

Communication with parents



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1. Parental role in decisions - ethical framework
2. Communication with parents - principles and pitfalls
3. (Disagreement)



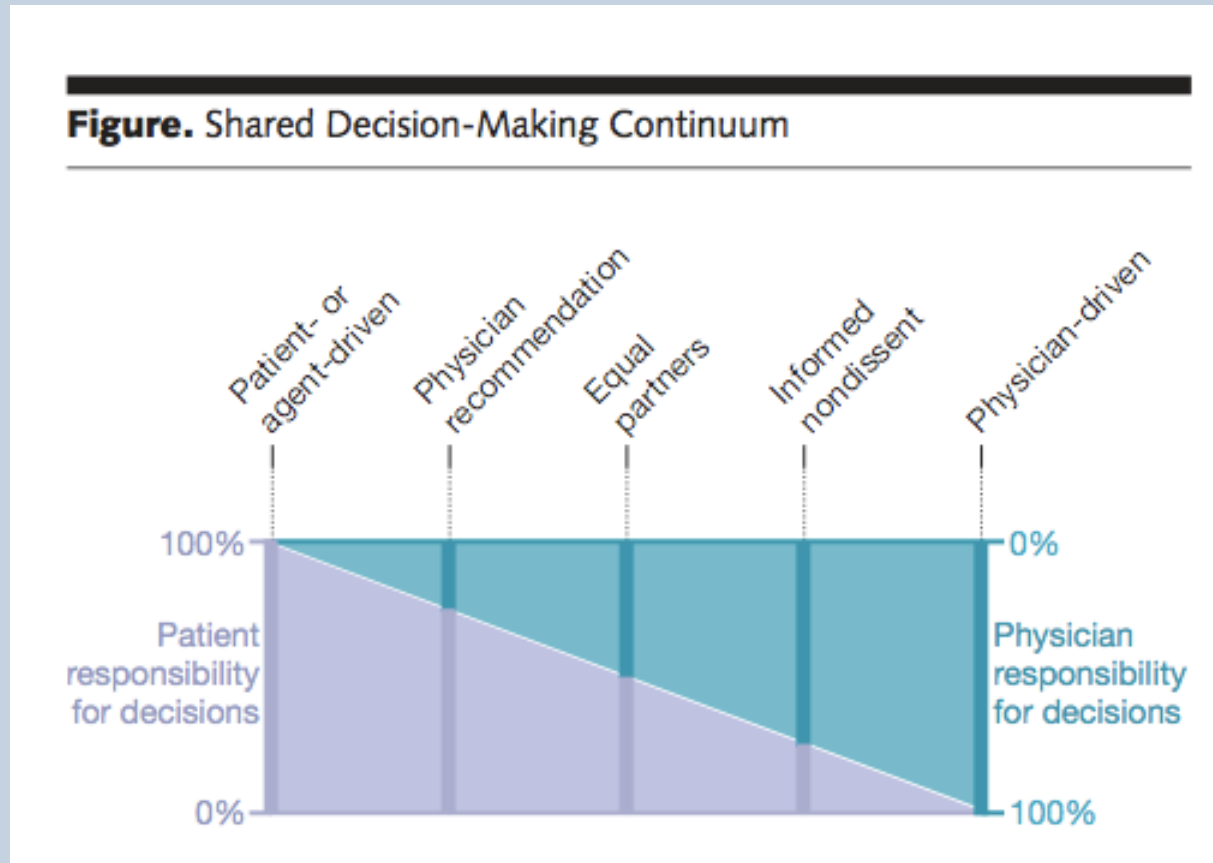
Who decides?

