



Digital health at the National Aspergillosis Centre

Aspergillosis is a serious lung condition caused by the mould *Aspergillus*, usually seen in people with underlying lung conditions (COPD, TB, asthma). There are allergic forms (ABPA, SAFS) and chronic infections (CPA), which all require specialist tests and drugs

Online resources are essential for rare diseases like aspergillosis:

- It's hard to find other patients locally → feelings of isolation, worse mental health
- NAC is the only specialist aspergillosis centre in the UK → long journey for some
- Local GPs/pharmacists rarely see patients with this disease → knowledge gap

#WorldAspergillosisDay



Awareness events



National Aspergillosis Centre Support (UK)

Private group

Patients support each other and share tips in our private Facebook group (~2400 members), which is moderated by NAC staff. Plus weekly Zoom socials

Peer support

Last year we released an *Aspergillus* knitting chart



Online craft group

Community Awareness Research Education Support

Info & advice

Patients phone our specialist nurses for advice about their symptoms and medication, or get general info from our dedicated comms team via a secure NHS-approved app



Monthly meetings

Our clinical/scientific staff give talks to help patients understand their condition and the latest research. And patients help us in return by sharing feedback on how to improve our service.



Distance appointments



During the pandemic, we held appointments virtually – many patients actually preferred this!



www.aspergillosis.org

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