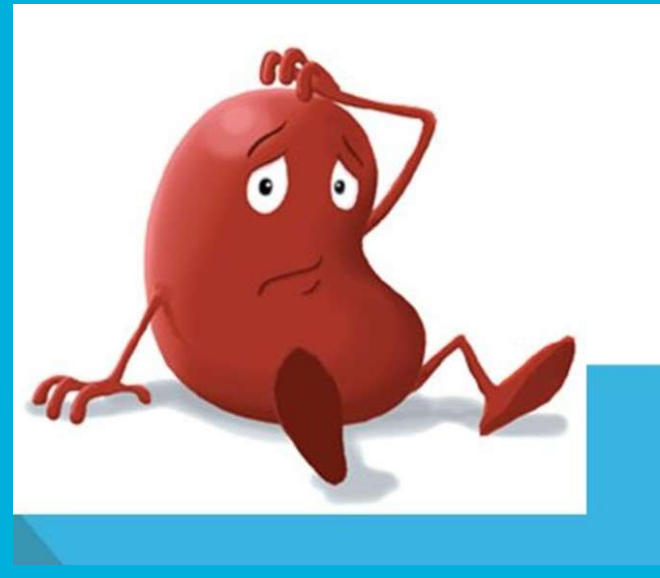


# Ethical dimension in pre-transplant counseling and decision-making

## Case Study - J child with short life expectancy

Nancy Kamphuis-Serpa  
Clinical Social Worker





- Story of J – Case study
- Ethical questions
- ‘Nijmegen Method of Ethical Case Deliberation’

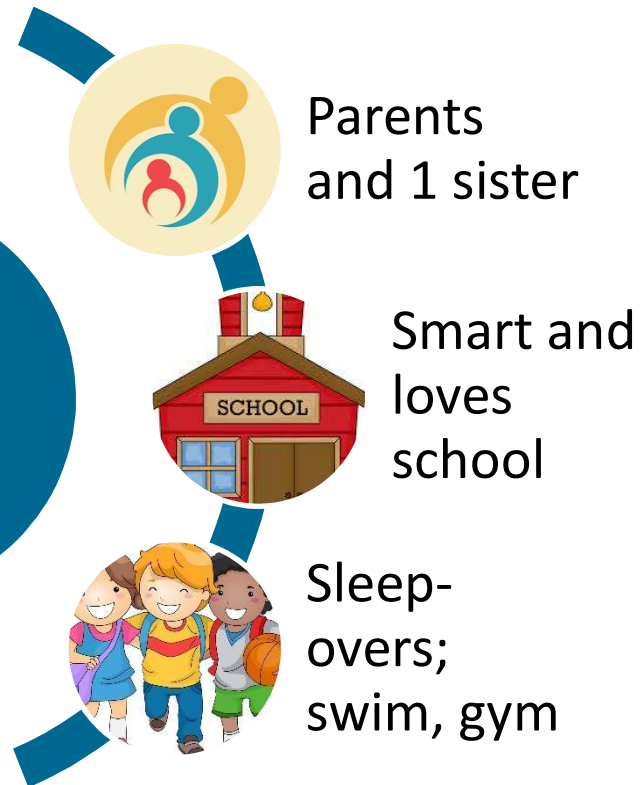
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# Introduction of J – 6 years old