- Who should make major decisions about newborn infants?
 - Health professionals (doctors/nurses/team)
 - Health professionals should decide, but parents must agree
 - Health professionals and parents together
 - Parents should decide, but with the help of health professionals
 - Parents
 - It depends

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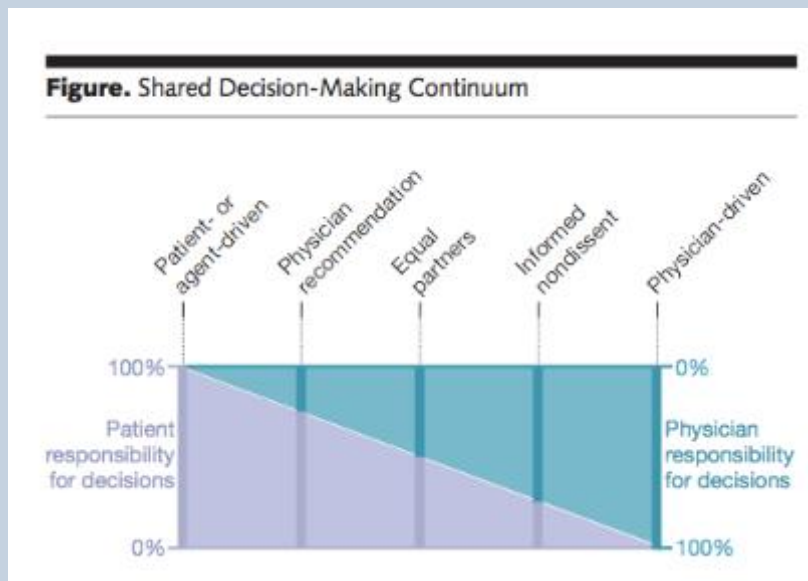
The spectrum of shared decision-making



Kon JAMA 2010; 304: 903

Where should we be on the spectrum?

- 1. It depends on parents' views



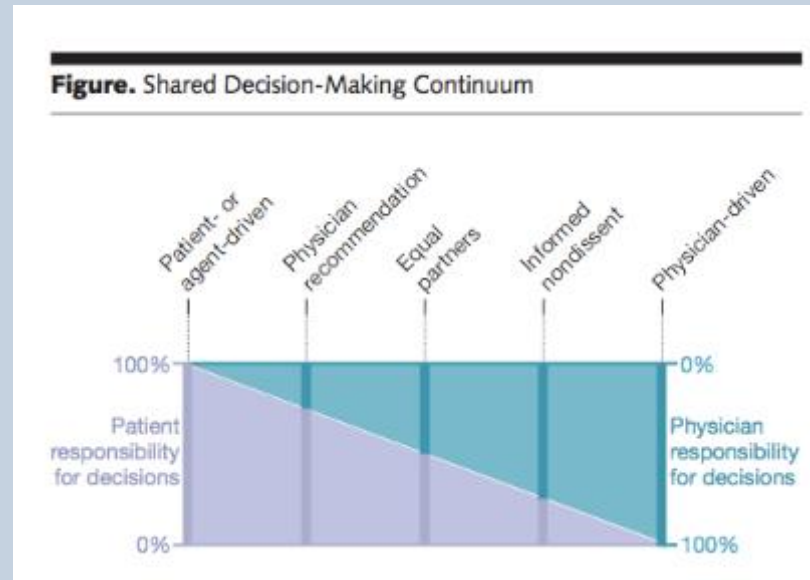
It shouldn't depend on which doctor is on service...

- (adult ICU)
- Audio-taped interviews

Expanding the paradigm of the physician's role in surrogate decision-making: An empirically derived framework*

Douglas B. White, MD, MAS; Grace Malvar, BA; Jennifer Karr; Bernard Lo, MD; J. Randall Curtis, MD, MPH

