

# ECMO treatment

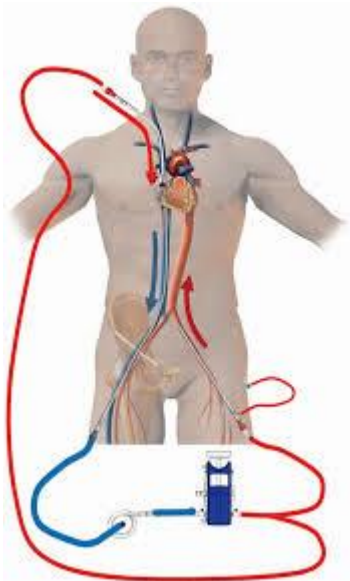
*- patient experience of the ICU and rehabilitation*

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# Presentation

- **What is ECMO treatment**
- **Two patient cases**
  - Patient experience and rehabilitation
  - Relatives' experience
- **Follow up**

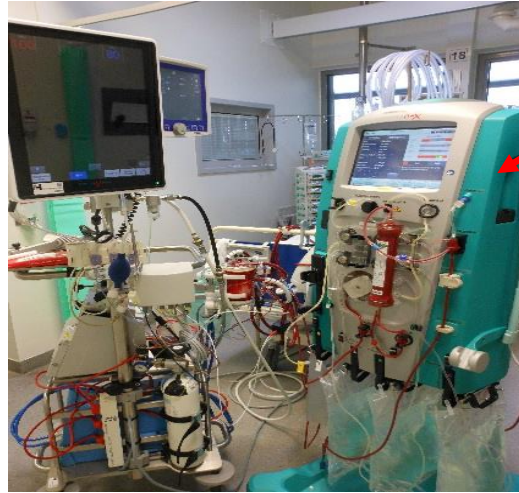
# Extra Corporal Membrane Oxygenation (ECMO treatment)



- Extra-corporal support of heart-lung function
- A cardiopulmonary bypass simplified and modified for extended use in intensive care



