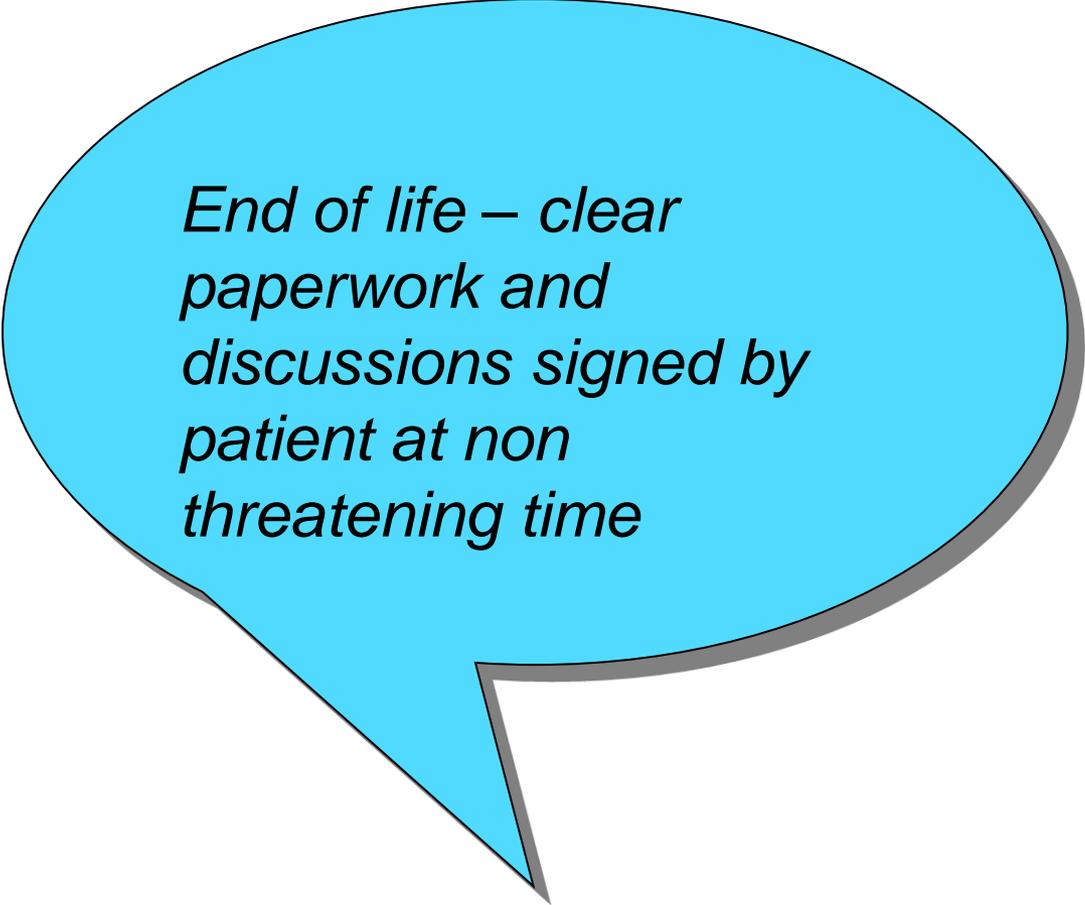
Miscommunication

She was able to give a convincing performance to both consultants and staff that she had fully understood their explanations/discussions, and was happy to give consent to undertake any further necessary tests etc, when all she was trying to do was leave the room as quickly as possible!