Crit Care Med 2010

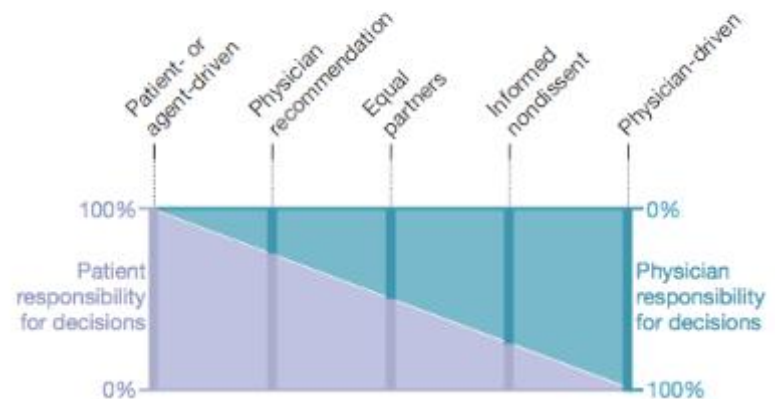


Informative Facilitative Supportive Directive

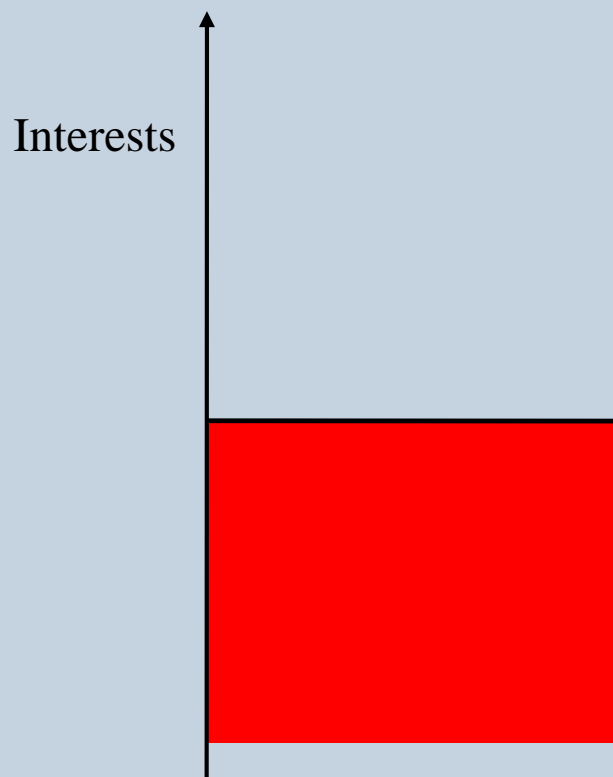
Where should we be on the spectrum?

