Decision making in palliative care and what ethical considerations do we need to keep in mind?

Sharon Lambie, Clinical Nurse Specialist in palliative care

Aims of the session

- Discuss the 4 main ethical principles within palliative care practice
- Explore the effectiveness of an ethics model in relation to a clinical case.

Some difficult decisions in palliative care

- DNA CPR?
- Withdrawing and with-holding treatment
- Managing difficult symptoms
- Managing complex families
- Truth-telling / collusion
- Preferred place of care
- Sharing of information/consent
- Patient advocacy

"Help – What should I do?"

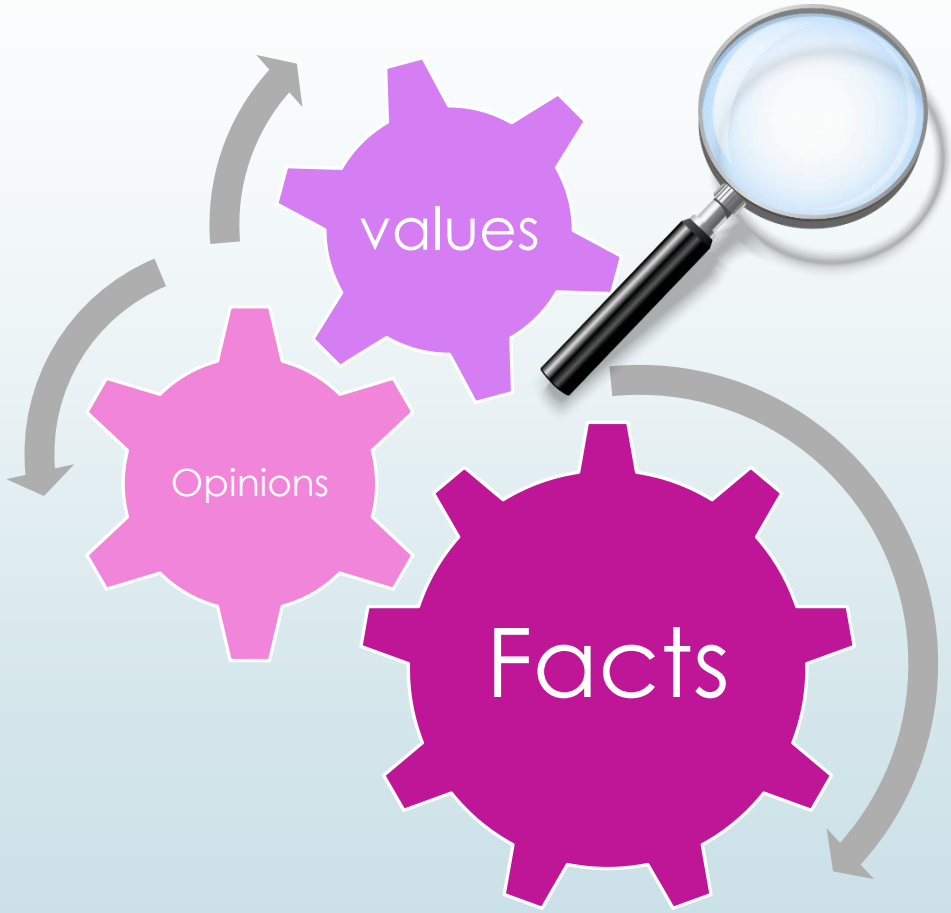
What do we do when…

- 48yr old, admitted to critical care following a significant AKI eGFR requiring dialysis.
- Found to be HF and new dx of metastatic o'geal cancer with liver mets.
- Confused due to HAP/AKI
- Consultants discusses a TEP and DNA CPR and wants to withdraw active tx – not responding to tx and unlikely to get treatment for his cancer.
- He has a wife, 2 children 11 and 16. 16 is doing her exams at school and family don't want to upset her even further and want her to complete her exams. They are angry with the consultant as they think they are giving up on their husband/Dad.

