

# SCALE IEXPAC CAREGIVERS

The experience of caregivers of persons who suffer from chronic conditions



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## INSTRUCTIONS

To respond to the statements, please read each one in the order in which they appear and choose the option that best reflects your opinion. There are no right or wrong answers, it is your own personal experience that matters. All statements refer to the last 6 months.

The statements refer at all times to the group of professionals who care for you. To answer, think about your doctor and nurse at the health centre, the specialists and nurses at the hospital, pharmacists, the case manager, physiotherapist, psychologist; think also about other professionals such as the social worker at the health centre or at the municipality social services and, generally, about the whole group of people who care for you. Think about these people whenever we mention the professionals who care for you.

Your answers will be kept confidential and will not be shared with the professionals who care for you.

Mark with an X the option that best reflects your personal opinion. Please do not leave any statements unanswered.

Thank you very much for your cooperation.

## STATEMENTS

Of the questions below, describe how often you live with these situations (mark the appropriate box with an X). It is important to focus your answers on the specific person with whom you have had significant experience as a caregiver in the last 6 months.

Never  
Almost never  
Sometimes  
Almost always  
Always

### 1. They respect the lifestyle of the person I care for

The healthcare professionals who care for the person in my care ask me about their needs, habits and preferences to adapt their treatment and care plan.

### 2. They are coordinated to offer us good care

The healthcare professionals who care for the person in my care at the health centre and those who care for them at the hospital talk to each other and coordinate to improve their wellbeing and quality of life and those of the family.

### 3. They help me become informed via the Internet

The healthcare professionals who care for the person in my care inform me about websites and Internet forums that I can trust to better understand their disease, its treatment and the consequences they may have on their lives.

### 4. I now know how to look after them better

With the support of the healthcare and social professionals caring for the person in my care, I feel I have more confidence in my ability to take care of them, manage their health problems and approach their situation better.

### 5. They ask me about and help me follow the treatment plan of the person in my care

I review the adherence to their treatment and care plan with the healthcare professionals who care for the person in my care, and if I have questions, they answer them.

### 6. We agree on the most important objectives of their care to control their health problems better

I've been able to discuss and agree with the healthcare professionals who care for the person in my care the most important health and social problems and how to manage them adequately to maintain their quality of life.

