

What is it like to be a patient during neonatal intensive care treatment?

Can NICU design make babies feel better?

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What is the wish of the newborn infant?

- Close physical and emotional contact with parents
- Stimulation adapted to age and situation.
- No stress or pain
- Normal sleep pattern (18-22 hours a day) with longer sleeping periods
- Competent and self-confident parents

Can newborn babies have a perception of meaning of life?

- Newborn babies are able to feel safe and be satisfied as well as feeling fear and pain.
- Feelings are newborn infants compass to start navigating the world
- Infants do not have an inborn knowledge of how to regulate their feelings.
- Newborn infants gets knowledge and creates meaning of the world through the physical inputs and the emotional response they receive from their surroundings

What is it like to be patient in a traditional open-bay NICU

- Contact with your parents are limited to a few hours/day
- Parents are not present when you really need them during pain- and stressful procedures
- Noisy physical environment from medical equipment and activities in the room
- Incubators is a toxic sound environment?
- Lightening does not support a normal sleep-pattern
- Frequent disturbances from caring-routines, blood-samples and other procedures
- Treatment causes both acute and chronic pain in addition to high levels of stress

What limits parental presence in the NICU?

- Lack of free access 24/7 for parents and siblings.
- Feeling of little control
- Unprotected physical surroundings
- No private area to be with the infant
- Light and noise
- Lack of support from the staff to stay as much as they want
 - Heinemann et al; Acta Paediatrica 2013
 - Pineda et al; J Perinatology 2011

Daily life at RH, OUS

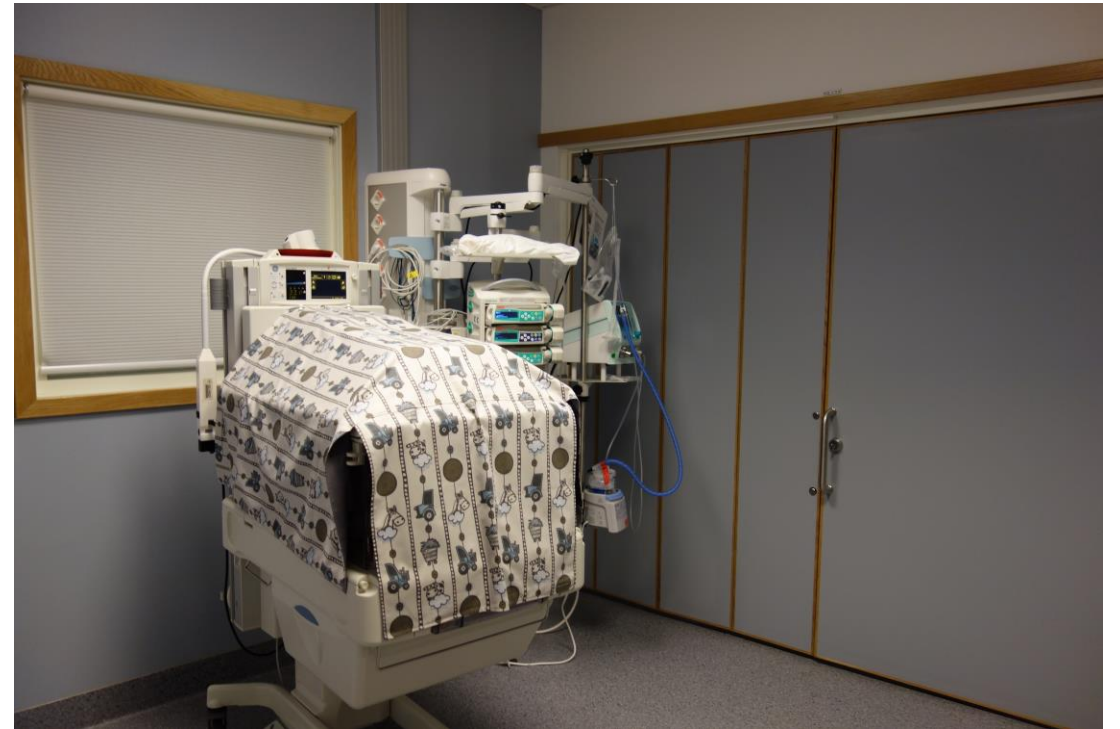




NICU Drammen



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Single room NICU Birmingham Alabama USA, 60 intensive care beds, 60 stepdown beds



How to get there?

- The most complex and challenging part of planning for a modern single-room design with unlimited parental presence is not funding, engineering or architecture.
- The big challenge is to change the mindset of administrators, clinical leaders, doctors and nurses

The problem with experience

- Although NICU healthcare professionals may be very experienced in what they are doing, it should be kept in mind that experience is most valid in the setting where it was gained.
- Single-family rooms with unrestricted parental presence change the rules of the game and parents start to behave differently.
- Parents become experts on their child's history and medical condition
- Parents become their infant's best advocates and build a new confidence to ask critical questions about care and treatment

How to communicate and implement change?

- Create a new narrative about the sick infant as a person with full human and legal rights as well a developing individual with emotional, social and psychological needs
- Clinical leaders must believe in the necessity for a change
- Clinical leaders must be clear and outspoken on behalf of patients towards politicians, health and hospital administrators and patients right organisations and to use mass media strategically
- Clinical leaders must start years before moving into a new unit to change the culture of care among staff members

NICU design standards of care.

Recommendations

- Uncompromised infant perspective of NICU-care
- Close collaboration with parents and NICU staff from initial planning to implementation
- There may be a conflict between the patient and families' preferences and the preferences of other stakeholders. Such conflicts should be handled with caution and respect for the patients' perspective. Free-speaking competent advocates for the patients' interests should be appointed early in the planning process.

Conclusion

- Single family rooms and NICU design is no goal in itself; it is a tool to fulfill the UN charter of the rights of the child to have its parents present without restrictions and to improve short- and long term medical and neurobehavioral outcome.
- Good NICU design creates a protective physical environment for the vulnerable sick infant and encourage parents to take an active part in the care and medical treatment for their child.