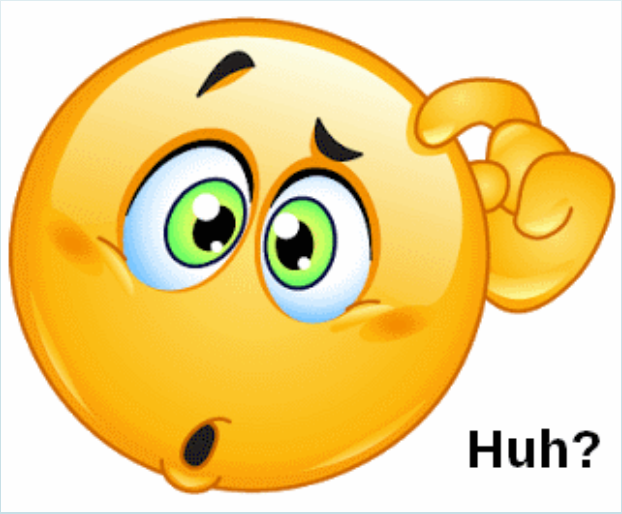
➡What do we do?

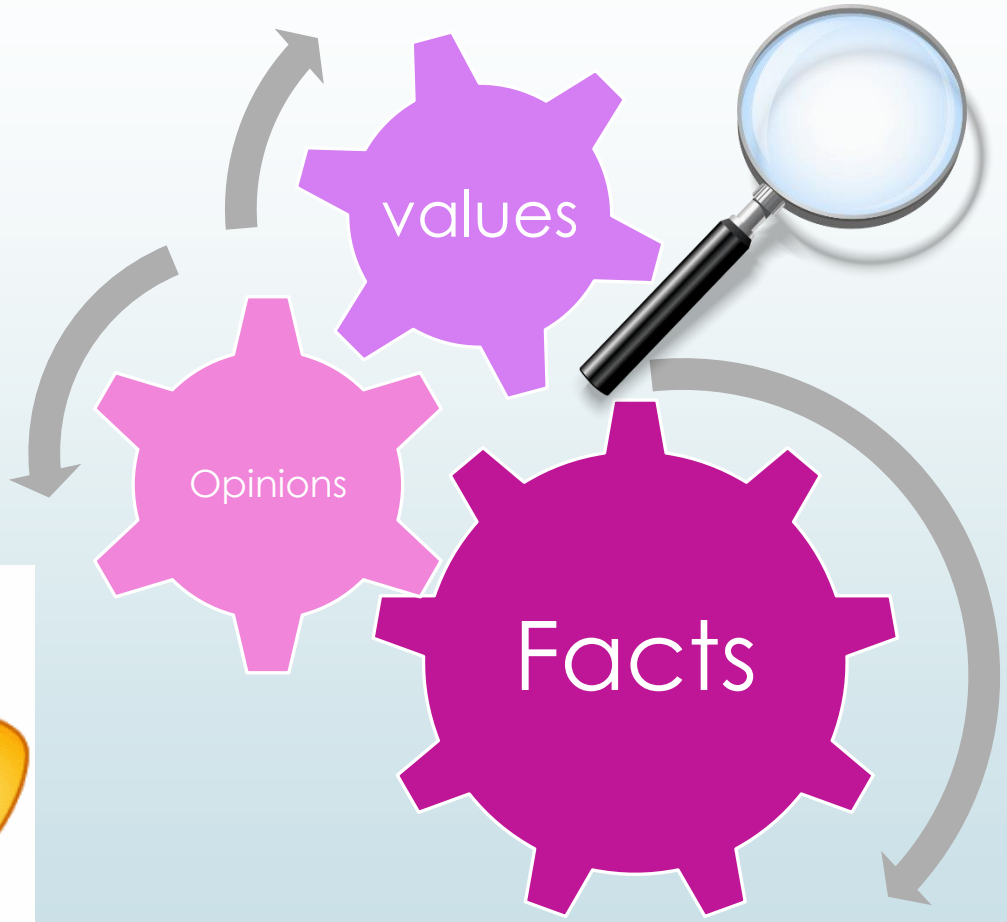
Ethical dilemmas

- Ethical dilemmas typically occur when values conflict
- To resolve ethical dilemmas, we need to identify, and separate the facts, the opinions and the values
- Ethical practice GUIDES us to what is morally right and wrong



Making decisions in healthcare





Group Work – How do we go about making decisions?

