

## Patient information factsheet

|               |  |
|---------------|--|
| Name          |  |
| Date of birth |  |
| Address       |  |

# Conversations about living with pulmonary fibrosis

Living with pulmonary fibrosis (a condition in which the lungs become scarred making it difficult for them to function properly) can raise many questions and concerns. This is because the condition affects multiple aspects of a person's life.

To help guide your conversations with your interstitial lung disease (ILD) clinical nurse specialist (CNS) during your appointments, we would like you to complete a self-assessment checklist. This checklist is designed to help us:

- understand your health and wellbeing concerns and feelings in relation to your pulmonary fibrosis
- identify any additional support or information you may need
- tailor our discussions to your individual needs

We hope that by completing this checklist, you will have a more meaningful appointment with your ILD CNS.

### Self-assessment checklist

Tick all the concerns that you feel are most relevant to you. You may have some of them, none of them or there may be other things that you would like to discuss that are not listed. We have included some blank sections at the end for you to make a note of anything else you would like to discuss.

Please note that we may not be able to discuss all your concerns during your 45-minute ILD CNS appointment, but your answers will help to guide future discussions.

**Please bring your completed checklist with you to your ILD CNS appointment.**

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## Physical concerns

- ☐ Breathlessness
- ☐ Cough
- ☐ Secretions (phlegm or sputum)
- ☐ Infections
- ☐ Fatigue (extreme tiredness)
- ☐ Diarrhoea
- ☐ Nausea (feeling sick) and vomiting
- ☐ Weight loss
- ☐ Appetite changes
- ☐ Mobility or exercise tolerance
- ☐ Sleep

## Emotional concerns

- ☐ Worry, anxiety or fear
- ☐ Sadness or depression
- ☐ Uncertainty
- ☐ Loneliness or isolation
- ☐ Anger or frustration
- ☐ Hopelessness

## Practical concerns

- ☐ Travel
- ☐ Housing
- ☐ Finances
- ☐ Daily household tasks
- ☐ Personal hygiene
- ☐ Work
- ☐ Stopping smoking

## Information and support

Please tick all the topics you would like more information about or support with:

- ☐ Exercise
- ☐ Diet and nutrition
- ☐ Oxygen therapy
- ☐ Vaccinations
- ☐ Benefits
- ☐ Planning for the future
- ☐ Support groups
- ☐ Research trials

## Questions about my diagnosis, treatment or side effects

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## Anything else I'd like to discuss

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## Notes

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## Contact us

If you have any questions or concerns about pulmonary fibrosis or your health, please contact us.

ILD CNS team

Telephone: **023 8120 6277** (Monday to Friday, 8am to 4pm, excluding bank holidays)

Email: [ILDclinical@uhs.nhs.uk](mailto:ILDclinical@uhs.nhs.uk)

## Useful links

[www.nhs.uk/conditions/idiopathic-pulmonary-fibrosis](http://www.nhs.uk/conditions/idiopathic-pulmonary-fibrosis)

[www.asthmaandlung.org.uk/conditions/pulmonary-fibrosis](http://www.asthmaandlung.org.uk/conditions/pulmonary-fibrosis)

[www.pulmonaryfibrosistrust.org](http://www.pulmonaryfibrosistrust.org)

[www.actionpf.org](http://www.actionpf.org)

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