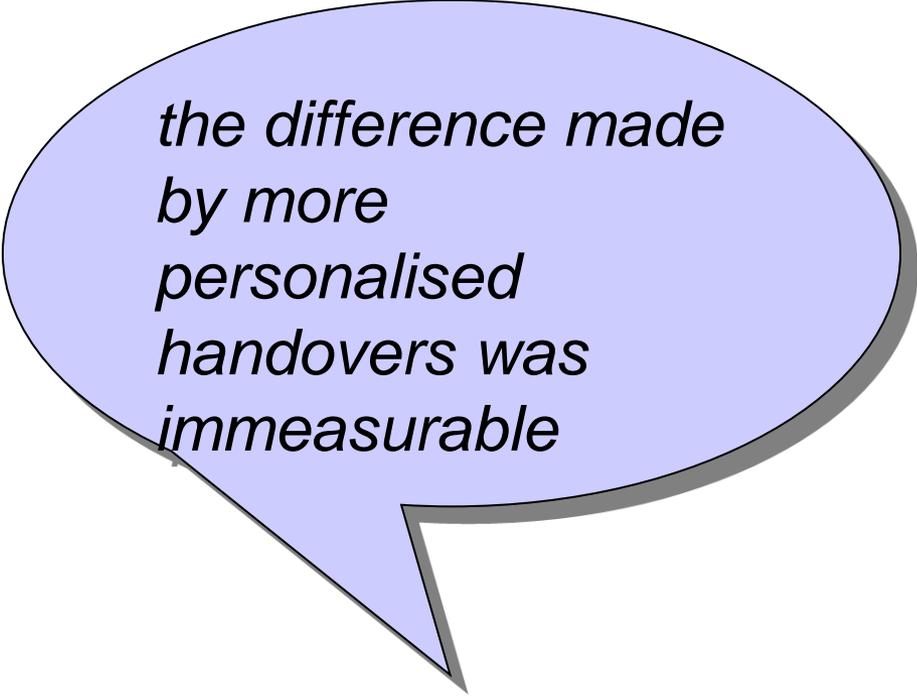
Jargon

Ward rounds – Whilst appreciating that these are learning opportunities for practitioners, the **medical language** utilised was inaccessible and daunting. She found this intimidating and frightening. Young people are anxious not to appear as if they don't understand, but the discussion is about their condition and their care, and **they want to know**. She lacked the courage to ask for an interpretation in front of a group, and didn't want to be patronised **either**. Being in hospital was **terrifying for her, and this also had an impact on her processing of information**. The **volume of people standing over her, when she felt so disadvantaged academically, physically and emotionally, and was just so tired, was difficult for her**.

Management/support



*End of life – clear
paperwork and
discussions signed by
patient at non
threatening time*



*the difference made
by more
personalised
handovers was
immeasurable*

Education

Training – centre of excellence, utilise the immense skill and knowledge base you have here to teach

Education – enable staff to be aware of the impact of their own anxieties on patient's wellbeing.

Read the Notes

*She had to constantly retell and explain her life story; **this exhausted her, and must have been in her notes.***

..zero control over her congenital condition; this triggered the need to control other (often ridiculous) minor things, and would benefit from greater understanding. Her fear of all things medical, and knowledge about how ill she was, was enormous and irrational. It controlled every part of her but was difficult for anyone else to truly understand, or see just how much it coloured her world.



SOMETHING NEW

SAME OLD WAY

Dying Matters 2015

The research found:

32% think about dying and death at least once a week,
72% believe people in Britain are uncomfortable discussing dying, death and bereavement.

35% public have written a Will

32% have registered as an organ donor or have a donor card

31% have taken out life insurance

27% have talked about their funeral wishes

7% have written down their wishes about their future care, should they be unable to make decisions for themselves.

- **Letter**
- **Family sometimes return**
- **No annual reminder**
- **Flowers to well known patients**



Support

- Cruse Bereavement Care <http://www.cruse.org.uk>
- Caring and bereavement BHF www.bhf.org
 - Publications for carers and people who have lost someone to heart disease.
 - Dying Matters
www.dyingmatters.org/overview/resource
- The Harbour, a Bristol-based charity, offers free counselling and psychotherapy to people
- www.the-harbour.co.uk/

References

- DH (2008) End of Life Care Strategy Promoting high quality care for all adults at the end of life.
- Dying matters (2009) by National Council Palliative Care
- RCN (2014)

Thank you



questions?

Early communication

