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Transition of patients with Cystic Fibrosis from Pediatrics to Adult care

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Life expectancy of cystic fibrosis (CF) patients

60's
10 years

70's
16 years

80's
18 years

Now: 38 years!

The increase of CF patients life expectancy is due to:

- Earlier diagnosis
- New therapies
- Care in specialized centers
- Care by well trained multidisciplinary teams

As life expectancy increases more patients reach adult age and so there is a need to transfer them to adult care teams

In the dictionary transition (lat. Transitione):

- **To move from one place or state to another.**

Our Cystic Fibrosis Center (Centro Hospitalar Lisboa Norte – Hospital de Santa Maria)

- Follow up of CF patients started in the 80's
- In the beginning appointments were made in the space of inpatient care
- Outpatient clinic in a dedicated space started in the 90's
- In 2000 follow-up by the pulmonology adult team began, in adult facilities

- From the beginning of the adult CF center in 2000, regular meetings with the pediatric and the adult team began. Transition has been one of the main concerns.

Our Cystic Fibrosis Center follows:

- 58 Children and teenagers (7 months to 18 years)
- 44 Adults

The process of transition from pediatric to adult care must be planned and prepared by both teams and involve the youth and the family!

- It must be a progressive process, prepared with antecedence (months or years) taking into account the Preparation/Maturity from teenager and his family!
- The duration of the transition period should be individualized
- In general this process begins between 16 and 18 years of age
- It takes from 1 to 2 years (until 21 years)
- During this period the patient has sheared clinics by the two teams (pediatrics and adult care) together at pediatric facilities

The transition process is not done at the normal age in severe or instable patients and specially if there is a short term bad prognosis

During the transition process

- We clarify doubts/questions
- We involve the patient and his/her family in the process
- We provide all the information available
- We show the facilities for outpatient clinic and internment for adults
- We present the different professionals of the adult team to the patient and family

We must provide security, confidence and protection to the patient and family

- Listen the patient and family opinion
- Take time to talk about the process
- Talk about eventuals/possibles planned transplants
- Take in account the age and maturity of the patient
- Evaluate how the patient and family are prepared to the transition

- It is necessary that the pediatric and adult care teams discuss each transition process in a team meeting
- The process must be planned by all the concerned partners
- It is necessary to gradually transfer the responsibility of the decisions from the parents to the young adult
- The time for the transference must be flexible, according to the individual necessities

The patient should …

- Know the differences between pediatrics and adults care
- Talk with both teams together
- Know the adult team constitution and visit the facilities
- Know who are the reference professionals and their contacts
- Obtain written information
- Know that the Guidelines for CF care are the same for both teams

The pediatric nurse should…

- Define transference date according with team
- Program a visit to the adult care facilities
- Elaborate a transference report
- Provide hosting guides or other existing documentation
- Provide other support that the patient need as psychological support, social service or any other element from the multidiscipinary team (family, medical, dietist, physiotherapist,…)

The adults team nurse initially…

- Sould provide phone contacts to the patient
- Establish a relationship of trust with the adult team
- Present herself as co-responsible for the training in new treatments
- The nurse should act to minimize the concerns of the patient and family in this process

Main concerns of the patient are…

- To leave the pediatrics team
- To know the new adults team
- If he/she will keep the same level of care
- If he/she will be in greater risk of infection
- To have to adult emergency service and to be hospitalized in adult units

To leave the pediatric team is not the main concern because it means Maturity and Hope!

Major Wishes from Patients are…

- To know the adults team in advance
- To have a direct phone access to doctors and nurses from the new team
- Have direct access to the consultation
- To be well followed and always informed

In conclusion

It is essential that in this process the patient:

- **Feel that he/she knows the adult team**
- **Recognize skills in the new team**
- **Is always informed about the evolution of his/her health**
- **And that there is a good communication between all**

A multidisciplinary team around the patient and family

Quotes from a patient

"…It's like moving to another school, I've changed school sometimes in my life…"

"…I have to be responsible."

"…,then I come visit you."