### 7. They ensure that they take the medication correctly

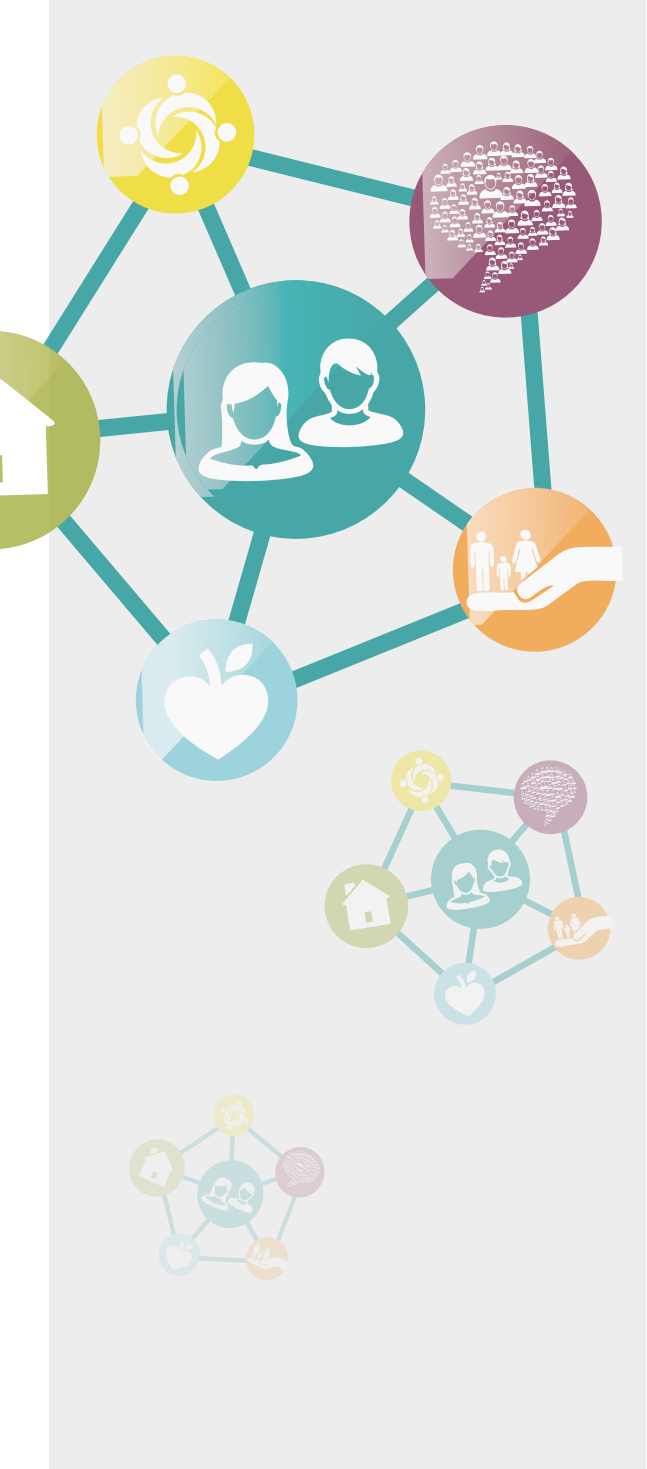
The healthcare professionals caring for the person in my care review with me how to administer the medication and review with me if they are taking it correctly and how they are feeling.

### 8. They are concerned about the wellbeing of the person in my care

The healthcare and social care professionals who care for the person in my care are concerned about their quality of life and I feel they are committed to improving their wellbeing.

### 9. They are concerned about my health and wellbeing

The healthcare and social care professionals who care for the person in my care are concerned about my health and quality of life and I feel they are committed to my wellbeing.



## STATEMENTS

Of the questions below, describe how often you live with these situations (mark the appropriate box with an X). It is important to focus your answers on the specific person with whom you have had significant experience as a caregiver in the last 6 months.

Never Almost never Sometimes Almost always Always

### 10. They are concerned about my emotional and physical burden

The healthcare and social care professionals who care for the person in my care are concerned about the emotional and physical burden involved in being a caregiver and inform me about how I can prevent it.

### 11. They inform me about health and social resources that can help me

The healthcare and social care professionals who care for the person in my care inform me about the health and social resources available (in my neighbourhood, town or city) that I can use to improve the care I provide and to take better care of myself.

### 12. They encourage me to talk to other caregivers

The healthcare and social care professionals who care for the person in my care encourage me to participate in caregiver groups to share information and experiences on how to care for ourselves and improve our competence as caregivers.

**From now on, please respond to the following questions if you have been in these situations:**

**If the person in your care has been hospitalized in the last 6 months and you were already caring for them:**

### 13. They care about the person in my care upon their arrival home after being in hospital.

After the person in my care had been discharged from hospital, they have called or visited us at home to see how they were, what care they needed, and what difficulties I have faced to take care of them correctly.

**If you have needed emergency care in the last 6 months:**

### 14. I know where I have to contact when the person in my care has an emergency

The professionals who care for the person in my care have given me a telephone number I can call if complications arise in their disease.

**If the person in your care has received healthcare in their home in the last 6 months:**

### 15. They care for the person in my care well in their home

The professionals who care for the person in my care in their home try to solve their health problems in coordination with the professionals of the health centre and the hospital.

**If the person in your care has received care of the social services in the last 6 months:**

### 16. Social services are coordinated with the health services to provide us with good care.

The professionals who care for me in social services talk to and coordinate with the healthcare professionals to provide us with good care.

Thank you for your cooperation.