- 1. It depends on parents' views
- 2. It depends on the situation

Figure. Shared Decision-Making Continuum



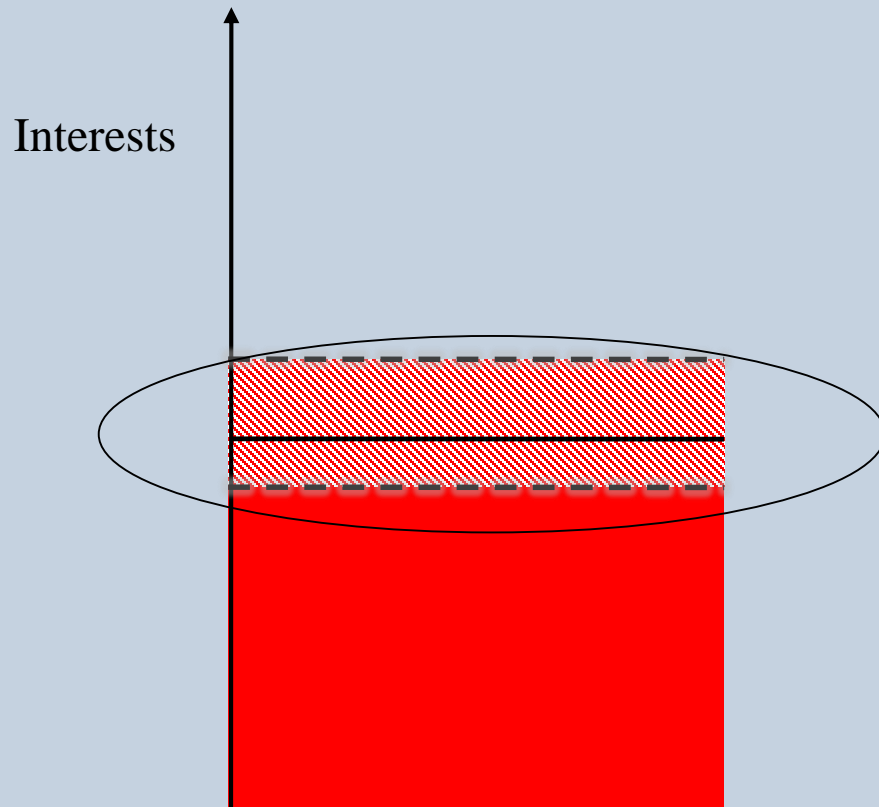
A framework for decisions



- Best interests



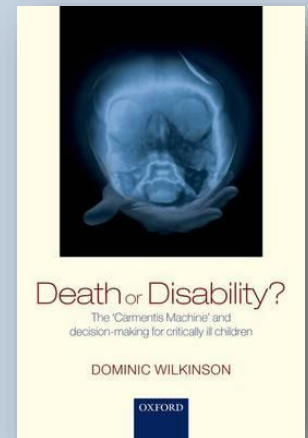
A framework for decisions



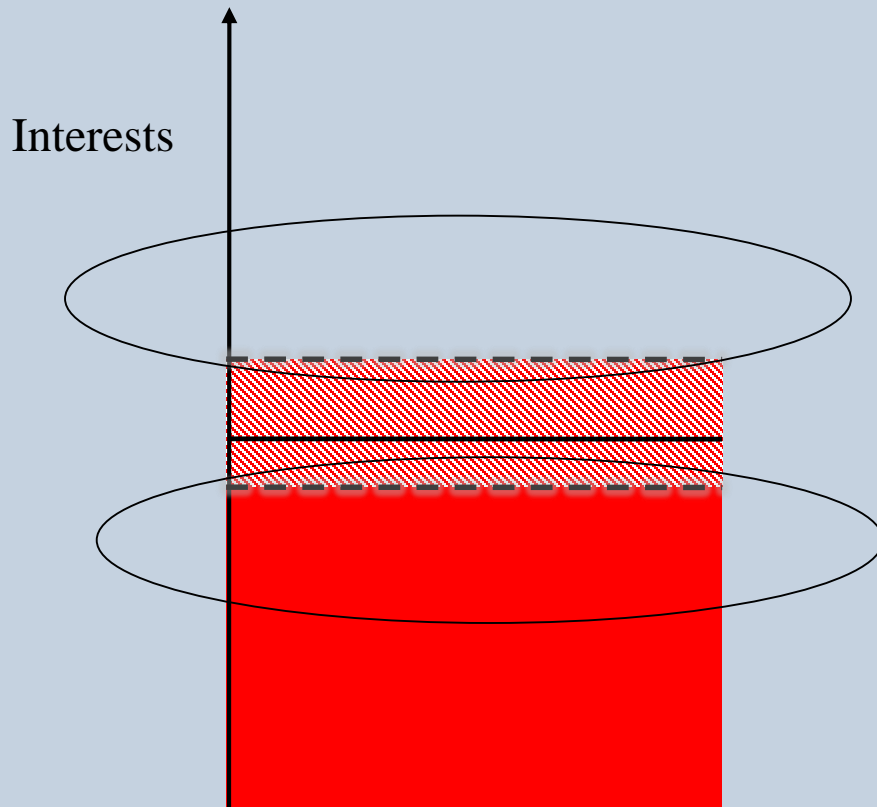
“Zone of parental discretion”

- In some settings it may be reasonable either to continue treatment or to limit treatment

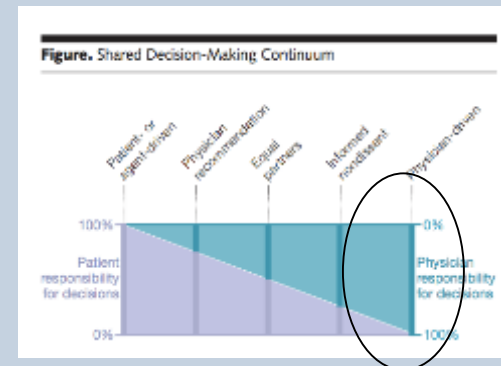
“grey zone”



A framework for decisions



- In other settings it may be **unreasonable** to continue or withhold treatment
- Counselling should be directive