PC 18 years

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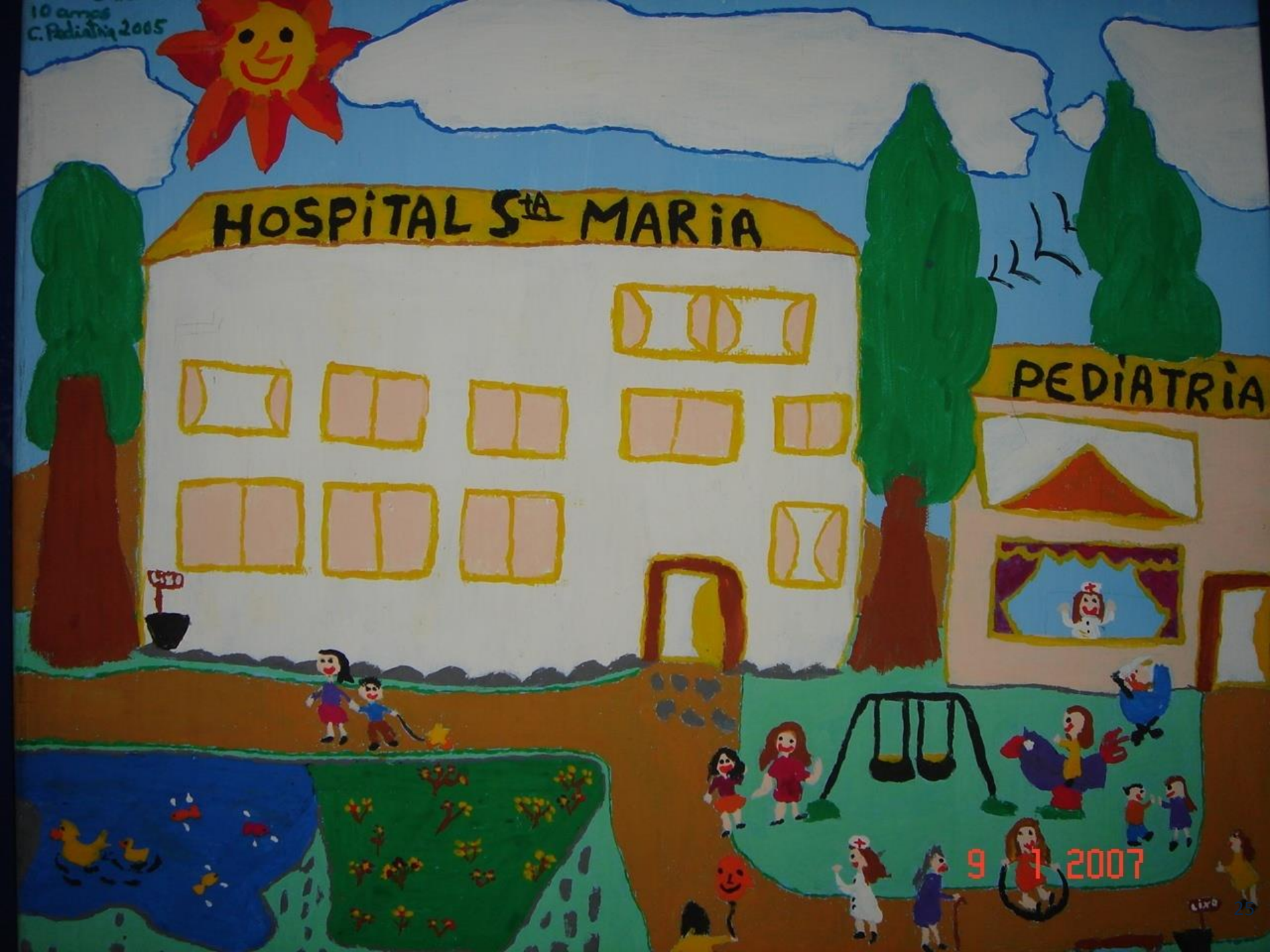
10 anos
C. Pediatria 2005
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Gilead

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