

CF MDT Conference 2025

The future of CF care

**Birmingham Conference
and Events Centre**

Thursday 20 March 2025

Gold sponsor



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a life unlimited**

Welcome

We hope you will enjoy the day, which aims to bring together CF professionals from a range of disciplines to discuss some of the key topics and emerging issues in CF care and treatment.

February 2025 marked the end of Cystic Fibrosis Trust's 60th anniversary, and the past 60 years have seen incredible developments in the understanding of CF care and treatment. The latest data from the UK CF Registry shows there are more adults than children living with CF, and median predicted survival for babies born today now stands at 64 years.

But we know there are challenges ahead. As cystic fibrosis continues to evolve as a condition, as care teams, we must also evolve to ensure we are meeting the needs of those we care for. As such, this year's conference theme is **the future of CF care**.

Recent years have seen significant changes in CF. Modulator therapies have transformed life for many, but they are not a cure and don't work for everyone. The advances in survival for people with CF are to be celebrated; but with longevity of life, we must also ensure quality of life. The NHS itself is undergoing change, presenting both challenges and opportunities for CF teams. A recent workshop held on the future of the NHS touched on topics such as the role of technology in care, models of care delivery, and the prevention of ill-health. The rich discussion highlighted where the experiences of people with CF could inform changes across the whole NHS, generating many ideas for improved ways of working to tackle some of the common challenges experienced both by patients and care providers.



We will touch on many of these topics during the course of the day. In our opening plenary, we will hear from an adult with CF and a parent of a child with CF, sharing their personal journeys and their hopes for the future of CF care. Our morning and afternoon workshops allow a deeper dive into some key topics in CF care, providing both an overview of these topics as well as time for discussion and debate. We encourage your active participation in these sessions.

The CF workforce has been a topic of much debate, and the afternoon panel discussion will explore topics such as inter-disciplinary working, succession planning, emerging roles, and how we can attract and retain the CF workforce of tomorrow.

Our closing plenary will explore where we go next and how we ensure that as care needs change, the population ages, and treatment effectiveness varies, no one with CF is left behind.

We hope you'll find it valuable to connect with colleagues across all CF disciplines, discuss challenges and opportunities, and collaborate to ensure the best possible care for people with CF now and in the future. Please share your thoughts on the day by completing our feedback questionnaire, which will help us shape and improve future events for CF professionals.

Dr Maya Desai
Trustee, Cystic Fibrosis Trust

Agenda

9.00am Registration, refreshments and networking

10.00am Welcome and introduction

– Mercian 1

Dr Maya Desai (Conference Chair), Trustee, Cystic Fibrosis Trust

David Ramsden, Chief Executive, Cystic Fibrosis Trust

10.10am Opening plenary: Our hopes for the future of CF care

– Mercian 1

Michelle Shore, Adult with cystic fibrosis and Trustee, Cystic Fibrosis Trust

James Vain, Parent of a child with cystic fibrosis

10.40am Workshop sessions (morning)

WS1 Gastrointestinal care in CF

– Mercian 1

Dr Caroline Elston, Consultant in Adult Cystic Fibrosis and Respiratory Medicine, King's College Hospital

Professor Bu Hayee, Consultant Gastroenterologist, King's College Hospital

Dr Rachel Massey-Chase, Principal Clinical Psychologist and Co-chair of the Psychosocial Professionals in CF Group, King's College Hospital

Kerry-Lee Watson, Clinical Lead CF Specialist Dietitian, King's College Hospital

WS2 Considerations and complications of aging with CF

– Mercian 2

Wendy Foo, CF Occupational Therapist, Manchester Adult CF Centre

Professor Daniel Peckham, Professor of Respiratory Medicine, University of Leeds

Michelle Shore, Adult with cystic fibrosis and Trustee, Cystic Fibrosis Trust

Jacqui Wainwright, CF Social Worker, West Midlands Adult CF Centre

WS3 Pain and musculoskeletal issues in CF

– Imagine

Dr Beth Clarke, Rheumatology Consultant, NHS Greater Glasgow and Clyde

Julia Taylor, Musculoskeletal Physiotherapist Advanced Practitioner, Manchester Adult CF Centre, Manchester NHS Foundation Trust

Workshop sessions (morning) continued

WS4 Diet and exercise

– Connect 4

Dr Steve Jones, Principal Clinical Psychologist, Sheffield Children's Hospital

Fiona Moore, Specialist CF Dietitian, West of Scotland Adult CF Service

Lisa Morrison, Principal Physiotherapist, West of Scotland Adult CF Service

Dr Zoe Saynor, Associate Professor in Clinical Exercise Physiology, University of Southampton

WS5 Diabetes – current approaches

– Innovation

Claire Berry, Specialist Paediatric CF Dietitian, Alder Hey Children's NHS Trust, Liverpool

Paula Dyce, Advanced Nurse Practitioner CF Diabetes, Liverpool Heart & Chest Hospital

12.00pm Lunch and networking

1.15pm Workshop sessions (afternoon)

See morning session details

2.35pm Coffee break and networking

3.00pm Panel discussion: How can CF teams evolve to meet new challenges?