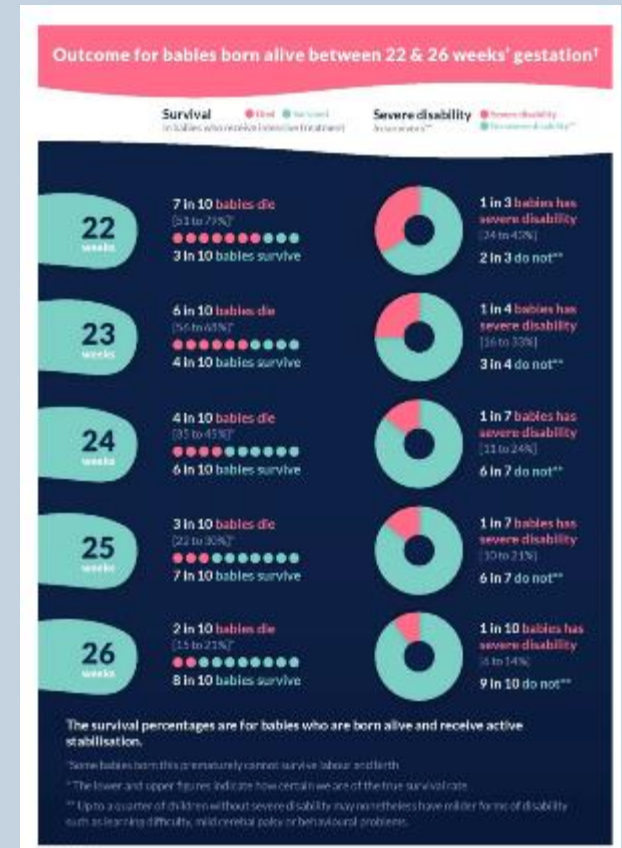


- Mary presents in preterm labour at 23+6 weeks gestation
- You have been asked to “counsel” her

- How should you approach this?

Step 1: Get your facts straight...

What is the outcome...?



Step 2: Get all the relevant facts

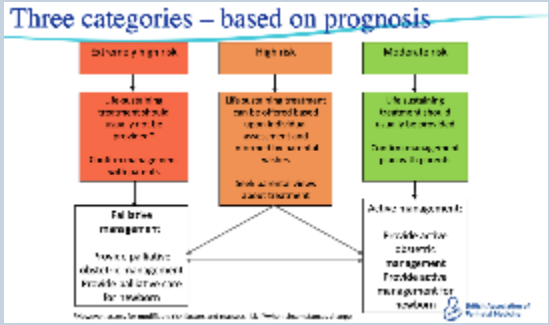
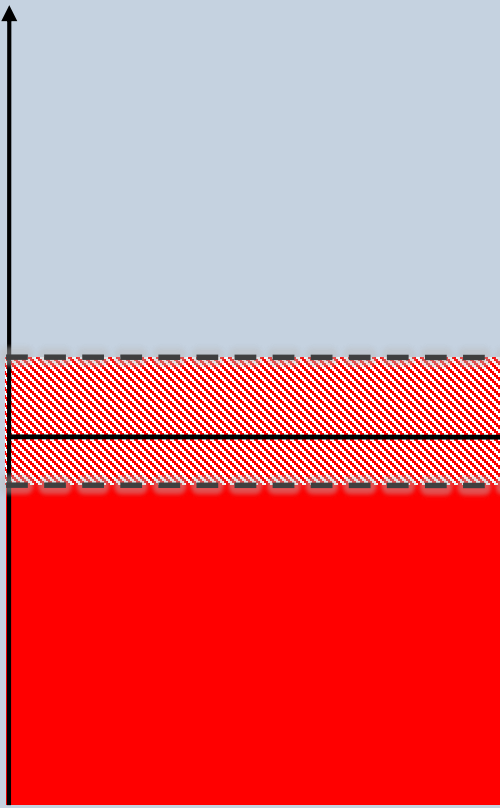
- | | |
|----------------|--------------|
| ▪ 23+6 | 23+6 |
| ▪ 400g | 600g |
| ▪ male | female |
| ▪ PPRM 4 weeks | no ROM |
| ▪ Level 2 | level 3 |
| ▪ No steroids | 2 x steroids |

Step 3: Work out what sort of discussion this is

3 groups of patients/situations

- Resuscitation not an option
- Resuscitation optional
- Resuscitation mandatory

Interests



Step 4: remind yourself that the parent is not a Vulcan



Figure 1 Star Trek character Mr Spock.

