

# Proposal of a questionnaire for cystic fibrosis patients who have just been transplanted to ensure their safety before the first return home after transplantation

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## Objectives

After lung transplantation, cystic fibrosis patients have a lot of new skills to acquire and some are essential for patient's safety, particularly before the first return home.

## Methods

In 2009, we elaborated a referential of skills, both for the immediate post-operative period and the long-term follow-up (ECFS Dublin 2012). We identified in the list **twenty essential objectives** that must be acquired by all patients, during educative sessions.

Generally, patient education begins around the 15th day after transplantation, after the reanimation period. Patients begin to ask questions about their new medications, diet, hygiene etc.

About fifteen days later, patients are ready to go back home for the first time, it is the moment to assess that they have reached all the essential objectives.

For that, we built a **questionnaire which includes 9 True/False questions with degrees of certainty and 4 multiple-choice questions.**

Questions essentially relate to the modalities of taking medications, adherence to treatment, the emergency situations but also the prevention. The multiple-choice questions relate to their daily life.

## Pedagogic recommendations for questionnaire use

In order to conduct the questionnaire, health-care givers have to adopt an educational posture :

- listening attentively and compassionately
- eliciting reflection
- reformulating
- being non-judgmental

## The twenty essential objectives

### Patients must be able to:

- 1- identify the warning signs of altered respiratory status
- 2- respond to the warning signs of altered respiratory status
- 3- draw the connection between pulmonary function testing/spirometry results and bronchial status
- 4- recognize the risk factors in his environment for worsening respiratory status
- 5- explain the reasons for regular follow-up
- 6- explain the importance of laboratory monitoring
- 7- state the role of the medications
- 8- list their medications
- 9- take the medications as directed
- 10- describe what to do if they forget their treatment or vomit
- 11- describe the life-saving nature of immunosuppressive drugs
- 12- manage stocks of medications and supplies
- 13- identify high-risk foods
- 14- explain the importance of hydration
- 15- explain the importance of adjusting salt in the diet
- 16- practice contraception and sexually transmitted disease prevention
- 17- state the risks of pregnancy and constraints for mother and child
- 18- state the effects of active and passive smoking
- 19- describe what to do if they develop a skin lesion
- 20- avoid the immunosuppression-related dermatologic and infectious risks (sun)

## True/false questionnaire

1. It is possible to take the anti-rejection treatments before taking blood for assaying ciclosporine, tacrolimus and everolimus.
2. When bronchoscopy is programmed, the patient must be strictly empty stomach and take ciclosporine, tacrolimus and everolimus.
3. By taking irregularly anti-rejection treatment, the transplanted patient takes risks for his health and life.
4. Anti-rejection treatments increase the risks of skin cancer.
5. At home, if respiratory function measure shows a 10% decrease, it is possible to wait for 4 days before calling the transplantation centre.
6. A transplanted patient is allowed to take medications without the transplantation centre agreement.
7. A transplanted patient can be present during renovation works (tapestry, plaster, paint).
8. In case the transplanted patient vomits within 30 minutes after taking anti-rejection treatment, he has to take the complete dose again.
9. A woman that is old enough to procreate must take a contraception even if she has no menstruation.

## Multiple choice questions

1. A transplanted patient can eat without risks for his health:
  - Grapefruit
  - Well-washed tomatoes
  - Smoked salmon
  - Beef carpaccio
2. It's Saturday evening, 8pm, you are sick with high fever and chills. What do you do?
  - You decide to wait for Monday to call the center of transplantation
  - You immediately call the center of transplantation or you decide to go the nearest emergency unit
  - You take paracetamol
  - You take the antibiotics you have at home
3. A friend wants to visit you but he has a cold. What do you tell him ?
  - Don't come because it's a risk for me
  - Could you come next week ?
  - You can come and spend the afternoon with me but we have to take hygiene precautions : no physical contact, hydroalcoholic solution on hands and wear a mask
4. To celebrate your transplantation, your best friend decides to organize a party with 30 people. What do you do ?
  - You restrict the number of guests
  - You will go without special precautions
  - You postpone the party for up to six months
  - You will go wearing a mask and with hydroalcoholic solution for your hands

## Results

Patients must correctly answer the questions before they first return home. In case of errors, new educative sessions will be organized to ensure patients' safety. The questionnaire is now used in most French transplantation units. Both patients and health-care givers are satisfied.