

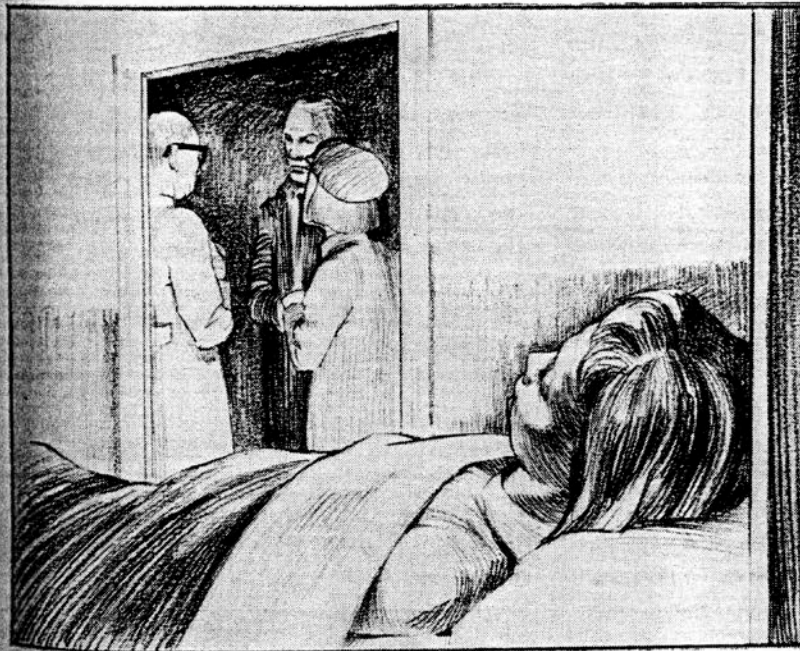
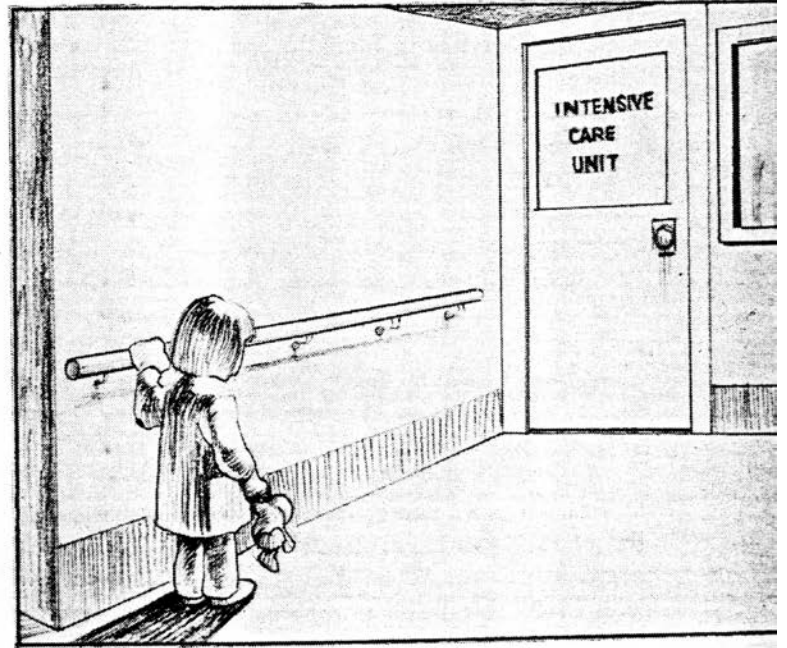
‘She doesn’t know. I don’t want
her to know’

Phoebe

- 9 years old
- Brain stem glioma
- Regrowth despite chemo, XRT, multiple resections (multiple admissions)
- Prognosis is months
- Currently quite well
- Her parents ask you if they should tell Phoebe what is happening to her
- How do you respond?

Waechter 1971

- 64 children aged 6-10 years
- 4 groups
 - Fatal illness
 - Chronic illness but good prognosis
 - Brief illness good prognosis
 - Well
- Administered General Anxiety Scale and asked children to tell stories about a series of 8 pictures



Results

- Anxiety scores in the 'fatally ill' group were double that of children in other groups
- Although only 2 of the fatally ill children had been told their prognosis, 63% told stories containing death themes
 - Also themes of isolation and separation

Mutual Pretence

- Myra Bluebond-Langner

Child awareness

- Study of children with cancer
 - 32 children aged 3-9 years
- Children more aware of their prognosis than parents and health professionals imagine
- Many sources of information
- Concept of 'mutual pretence'

Decision-making

- Survey of 50 children with cancer aged 8-17 years and their 60 parents
 - 76% of children wanted to know chance of cure (vs 38% of parents wanted the child to know)
 - 95% of children wanted to know if they were terminally ill (vs 64% parents)
 - 28% of children wanted the opportunity to discuss things with their doctor that they did not want their parents to know
- Desired **input** into decision-making

- Used 2 hypothetical cases to ask adolescent cancer survivors about acceptability of discussing EOL decisions
- Where the case described a terminal situation, 70-90% felt it was appropriate to discuss
- Young people with chronic illness more likely to find this acceptable

The parent's view

- Swedish survey of parents of children who had died of cancer
- 147 had talked with their child about death
 - None regretted it
- 258 did not talk with the child
 - 69 (27%) regretted it
 - More likely to have regrets if they felt the child was aware

Communication

- Interviews with 19 parents and their 13 children aged 8-17 years with cancer
- Parents wanted to appear strong and optimistic for the child
- Most children wanted their parents to be involved but some felt marginalised

Working with parents

- Concerns of children
 - ‘it is my fault’
 - ‘will I be in pain?’
 - ‘will I be alone?’
 - ‘will I be forgotten?’
 - ‘Mum and dad are angry with me’
- We can all reassure children about these things, even if we don’t talk about death

Working with parents

- Acknowledge and respect their need to do the 'right thing' by the child
- Provide them with information
 - Children generally know more than they let on
 - They may be protecting their parents
 - They often form their own explanations for what is going on (sometimes very scary ones!)

Honesty

Positives

Builds trust

Allows the child the opportunity to say and do things that are important to them

Reduces feelings of isolation

Allows fears to be discussed and reduced

Negatives

May confront the child with information they don't wish to know

May cause them to feel frightened

It is difficult for parents to do

- It's not about 'telling'
- Encourage parents to create an environment where the child can come to them with worries, knowing they will get an honest response. The child then controls what information they receive.