VIEWPOINT ARTICLE

Antenatal counselling for parents facing an extremely preterm birth: limitations of the medical evidence

Annie Janvier (anniejanvier@hotmail.com; annie.janvier@umontreal.ca)¹, John M Lorenz², John D Lantos³

1.Division of Neonatology and Clinical Ethics, Department of Pediatrics, University of Montreal, Sainte-Justine Hospital, Montreal, QC, Canada

2.Division of Neonatology, Department of Pediatrics, Columbia University, Morgan Stanley Children's Hospital of New York Presbyterian, New York Presbyterian Hospital, New York, NY, USA

3. Department of Pediatrics, Children's Mercy Bioethics Center, University of Missouri Kansas City, Children Mercy Hospital, Kansas City, MO, USA

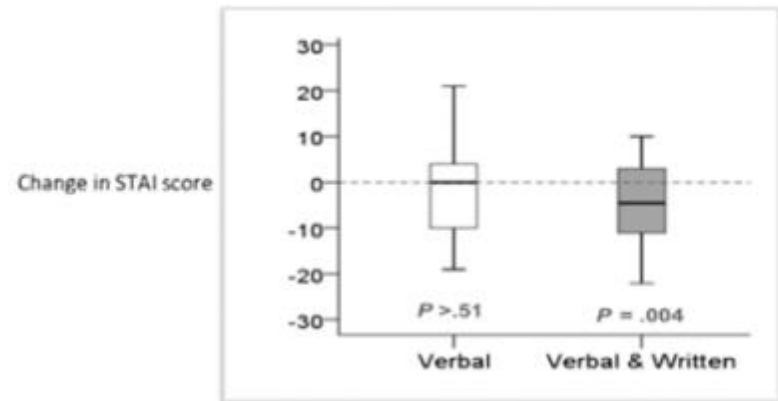
Step 5: Bring some written information if you can

Supplemental Written Information Improves Prenatal Counseling: A Randomized Trial

Muthusamy, A. D. A., *PEDIATRICS*, 129(5), e1269–e1274.

60 pregnant participants

Randomised to either
Verbal information
Verbal plus written



Written group

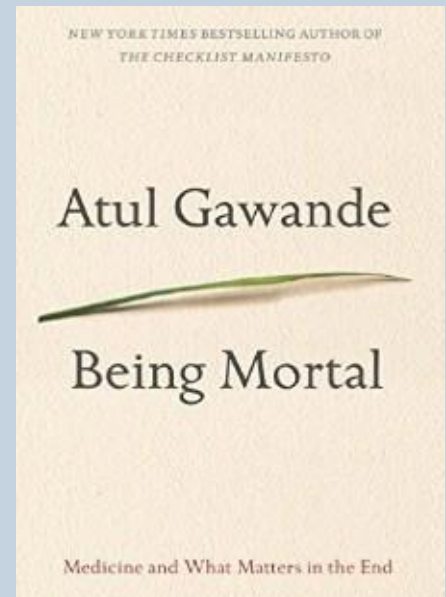
Better – recall of information
50% vs 80% recall of statistics
about long term outcome

- Azoulay
 - Family information leaflet provided at time of admission to intensive care
 - Reduced (40% to 11%) proportion of families with “poor understanding of diagnosis and prognosis”
- Lautrette
 - Brochure on bereavement – for families of dying patients
 - Reduced anxiety/depression and post-traumatic stress 3 months after death

Step 6: Ask, tell, ask

Four questions (ask ask ask ask tell ask)

- *(Is now OK to talk? Is there anyone else you'd like to be here?)*
- ***What's your understanding of what's going on?***
 - *What have you been told? (What have you read?)*
 - *Also –has anyone you know been in this situation?*



- ***What are you hoping for? What is most important for you?***
- ***What else are you hoping for? (Aiming to gain an understanding of realistic hope and achievable goals, to inform development of a plan)***

- ***What are your fears? What is worrying you or scaring you the most?***
- (4. What outcomes are unacceptable to you? What are you willing to sacrifice and not?)
- (5. Do you have a name for your baby yet)

Tell

- The Big picture
- Options
- Specifics – based on situation and what you know of the parents' priorities and fears



If 10 babies are born at around 23 or 24 weeks it is likely that five of them will die even if they have intensive treatment (the red figures).