Dialysis



Ventilator



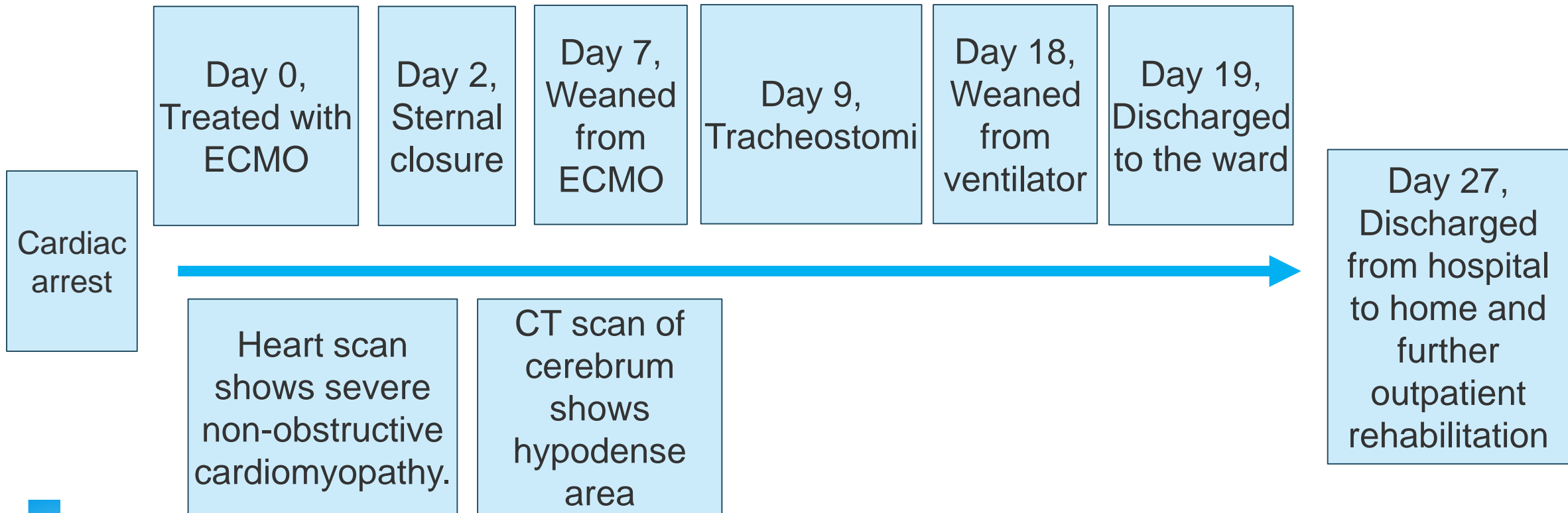
ECMO-Machine

# Patients experience

- To gain knowledge about patient experience of ICU and rehabilitation after ECMO treatment we conducted two qualitative interviews 6 month after discharge from ICU.
  - **The two informants were:**
    - Woman 1, 20 years old
    - Man 2, 23 years old

# Patient case - 1

20 years old former healthy young woman. Have been in good health until developing cardiac arrest at home.



## ”It takes a very long time”



### Physical challenges

- *“In the beginning after discharge from hospital it was difficult to swallow” (1)*
- *“I have scares from pressure ulcers in the back of my head” (1)*
- *“It is difficult to wear shoes because of fluid wounds from amputated toes, some of my toes are black, they smell and have been operated. It's painful – the bones have been exposed. I cannot use shoes, and it hurts, when I do my workouts“ (1)*
- *“I was offered rehabilitation on a cardiac rehabilitation team along with other patients, who had an average age of about 70 years” (1)*
- *“He was very weakened in general, and due to the limited offer of training, I had to help him a lot with his exercises” (Mother)*

## *“I do not remember, I cannot understand”*

### Difficult to remember:

- *“I may have some pictures in my head, that I cannot describe correctly - was it a “suitcase” that lay over my legs? I have some ideas about how the machines looked, but do not know, if they are right” (1)*
- *“Have been to the department several times, and would really like to see the ECMO machine and the dialysis and the other machines” (1)*
- *“I really want to see pictures, I've had many tubes in my stomach and elsewhere. I need an explanation of all my scars on my body” (1)*
- *“Important to be in ICU all the time or nearby” (Mother and father)*
- *“It was quite bad for the first time to see her like that - says father, and mother says she did not notice all the machines, that was needed to save him” (Mother and father)*
- *“It gives great confidence, that the staff tells, that they have seen this before, and can tell that they have tried this before, it is not a new situation” (Mother)*



## *“It's not easy to see my friends again”*

### **The social network suffers:**

- *“The friends fall away - I feel weakened – and my friends must not see me like that” (1)*
- *“There are times, when I want to give up” (1)*
- *“Because of my bad sight, I cannot drive a car, so my family spend a lot of time and energy driving me to hospitals, rehabilitation and sometimes to friends” (1)*