In pairs/groups, discuss the following –

There is a promotion at work, but in a different hospital. Which would add an extra 25 minutes to your journey each day (each way) and cost you an extra £80 per month in travelling costs.

It's a busy job and there's an expectation that you may have to work additional hours occasionally.

You would be paid an additional £1800 for the first year and you would start going up increments again. This job is Monday – Friday. No more shifts or nights.

Would you take the job? What helped you make the decision?

Some ethical frameworks

- Consequentialism
- Deontology
- Ethics of care
- The 4 principles

The 4 principles in healthcare

- **Autonomy**
- **Beneficence**
- **Non-maleficence**
- **Justice**

Beauchamp and Childress (2001)

In essence

Making decisions in healthcare is often about balancing ‘the risks versus the harms’

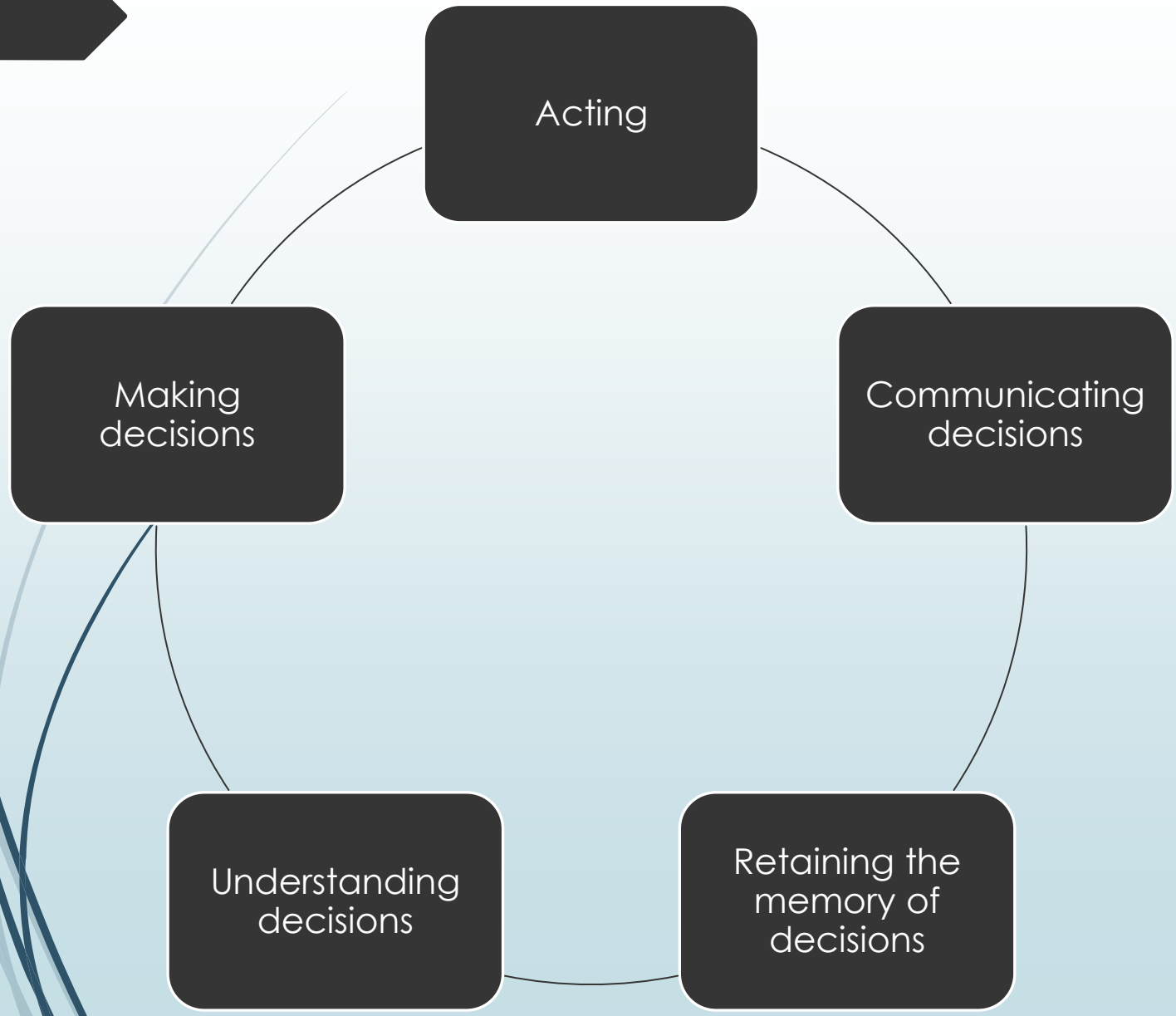
And then taking these back to the patient and those close to them to make a decision

