

A Support Group for Interstitial Lung Disease and Pulmonary Fibrosis Patients

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What is Interstitial Lung Disease / Pulmonary Fibrosis



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- Interstitial lung disease (ILD) is an umbrella term for a large group of diseases that cause inflammation and scarring (pulmonary fibrosis) to the lungs. ILD can affect adults and children
- The scarring damages the tissue in or around the alveoli (lung's air sacs) and airways.
- This tissue becomes stiff and scarred, the air sacs cannot fully expand. This makes it harder to inhale and get oxygen into the body.
- Symptoms include progressive breathlessness, cough, weight loss, fatigue
- There are many known causes, however in the most progressive form idiopathic pulmonary fibrosis we do not know the cause
- Lung damage from ILDs is often irreversible, progressive and life limiting

Importance of support groups in ILD



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Emotional Support

- Helps with feelings of isolation, loneliness, depression
- Sharing experiences, fears
- Meet with others who understand the challenges

Access to Information and Resources

- Exchanging tips on managing symptoms, adjusting daily routines
- Updates on treatments, research, oxygen

Benefit for families, friends, carers

- Learn from others in same circumstance, feel part of a community
- Understanding the condition better
- Building a support network

Challenges of setting up the HDdUHB support group



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Supporting patients from
Pembrokeshire, Ceredigion and
Carmarthenshire

How many groups are required

Distance for patients to travel

Who should run the group (HCP vs
patient/carer)

Infection control

Suitable room, parking, accessibility

Cost, fundraising

Ongoing challenges

- Planning agendas
- RIP of patients
- Addressing difficult subjects
- Avoiding answering specific individual questions
- Managing patient advice vs evidenced based
- How to share dates/agendas/invite patients



This short video captures the real difference the ILD support groups are making.

[Support Group Impact](#)



DIOGEL | CYNALIADWY | HYGYRCH | CAREDIG
SAFE | SUSTAINABLE | ACCESSIBLE | KIND



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