– Mercian 1

Dr Charlotte Addy (Chair), Consultant in Respiratory Medicine and Cystic Fibrosis, University Hospital Llandough, Cardiff

Panelists

Kate Channon, CF Practitioner, King's College Hospital

Professor Bu Hayee, Consultant Gastroenterologist, King's College Hospital

Dr Jonathan McCormick, Consultant in Paediatric Respiratory Medicine, Ninewells Hospital, Dundee

Lucy Paskin, CF Pharmacist, Birmingham Children's Hospital

Caroline Whitton, Lead Cystic Fibrosis Specialist Nurse and Chair of the CF Nursing Association, Derriford Hospital, Plymouth

4.15pm Closing plenary: Leaving no one behind

– Mercian 1

Professor Daniel Peckham, Professor of Respiratory Medicine, Leeds Teaching Hospitals NHS Trust

4.45pm Closing comments

Dr Maya Desai (Conference Chair), Trustee, Cystic Fibrosis Trust

Speakers

Dr Charlotte Addy

Dr Charlotte Addy is a Consultant Respiratory Physician and Senior Lecturer, with specialist interests in CF and bronchiectasis, based at All Wales Adult CF Centre and Cardiff University. She's been privileged enough to work in England, Northern Ireland and Wales, in both NHS and academic roles.



Her clinical interests include lung infection, inflammation, palliative care and clinical research. She has keen interests in service development, education, training and workforce planning. She is co-chairing the upcoming Cystic Fibrosis Trust antimicrobial guideline group, sits on the ECFS standards of care committee and helped write the ECFS standards of care. She also works with the ECFS education committee and CTN standardisation committee.

She currently sits on the BTS Council and Education & Training committee, SAC and is Training programme Director for South Wales. She chairs the Taskforce for Lung Health Workforce group, and recently chaired the BTS Workforce and Service Development committee. She is focused on creating future multiprofessional teams delivering a shared vision of respiratory and CF care.

Kate Channon

Kate Channon is a Cystic Fibrosis Practitioner in the Adult Cystic Fibrosis Centre at King's College Hospital, London. She has been in this role for 2.5 years. Prior to this Kate was a Physiotherapist in the Adult CF Team at King's for 10 years. Kate is a keen member of the Association of Chartered Physiotherapists in Cystic Fibrosis and has previously presented at both the European and North American CF conferences.



Dr Maya Desai

Dr Maya Desai was a Consultant Respiratory Paediatrician at Birmingham Children's Hospital from 2002 until 2024. During that time, she led the paediatric CF service and was involved in setting up the West Midlands (South and Central) Paediatric CF network. She has sat on the executive committee of the UK Cystic Fibrosis (UK CF) Medical Association, the clinical advisory board of the newborn screening programme for CF at NHSE and was co-chair of the working group which revised the national CF standards of care document, published in August 2024. Since 2024, she has been a Trustee of Cystic Fibrosis Trust.



Professor Bu'Hussain Hayee

Professor Hayee is a Consultant Gastroenterologist at King's College Hospital and has been Clinical Director for Liver, Gastroenterology, Endoscopy since October 2022. He trained at Guy's Hospital (GKT Medical School), graduating in 1999, and was appointed a Fellow of the Royal College of Physicians in 2015. His PhD, awarded in 2010, examined the role of innate immunity and neutrophil function in Crohn's disease. He is a Professor in Gastroenterology at King's College London and maintains an active research interest, supervising several PhD fellows and basic scientists. He has delivered the CF-GI clinic at Kings since 2014 and organised two national conferences in the topic.



He is a member of the British Society of Gastroenterology (for whom he serves as a member of the Endoscopy committee), the American Gastroenterological Association, the European Crohn's and Colitis Organisation, the American and European Societies for Gastrointestinal Endoscopy and the Association for Bariatric Endoscopy.

Dr Jonathan McCormick

Dr McCormick is co-chair of the Scottish CF Group and Clinical Lead for Paediatric Respiratory for the North of Scotland. He undertook his National Grid training in Paediatric Respiratory Medicine in Glasgow, and his MD explored sex and ethnic differences on clinical outcomes in CF using the UK CF Registry. Since his appointment as Consultant in Paediatric Respiratory Medicine in 2007, he has worked with the Dundee, Aberdeen, and Inverness teams responsible for a catchment area covering half the land mass of Scotland. Maintaining CF MDT staffing with sufficient experience, expertise, and protected time in order to deliver high quality and equitable services in remote and rural areas is a constant challenge. Outside of medicine, he appeared in the first ever Netflix original documentary movie with Vince Vaughn in 2012, his work appeared on the cover of Shep Fairey's influential Swindle magazine before Banksy, and he is contributing editor for Whisky Advocate magazine in the U.S. which has a reach of over a million people. His book Whisky Opus (2nd ed., Dorling Kindersley), co-authored with Gavin D. Smith, was published in October 2024.