Autonomy – In law….

- Always assume that an adult is competent to make a decision, unless you can prove otherwise
- A competent adult has the right to make 'bad' decisions/take risks
- Competent adults can refuse any medical treatment, including withdrawing from current treatment even if it means that death is likely to follow
- Patients cannot request/demand treatment
- Decisions are made free from coercion

Should Autonomy Always Be Respected?

A person **is competent**, if they are **capable** of ….



- **If a patient lacks capacity**

then adopt the 'best – interests' approach to make decisions.

Key principles of 'best interests' decision making

- Not just medical best interests – consider a person's welfare
- What would a 'reasonable person' want?
- Need to really consider the person and not what is best for those, roundabout them.
- Take all reasonable steps to include the person in the decision making.
- Consider previous and present expressed wishes, feelings
- Include those caring for the person in decision making
- It will depend on what is reasonable, practical and appropriate
- It's not just about reaching the right decision or a threat of being sued – but also whether the correct process is followed

For patients without capacity

Need to demonstrate/document that a person lacks capacity

- Formal tools – MMSE, MoCA, AMT, communication, psychiatry review?
- AWI, guardianship, PoA
- Act in the patient's 'best interests'
- Mental Health Act (2015)
- Need to assess capacity for the specific intervention

- And some patients may wish to hand over the decision making to their family.

Let's give it a go!

Treatment options case studies

Using the 4 principles

- **Autonomy**: do you want the job, have enough information to make a decision? Satisfaction?
- **Beneficence**: what benefits will the job bring?
- **Non-Maleficence**: will the job bring me/family more harm, stress,
- **Justice**: what are the costs, time involved?

Mrs B

- Admitted to hospital unresponsive and a dense left sided weakness. She is thrombolysed and showing some small signs of recovery. She is aphasic and is unable to swallow.
- She has previously told her daughter that she would not want to be artificially kept alive if there was NO chance of recovery but would want anything done to help her. A DNA CPR form is put in place.

- Should she be NG fed?

Case 1

- Mary is 83 yrs with advanced dementia. She is unable to communicate and does not recognise her family. She looks happy, spending her days looking after her baby doll.
- She had a advance directive/living will where she had stated that she did not want any life prolonging treatment in the event of her getting a progressive, incurable illness.
- She is now unwell with a severe chest infection.