1 baby will survive with very serious lifelong disability* (the grey figure).

4 babies will survive without a serious disability*. They may have a range of health problems and extra challenges in childhood and at school, but are still likely to be able to do many of the things that other children can do (the green figures).

* See later pages for more on disability.

We don't know what will happen for your child. We don't know if they will be one of the babies who survive, whether they will have a serious disability, or whether they will die. The chances for your baby may be better than these figures or they may be worse. Your doctor can give you some idea.

Talking about options

- Some families feel/choose...
- Other families choose...

Ask

- That is a lot to take in, and must be difficult to hear
- What are your thoughts?
- What is going through your head?

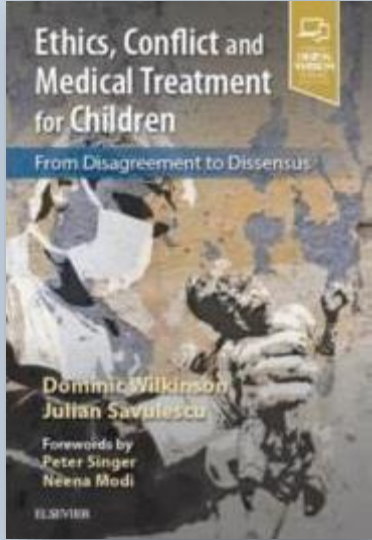
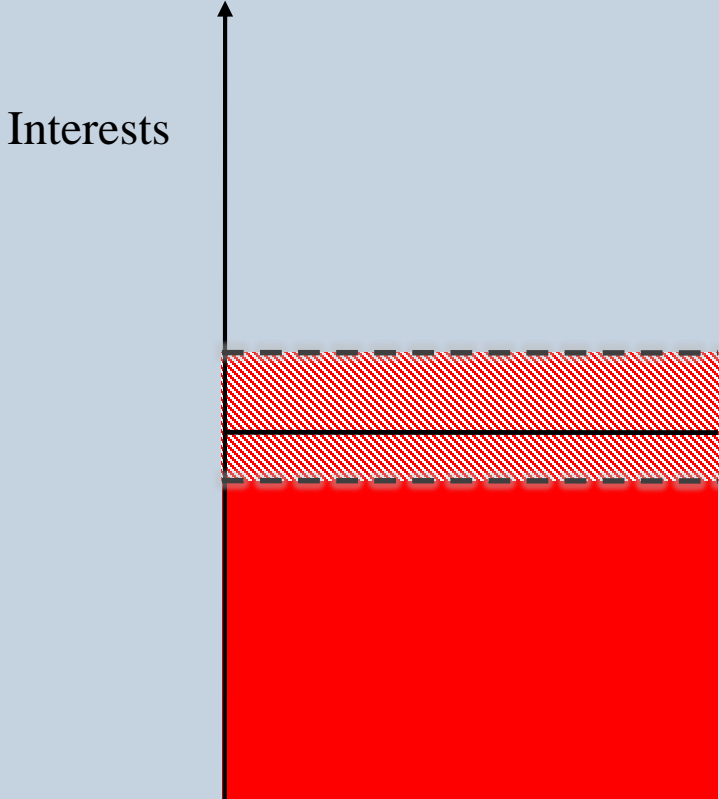
Please don't...!

- 1. Give the family a shopping list
- 2. Ask them if they want us to **do everything...**
 - (ask them if they want us to “resuscitate”)
- 3. Tell them that you will make a decision in the delivery room based on how the baby looks

Please do...