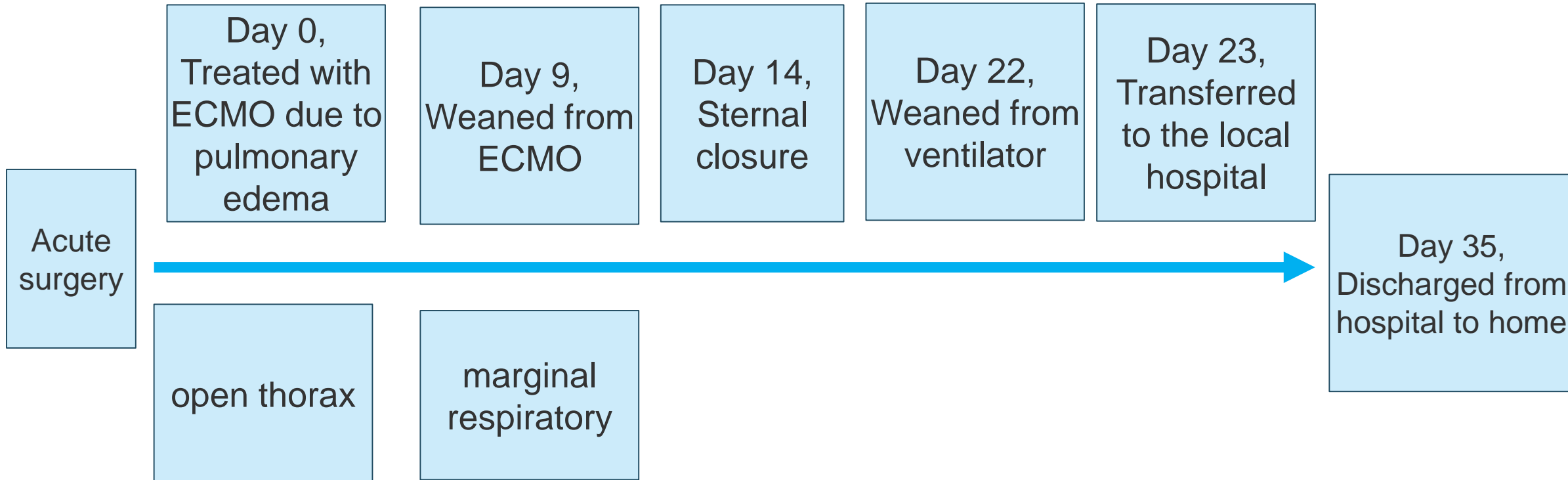
## ***“The family is so important, I am very dependent on their help”***

### **The family is indispensable:**

- *“For a long a time I was totally dependent on my parents help for almost everything, due to my limited sight and concentration difficulty” (1)*
- *“The local hospital forgot to check the cardiac status. It has been necessary to have one person, who could coordinate hospital visits and the entire rehabilitation - and that was me” (Mother)*
- *“I dare not let him sleep alone, I'm afraid that's going to happen again” (Mother)*

## Patient case - 2

23 years old man, known with Kongenit aortic stenosis, transferred from local hospital to Rigshospitalet, to acute surgery.



*"I've lost my hair - have had a lot of trouble  
with pressure ulcers in the back of my head"*

*"Much of my identity has always been my  
hair"*



**I lost my identity**

## *”The new person”*

### **Learning to live a new life:**

- *“I have subsequently been evaluated by a neuropsychiatrists, who find several areas in my brain, that have been damaged, which means that I am and will be cognitively challenged” (2)*
- *“It has been difficult to maintain all friendships - I see myself as a new 2” (2)*

## *"I need to learn many things again - I am making my own systems to make it work"*

### **Cognitively challenged:**

- *"I have a reduced short-term memory and becomes very tired quickly" (2)*
- *"I have to write everything down – It's hard for me to plan to cook potatoes, sauce and finish at the same time" (2)*
- *"It is a challenged to perform more actions at the same time - it's hard to walk and talk at the same time" (2)*
- *"I only drive a car locally - it is difficult to keep the concentration for a longer time" (2)*

# Cognitive challenges



*“My mom and dad are the most important people for me”.*

*“I feel unsafe when they are not nearby”*

*“I cannot remember anything from my stay at ICU.  
I would really like to see it again”*

*“There are times when I want to give up - especially at night”*



## *“My family is so important - I am very dependent on their help”*

### **Cognitively challenged:**

- *“After the hospitalization, I had moved home to my mom and dad, they have build a part of their house into an independent home for me” (2)*
- *“We are so happy that we have him alive, but we still need to help him with everyday life - she cannot cope without our daily help” (Mother)*
- *“He always try to be open and realistic about future challenges and possibilities, and know that it require strongly support from the family” (Mother)*





# Physical challenges



*“I have fallen several times after I returned home from hospital, and needed help supplies. It was my family, who had to provided it - my family experienced a lot of challenges with the municipality”*

*“I developed drip foot and I am still highly afflicted”.*

*“I was offered training locally, but I have been restricted by reduced lung function and pneumonia. Still I need to do training”*