- **Should she get IV antibiotics?**

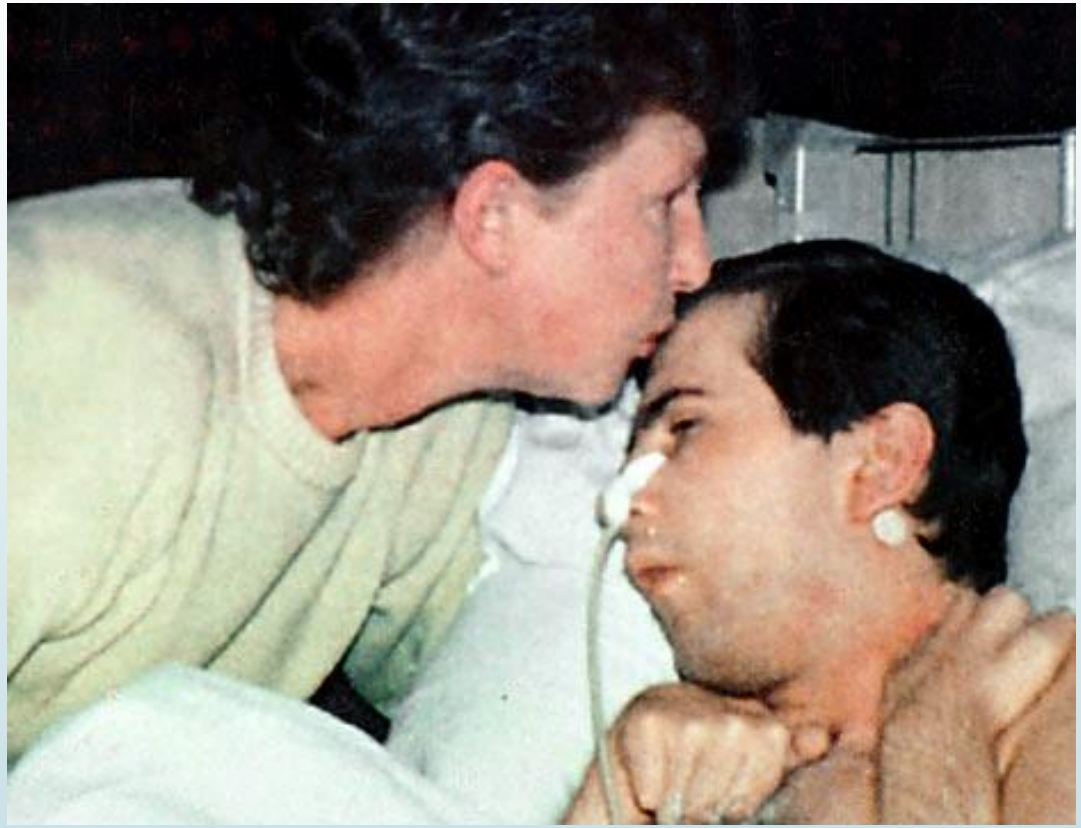
Withdrawing/withholding treatment

- Consider the following;-
- Both Smith and Jones will inherit £600,000 if their 6-year-old nephew was to die. Both Smith and Jones go in separately to kill the nephew.
- Smith sneaks in when the little one takes a bath and pushes the child under the water and he drowns.
- Jones sneaks in, attempting to do the same but when he gets there, he finds the child has slipped and knocked his head and he's struggling in the water. He leaves him to drown.

- **Who's worse, morally speaking?** (James Rachels)

Allowing to die, assisted suicide, killing

- Tony Bland
- 18 years old
- Victim of the Hillsborough disaster
- Lived for 4 years in a persistent vegetative state
- Courts argued it would be classed as murder if his nutrition was withdrawn



Futility

- Treatment is futile if it does not have the desired effect
- Treatment is futile when, although it does have the desired effect, the patient's situation does not improve
- Be clear about the intentions of an intervention (i.e. promoting comfort versus hastening death)
- What is the cause of death?
- Ie the disease, stopping tx.

Symptom control versus euthanasia

Papa G is an 87 yr old man who is dying of an aspiration pneumonia.

He has his JIC meds prescribed. His family feel that he is really sore and very distressed and they are coming out every 2-3 hours asking for more morphine/midazolam for him.

Every time you see him – you feel he is very comfortable and don't think he needs any morphine/midazolam

Would you give the morphine/midazolam?

Hastening death and the doctrine of double effect

- 1. the nature of the act must be for the good or at least morally neutral
- The harmful effect must be foreseen but not intended
- The harmful effect must not be a way of producing the good effect
- The good effect must outweigh the harmful effect, proportionately

- Originally formulated by Thomas Aquinas to apply moral dilemma in which it is impossible for a person to avoid all harmful effects.

