EU-PFF EUROPEAN PULMONARY FIBROSIS FEDERATION

COCOS-IPF

ELF EUROPEAN LUNG FOUNDATION

What matters most in pulmonary fibrosis care

People living with pulmonary fibrosis, carers and healthcare professionals from across Europe worked together to identify the things that matter most in treatment and everyday care.

These are the topics that should be monitored regularly in routine care. Talking about them with your healthcare team can help make your care more personalised and focused on what matters most to you.

health and symptoms

Pulmonary fibrosis can affect many aspects of my physical health, including:

☐ Breathlessness
☐ Cough
☐ Lung function
☐ Nutrition and weight
☐ Flare-ups or sudden worsening of your condition
☐ Side effects or complications from treatment

daily life and function

Pulmonary fibrosis can make everyday activities harder and affect my independence and quality of life:

☐ Physical activity (how active I am)
☐ Exercise capacity (how much activity I can do)
☐ Everyday tasks and independence
☐ Ability to do activities you enjoy
☐ Loss of independence

knowledge and self-management

Understanding my condition and managing treatment can help me cope and stay involved in decisions about my care:

☐ Understanding the disease
☐ Coping with the disease
☐ Following treatment plans

emotional wellbeing and satisfaction

Pulmonary fibrosis can also affect my mental health and experience of care:

☐ Feelings of anxiety
☐ Satisfaction with care
☐ Overall life satisfaction

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