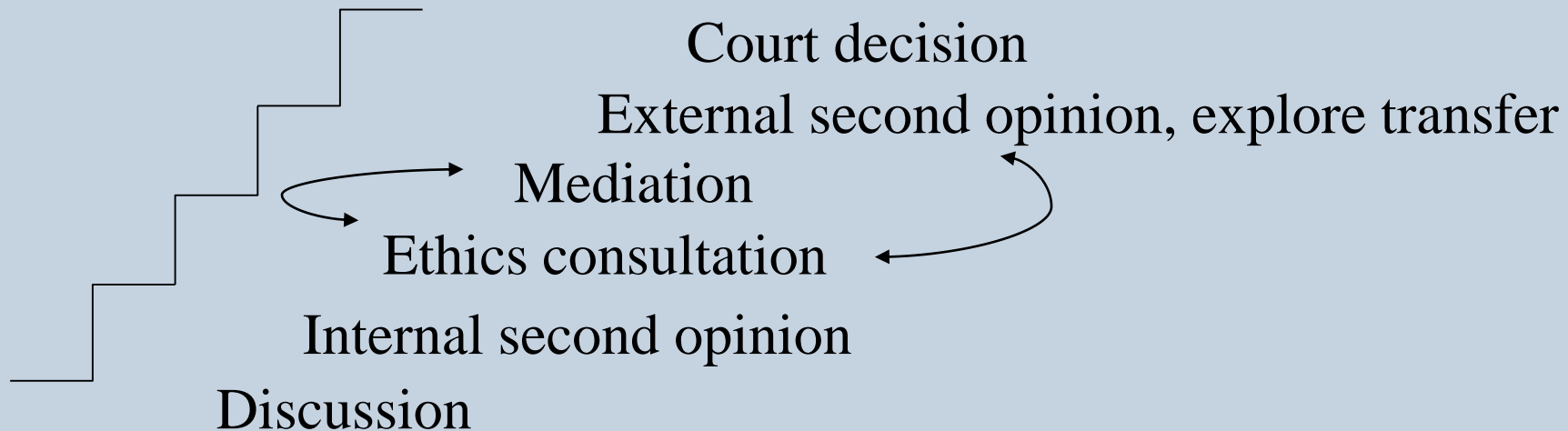
- Break information into chunks
- Give relevant facts
- Taylor discussion to family and their priorities
- Check in for understanding
- Sum up key points at the end

What to do if parents and doctors disagree?



- 1. It is OK to disagree!!
- 2. Work out why you disagree?
 - Facts
 - Values
- 3. Ask colleagues about parents' choices
 - – is this reasonable or unreasonable disagreement?
 - - Would it be harmful to do as parents' ask?

1. Identify disagreements early
2. Sequential approach to resolution
3. Minimise suffering x3



Conclusions

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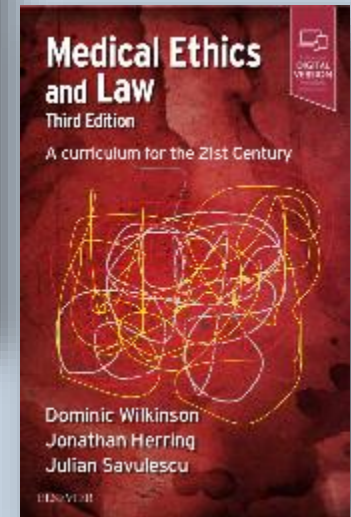
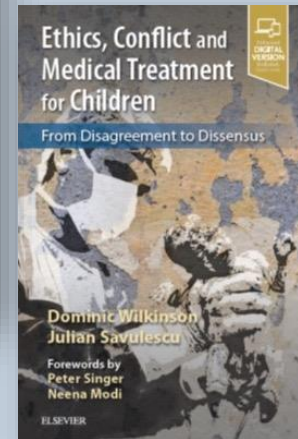
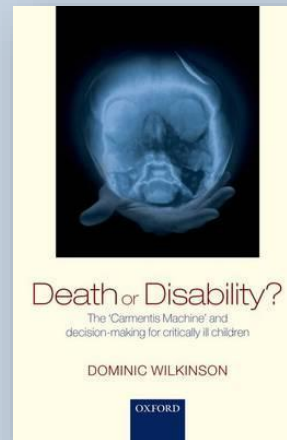
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