Autonomy

Sally has a dense R sided weakness, prone to falls due to poor safety awareness. She is a large lady. Deemed to have capacity. Wants home. She lives with her husband who agrees for discharge. PT/OT, docs, nursing staff and children do not feel that it is safe for her to go home. She says she's happy to lie on the floor till carers come in to lift her up.

Should she go home?

- Jack is a 59 year old man with NAFLD and is beginning to approach the end of life. He has been open with his family and they have discussed his wishes for when he's dying and he has a DNA CPR in place, he does not want to go back into hospital and wishes to stay at home for EOLC. His 2 daughters (in their 30's) are keen to support him with this.

- However, as he deteriorates, he becomes confused (at times), prone to falls, occasional incontinence. He's also becoming anxious and panicking. He's calling on his daughter more and more. One of his daughters had moved in with him but feels that she can't cope anymore and calls the ambulance for him to be admitted to hospital.

- The ambulance arrives but Jack refuses to go but his daughter insists….

- **Should he go into hospital?**

Autonomy

Grace is dying of end stage COPD. She is thought to be in the last hours/days of life. Her daughter asks whether she should be staying with Grace all the time. She is not overly keen to do this as she has a 5 year old daughter but feels that she should stay and be with her Mum. She asks the nurse '**what would you do if it was your Mum?'**

The nurse tells her 'I wouldn't go anywhere, if you want to be with her. She could deteriorate anytime'. Her daughter stays and her Mum dies peacefully 2 days later.

Did the nurse say the right thing?

Did her daughter make an autonomous decision?

John

- John is a 48 year old man who has oesophageal cancer with new liver mets. He sees his oncologist who tells him that there are no further treatment options and introduced the idea of palliative care, for further down the line when he needs it. John and his wife were left with the impression that he had short months to live, and felt reassured by this.

- He died 2 weeks later

- Did the oncologist do the right thing?

Autonomy

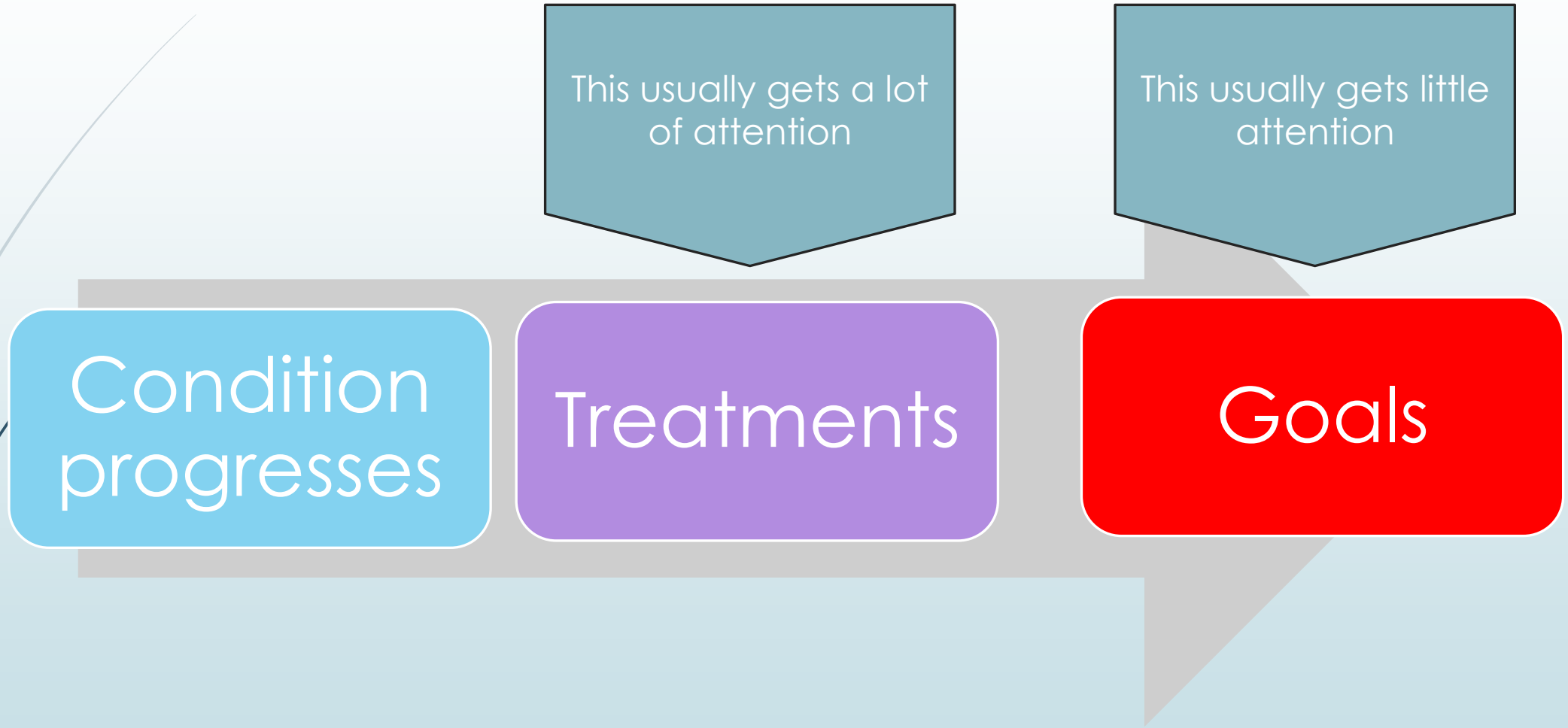
Thomas previously kept well but is now deteriorating (you think he's beginning to die) recently from his oesophageal cancer and the doctors talk to him about CPR. He's not for HDU or ITU level care.

