



Impact of IPF

Impact on the patient

Idiopathic pulmonary fibrosis (IPF) has a major impact on both the patient and their caregiver(s); as physicians, it is important to understand these impacts to ensure patients' needs are met, including access to disease and treatment information, appropriate treatment for their disease, psychological support and palliative care when needed.¹

Many areas of life are affected by IPF with impacts seen across both emotional and physical aspects of quality of life.²⁻⁵

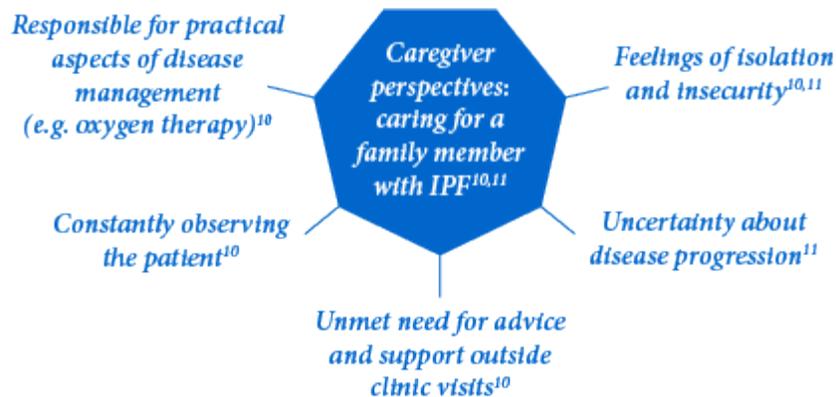
The most common symptoms that directly impact a patient with IPF are physical in nature, including shortness of breath, cough and fatigue.^{2,3,5} Patients with dyspnoea and greater impairment of forced vital capacity have also been shown to have significantly reduced levels of physical activity.⁶ Alongside physical aspects of quality of life, mood disturbances are a common comorbidity in patients with IPF.^{2,3} Current data also suggest a strong link between severity of IPF symptoms (e.g. worsening cough severity, dyspnoea) and mood disturbance.⁷ Due to the high prevalence of depression and anxiety in these patients, it is important that the patient is regularly questioned about these symptoms to ensure they receive appropriate care and support for both physical and emotional aspects.⁸

The emotional and physical impact of IPF²⁻⁵

Emotional impact	Physical impact
Loss of independence	Shortness of breath/dyspnoea
Thoughts on mortality	Chest tightness
Depression and anxiety	Impact of walking
Fear of being a burden	Fatigue
Isolation	Lack of energy
Support for carers	Comorbid conditions
Financial worries	Impact on sleep
Impaired sexual relations	Severe coughing
Lack of information on IPF	Gastrointestinal issues
Lack of energy	
Impact on social life	

Impact on the caregiver

As with many chronic, debilitating and/or fatal diseases, the impact is not only felt by the patient but also by the caregiver(s) of the patients.⁹⁻¹¹ Caregivers may be close family or friends and may have to come to terms with the diagnosis themselves, dealing with feelings of helplessness and the impact of reduced functioning of the patient. Caregivers also have to consider the future, with the associated worry and fear of life without the patient.⁹



Supporting the patient

There are multiple strategies to support patients with IPF and their caregiver – each aiming to reduce the burden of disease and its impact on their lives.⁹⁻¹¹ Along with strategies that healthcare professionals can implement or encourage, there are many organisations that provide support to patients with IPF, as well as advocate on their behalf.

Patient-focussed strategies^{10,11}

- Peer support groups
- Promotion of emotional well-being
- Encouragement of the patient to ask questions
- Provision of access to high-quality educational material
- Emphasis of the importance of a healthy diet and lifestyle
- Referral to a specialist centre/specialist nurses where possible

Caregiver-focussed strategies^{9,11}

- Proactive engagement by healthcare professionals, with the caregiver acknowledging their important role in the care of the patient
- Provision of caregiver resources Maintenance of support networks
- Access to resources to help understand the use of oxygen therapy
- Support groups, including respite care to enable the caregiver time for their own well-being
- Towards the end of the patient's life, the need might arise for formal emotional support

Planning for end-of-life care

Discussing end-of-life palliative care with both the patient and their families is a key part of providing them with high-quality healthcare. The goal of palliative care is to prevent and relieve suffering, and provide reasonable quality of life for both the patient and their caregiver. It is important that patients are made aware of support services available to them and to provide advice and recommendations on developing an advance care plan.^{11,12}

End-of-life discussion with patient and caregiver¹²

<i>Prepare</i>	<ul style="list-style-type: none">• <i>Tailor discussions to their existing level of knowledge</i>• <i>Provide a refresher on the disease, treatment options and their prognosis</i>• <i>Review any other potential options and recommendations</i>
<i>Discuss</i>	<ul style="list-style-type: none">• <i>The discussion is important to prepare those involved emotionally for the future and to reduce any fears they will have</i>• <i>Discuss the prognosis with them frankly, in a meaningful way</i>• <i>Allow the patient and their family to present their feelings, showing that you endeavour to understand the situation from their viewpoint</i>• <i>It is important to remain empathetic and help the patient and family to feel at ease</i>
<i>Conclude</i>	<ul style="list-style-type: none">• <i>Make recommendations about future care and advance care planning</i>• <i>Make sure to answer any final questions they have</i>• <i>Let them know that communication channels will remain open</i>

References

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