Schimke  
Immuno  
Osseous  
dysplasia

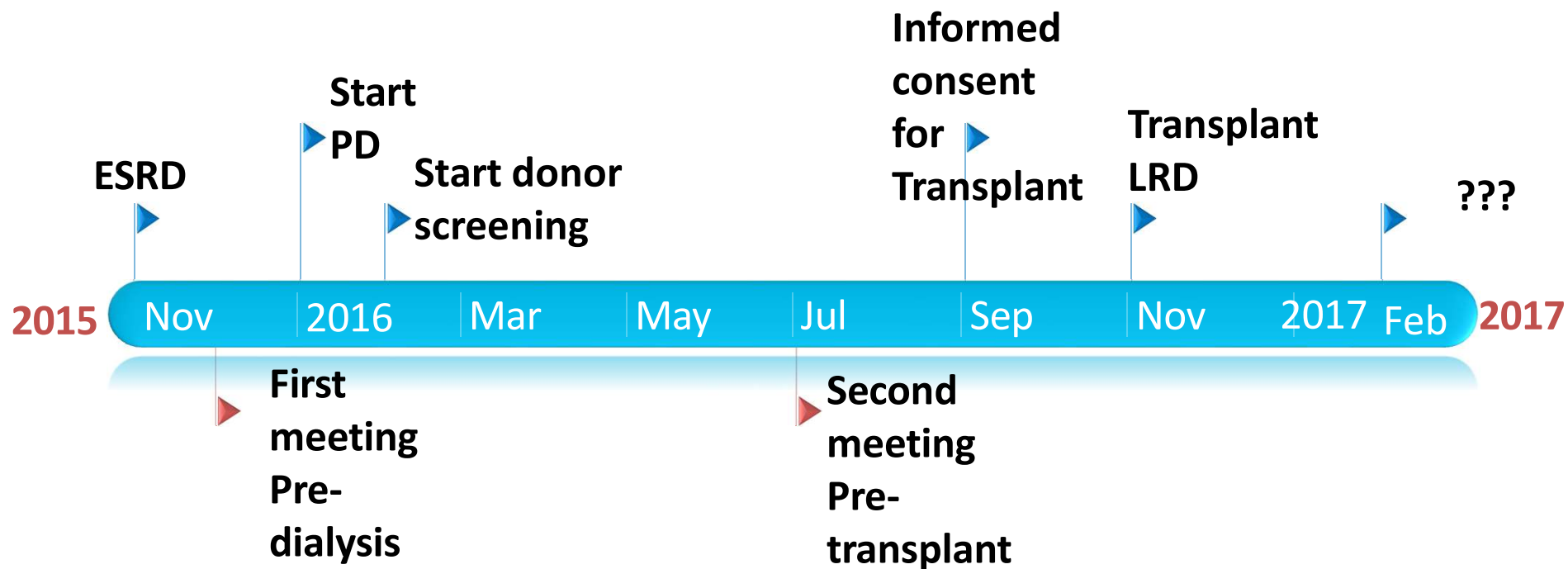
short stature  
ESRD  
T cell deficiency

Life expectancy  
childhood to early  
adolescence



# Story of J -

# Timeline



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# Informed consent

## Father/donor –

Would like to donate, even if J would die shortly after the operation. Wants to offer all chances for best QOL.

## J/recipient –

doesn't like PD; wants transplant to be able to swim and sleepover.

## Mother –

supports decision 100%, with LRD, even if there are complications.  
Trusts what the specialist thinks is best.



## Team –

continuing Dialysis is large risk of infections. Tx also risks. Mild IS after tx. Supports the wish of parents and child.