He says that he wants an attempt at CPR as he doesn't feel ready to die yet and he is desperate to get to his daughter's wedding in 4 months time.

The doctor does not put in a DNA CPR form – is this the right thing to do?

To summarise - good decision making in HC

Priorities


This usually gets a lot of attention
This usually gets little attention
Condition progresses
Treatments
Goals

Goal setting

But, I wonder… as disease progresses…

Autonomy

My wife is dying of dehydration – shouldn't she have a drip?

Use the 4 principles to think about this decision.

The four priniples can be applied to many dilemmas in healthcare

Example: My wife is dying of dehydration – shouldn't she have a drip?

Autonomy: How does the patient feel - Is she thirsty, hungry, dehydrated? What do they think the fluids would do?

Beneficence: What benefits would fluids bring -Reduce thirst, benefit for relative, comfort?

Non-Maleficence: What harms would the fluids cause – pain, swelling, secretions, ?prolong life

Justice: What is the cost involved?

BRAN

- **B –Benefits**
- **R- Risks**
- **A – Alternatives**
- **N - Nothing**

Summary - Making treatment decisions at end of life

- Explore treatment options – expectations, likely benefits, burdens or risks.
- Treatment should be offered if benefits are high and burdens are low.
- No legal obligation to offer treatment that is medically futile.
- Remember that patients/families may not always have a clear or realistic understanding of the diagnosis or risks of a treatment. This is particularly the case in CPR and parenteral nutrition and the public's knowledge of the clinical complexities may be limited.
- If the outcome of treatment is uncertain, then treatment can be offered to make a clearer assessment eg often happens with antibiotics at end of life
- Inform patients/families that treatment may be withdrawn if not having the desired effect.

What guides our practice?

- Our own professional codes of practice
- Scottish palliative care guidelines
- Treatment and care towards the end of life: good practice in decision making (GMC 2010)
- Realistic conversations: shared decision making in practice (NES emodule)
- Realistic medicine
- Healthcare quality strategy for NHS Scotland (2010)
- Decision making and consent (GMC 2020)
- Adults with Incapacity Act (Scotland) 2000
- BMA – best interests decision making for adults who lack capacity