Lucy Paskin

Lucy is a specialist Cystic Fibrosis Pharmacist working with paediatric patients at a large paediatric clinic based in Birmingham Children's Hospital since 2010. She graduated with a degree in pharmacy from Aston University and undertaken further qualifications including non-medical prescribing and is an active pharmacist independent prescriber. Lucy is on the steering committee of the UK Cystic Fibrosis Pharmacist group (UKCFPG). She is keen to understand more on the implications of medicines taken by CF patients in real world studies and has presented at European Cystic Fibrosis Conferences.



Professor Daniel Peckham

Daniel Peckham is Professor of Respiratory Medicine and Deputy Director of the Leeds Institute of Medical Research at the University of Leeds. He is the clinical lead for the Regional Leeds Adult Cystic Fibrosis where he pioneered the design and implementation of chronic disease electronic patient records and established a strong base for clinical and basic research in cystic fibrosis. Active research programs focus on CF related inflammation, CFTR modulators, gut dysbiosis, cancer, drug allergy, big data, electronic patient records and clinical trials. He is passionate about education and was the founding Director of Education for the European Cystic Fibrosis Society.



Michelle Shore

Michelle Shore has cystic fibrosis. She is a Trustee of Cystic Fibrosis Trust, chair of the people committee and a member of the finance committee. Michelle sits as a community representative on the steering committee of the CF AMR Syndicate. She works as a Consultant Solicitor for the professional support team at Richard Nelson LLP, supporting professionals with regulatory matters involving employment law and writes for a legal writing team.



Michelle lives in South Yorkshire with her family and spends her free time walking her two Labradors and taking her daughter to Starbucks.

Caroline Whitton

Caroline is Chair of the Cystic Fibrosis Nursing Association (CFNA) and Lead Cystic Fibrosis Specialist Nurse, in a developmental consultant practitioner role, at University Hospitals Plymouth NHS Trust.



Ms Whitton's CFNA role includes representation on the clinical advisory group for Cystic Fibrosis Trust as well as working with NHS England and NICE.

Over the past 18 years she has helped develop her local service and is currently in the final stages of MSc in advanced clinical practice and is passionate about transformational leadership and inclusivity.

X/Twitter – CFNurseCaroline

James Vain

James is the father of Olivia, a 3-year-old girl living with cystic fibrosis. They share the family home with wife and mum, Julia, and brother Ludo. Olivia is the only member of the immediate and extended family with CF.



She attends a CF clinic at the Royal Hampshire County Hospital, having initially been under the care of Oxford's John Radcliffe Hospital. She starts primary school this year and enjoys an active life of gymnastics, dance, and swimming.

Are you signed up to our CF Professionals newsletter?

Emailed quarterly, the newsletter includes the latest news, updates and events for professionals providing CF care and treatment.

Sign up here:

cysticfibrosis.org.uk/cf-professionals-newsletter
(you can opt out at any time).



Tell us about it!

MDT Conference 2025 feedback

Please take a few minutes to complete our evaluation survey. Your feedback will really help us shape and develop future conferences and events for CF professionals.

Visit www.surveymonkey.com/r/MDT2025 or scan the QR code to fill out the survey.



Scan the QR code to give us your feedback!

CF Professionals Survey 2025

Endorsed by CFNA, ACPCF, BDA-CF group, UKPPCF and CFPG

This survey was developed by Cystic Fibrosis Trust with CF specialist interest groups and members of the CF community to capture your experiences and perspectives of working within CF care. This will help inform future advocacy and work to support CF MDTs to adapt and secure the required workforce, training and resources they need.

The closing date for the survey is Friday 11 April. Please contact QI@cysticfibrosis.org.uk with any questions or queries about this survey.

Visit www.surveymonkey.com/r/CFProfessionalSurvey25 or scan the QR code to take part.



Scan the QR code to take part in the survey



Save the date

UKCFC 1-2 October 2025

We're delighted to share that our UK CF Conference is back! It will be a two-day hybrid event in London incorporating updates on all our research activities, including lab-based research, how data from the UK CF Registry is being used to advance research, and all the latest on clinical trials and clinical research.

Please add the date to your calendars and look out for updates on the preliminary programme and the opening of registration coming soon.
cysticfibrosis.org.uk/ukcfc

Emily's Entourage

Cystic Fibrosis Trust has partnered with Emily's Entourage, a US charity that supports research for people with CF who are unable to benefit from modulator therapies.

This partnership supports expansion of Emily's Entourage's CF Clinical Trial Connect database to the UK CF community.

The database aims to help members of the community hear about clinical trial opportunities.

Registered participants receive a direct alert notifying them of potential CF clinical trial opportunities in the UK.

More information can be found at
www.emilysentourage.org/ctc



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**EMILY'S
ENTOURAGE**

Whatever you do, do it in **yellow**

Cystic
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day

Friday 13 June

#CFweek
9–15 June 2025



Saturday 12 July 2025

10:30 – 16:00

Harewood House, Leeds, LS17 9LG

Walk, Jog, Run for CF this July and help make sure everybody with cystic fibrosis can live a life unlimited. Every step you take could help bring us closer to the next research breakthrough and continue to support people with CF.

**Sign up today and
help change lives,
one step at a time**



Scan the QR code to sign up