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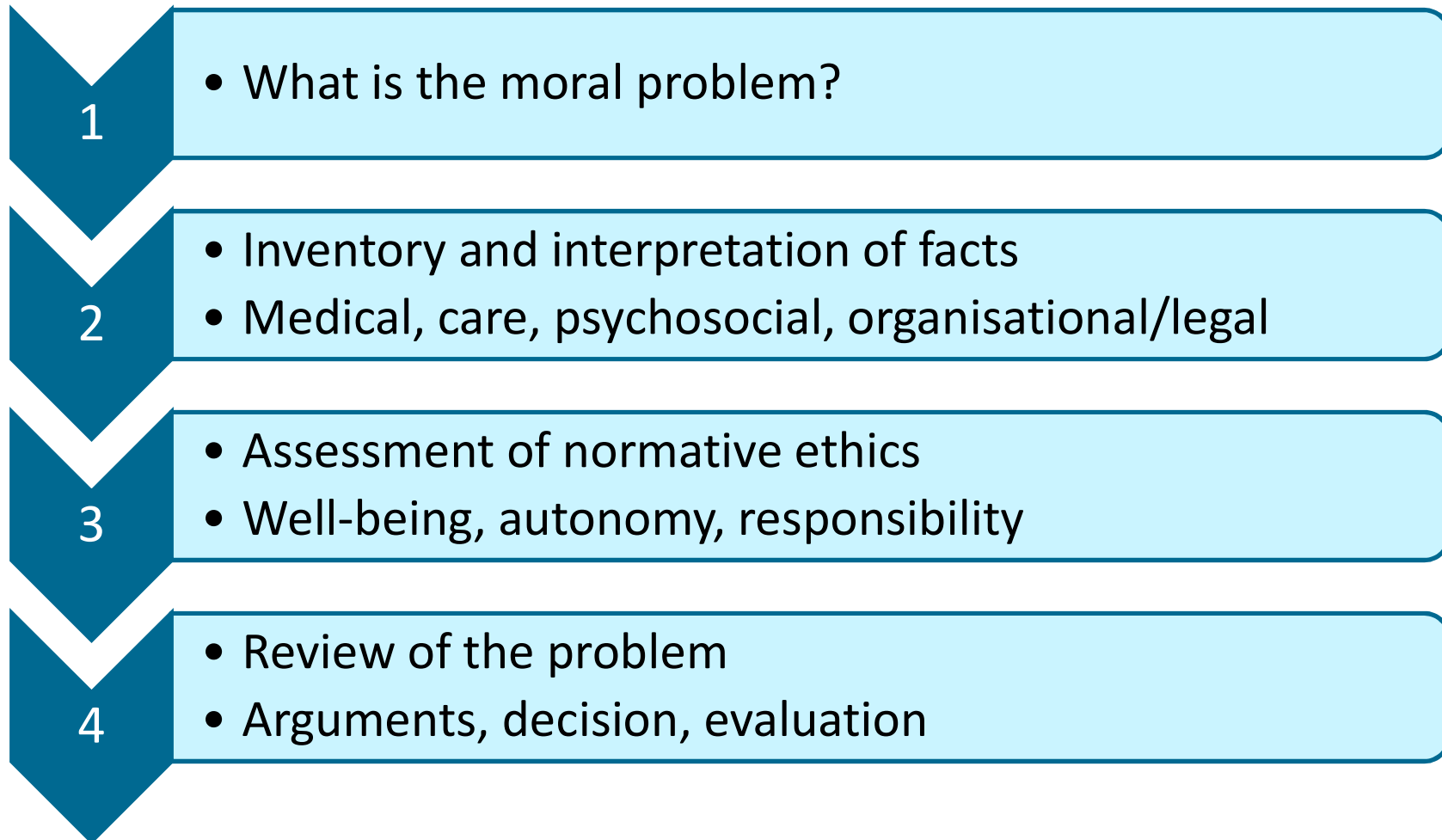
# What is right?



- ? What is the shortest life expectancy acceptable to transplant with a living donor?
- ? Is it acceptable to subject the parent/donor to the risk of surgery when expected outcomes for the child/recipient are poor?
- ? Can shared decision-making also be a burden for parents?

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# Nijmegen Method of Ethical Case Deliberation



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# Nijmegen Method of Ethical Case Deliberation



Colleague and family perspective



Pause for reflection



Suspended judgement

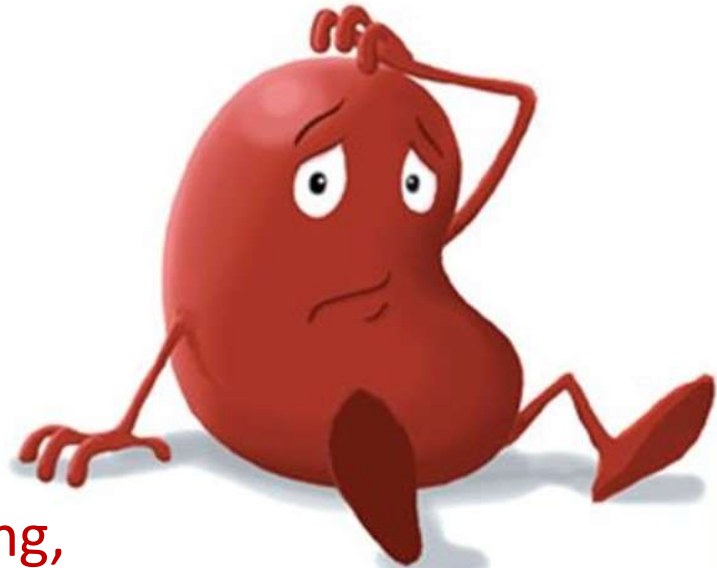


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# Conclusions and discussion

## What can be learned?

- Ethical dimension is important
- Relational autonomy
- Start early in the process
- Create room to interpret values and perspectives.



In real life there is no clear right or wrong,  
but a messy lived experience.