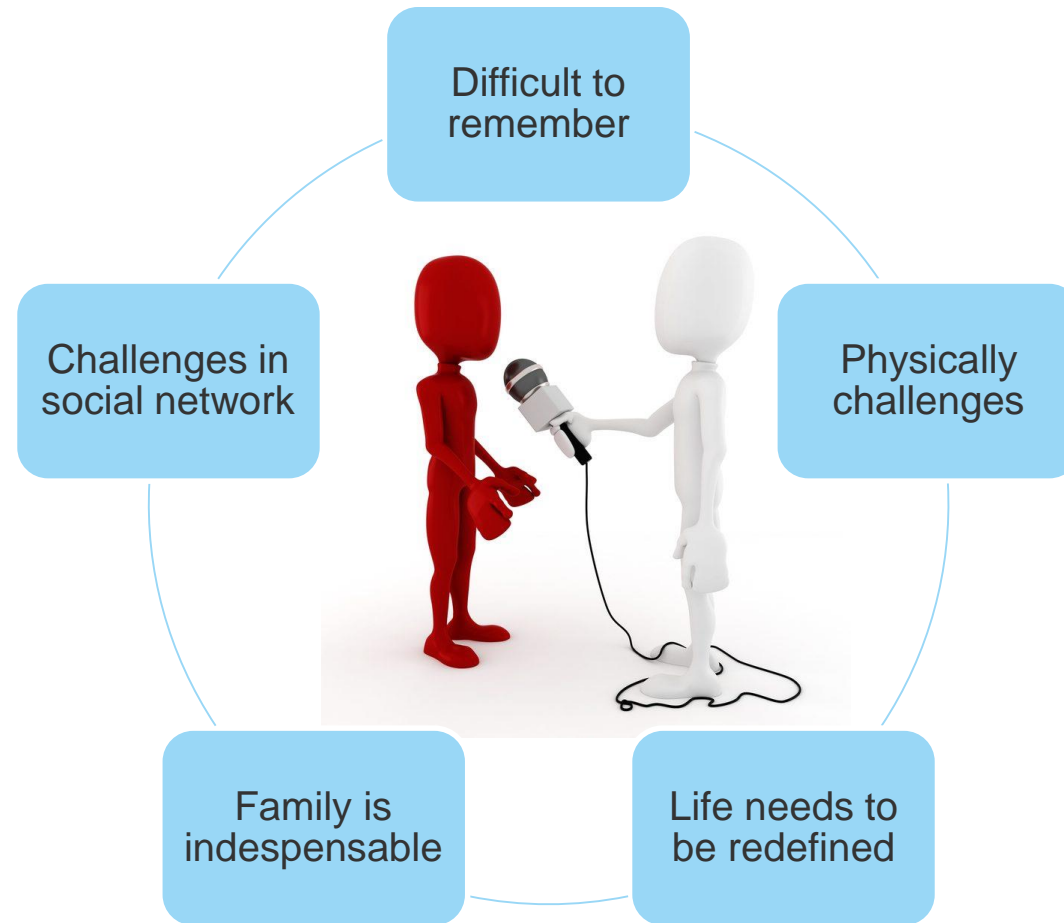


## Important knowledge from relatives:

- *“Important to be in ICU all the time or nearby - It feels absolutely fantastic, that the staff are constantly looking for the patient - that they have the care and professionalism, that gives safety” (Mother)*
- *“An economic challenge - it is very expensive to stay at the Patient Hotel, which has cost us a lot, and we have not been able to get them refunded, because our son is 23 years” (Mother)*
- *“It has been a great help to meet other families in the same situation - it has given us a new and important social network today” (Mother)*

# In summary

The interviews indicate, that patients who have been treated with ECMO, have a longer rehabilitation and recovery, than other critically ill patients





# Why ECMO follow up?

- Studies conclude, that patients often suffer from PTSD after critical illness
- Due to lack of knowledge about patients perspective, in patients treated with ECMO, we need to collect further data
- What are the specific needs when treated with ECMO?

# Purpose of ECMO follow up?

- To give the patients and relatives an opportunity to address the physical, psychological and neurological challenges they have after treatment with ECMO and discharge from ICU
- The ECMO follow up give the patients and relatives an opportunity to discuss specific problems with Health professionals from ICU
- The feedback enables the Health professionals to initiate the necessary interventions for ECMO-treated patients



# Thank you for your attention

