ON-DEMAND CONFERENCE GUIDE

Challenges in the Medical Consultation

Medically unexplained symptoms, doctor-patient bias, personas, gaslighting and diagnostic doubt



Artwork: Tony Pickering

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Revisit the conversations. Explore the ideas.

A joint meeting of the Guild of Health Writers and Forgotten Patients, Overlooked Diseases, examining diagnostic uncertainty, consultation dynamics and more connected care. Explore ten presentations spanning clinical, patient, research and ethical perspectives. Find out more at www.forgottenpatients.org.

FOUR MESSAGES FROM THE DAY

Listen and believe

Give patients space to explain their experiences without premature dismissal.

Validate symptoms

Acknowledge the patient's experience even when the cause remains unclear.

Share uncertainty

Honest discussion of diagnostic doubt can support trust and shared decisions.

Think beyond silos

Use flexible thinking and communication across specialties to connect care.

EXPLORE THE PRESENTATIONS

01-02 **Listening and lived experience**

03-04 **Diagnosis and research**

05-06 **Journalism and consultation**

07-08 **Patient experience and gaslighting**

09-10 **Education and ethics**

ON DEMAND / PRESENTATIONS 01-02

Listening and lived experience

Clinical and patient perspectives on unexplained symptoms.

01 The Problem of Medically Unexplained Symptoms

Dr Adrian Tookman

An introduction to the challenges faced by people with rare diseases and medically unexplained symptoms who struggle to access appropriate healthcare and support.

- Patients without a diagnosis can fall outside condition-specific support.
- Healthcare pathways may encourage siloed working and rapid diagnostic categorisation.
- Misdiagnosis of poorly understood diseases can occur.
- Diagnostic uncertainty and critical reflection need space within clinical practice.

Takeaway: Better support requires collaboration across specialties, acceptance of uncertainty and clearer signposting for patients.

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02 The Patient Perspective: Challenges in Consultation

Dr Minha Rajput-Ray

A lived-experience perspective from someone navigating the healthcare system as both a patient and clinician.

- Healthcare professionals need to be able to acknowledge medical uncertainty.
- Patients benefit when clinicians ask what matters to them and what they need from the consultation.
- Complex systems can be difficult to navigate even for people with clinical knowledge.

Takeaway: Listening deeply and thinking beyond diagnostic labels can help create more collaborative, patient-centred care.

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ON DEMAND / PRESENTATIONS 03-04

Diagnosis and research

Rare conditions, persistent symptoms and uncertainty.

03 Challenges in Diagnosing Rare and Genetic Conditions

Louise Fish

An exploration of diagnostic barriers for people with rare and genetic conditions and the importance of support even when diagnosis remains elusive.

- Diagnostic journeys for rare conditions can be prolonged.
- A diagnosis can still provide clarity and access to support even where treatment options are limited.
- Clinicians need to remain aware of uncertainty and the limits of current knowledge.

Takeaway: Care should not stop simply because a diagnosis has not yet been achieved.

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04 A Researcher's View on Medically Unexplained Symptoms

Professor Chris Burton

A research perspective on symptom meaning, persistent physical symptoms and the limitations of simple mind-body explanations.

- Historical mind-body models can oversimplify complex symptom experiences.
- Persistent symptoms may warrant consideration as significant problems in their own right.
- The term 'medically unexplained' can be limiting.
- Research increasingly explores multiple biological and perceptual mechanisms.

Takeaway: Persistent symptoms require nuanced approaches that allow multiple explanatory frameworks and genuine uncertainty.

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ON DEMAND / PRESENTATIONS 05-06

Journalism and consultation

Patient visibility, bias and the conversations that shape care.

05 Forgotten Patients: A Journalist's Perspective

Jo Waters

A journalist's perspective on the experiences of people with undiagnosed or poorly understood conditions, drawing on interviews and case studies.

- Patients may report not being believed, not being listened to or experiencing poorly coordinated care.
- Long waits and fragmented pathways can have emotional as well as physical consequences.
- Potential improvements discussed included continuity of care, symptom diaries, longer consultations and careful use of AI.

Takeaway: Journalism can help make overlooked patient experiences visible and contribute to wider discussion about system change.

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06 Why Consultations Sometimes Go Wrong

Dr Adrian Tookman

A closer look at how bias, patient and doctor personas, labels and diagnostic doubt can affect consultations.

- Frustration can develop on both sides of a difficult consultation.
- Patient and clinician communication styles can shape the interaction.
- Negative labels can damage trust and influence subsequent care.
- Validation remains important even when the diagnosis is uncertain.

Takeaway: Clinicians need space for uncertainty, reflection and respectful communication when answers are not clear.

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Patient experience and gaslighting

Listening carefully, recognising invalidation and preserving trust.

07 Patient Experiences

Christianne Forrest & Katia Chrysostomou

Personal and family experiences of seeking explanations for complex symptoms before ultimately receiving diagnoses of Ehlers-Danlos syndrome.

- Patients described feeling dismissed or judged for seeking answers.
- Some experienced unhelpful referrals or consultations that did not progress their care.
- Diagnostic labels can sometimes close down further exploration prematurely.
- Sharing uncertainty honestly may help preserve trust.

Takeaway: Patient accounts reinforce the need for careful listening, appropriate investigation and caution around labels that may prematurely end diagnostic exploration.

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Recording only

08 Medical Gaslighting - A Narrative Review

Dr Steven Walker

Findings from a narrative review examining gaslighting, disbelief and invalidation in healthcare while recognising that most consultations go well.

- The review considered minimising, dismissing or psychologising physical symptoms.
- It highlighted groups reported in the literature as particularly affected.
- Potential consequences include diagnostic delay, distress and disengagement from care.
- Poor communication can contribute to unsatisfactory consultations for patients and practitioners.

Takeaway: Further research is needed, alongside communication that validates patient experience and gives people space to explain their concerns.

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Education and ethics

Preparing professionals for compassionate, equitable care.

09 MUS and Medical Education

Dr Miranda Kronfli

How healthcare education and training might better prepare professionals to work with patients whose symptoms remain unexplained.

- Training should prepare clinicians for symptoms they cannot immediately explain.
- Patient lived experience can contribute to healthcare education.
- Communication, ambiguity and reflective practice can be embedded in training.
- Public and patient involvement offers opportunities for co-designed learning.

Takeaway: Patient perspectives should be integrated into education so future professionals are better prepared for diagnostic uncertainty.

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10 Ethics of Consultation in MUS

Chantal Patel

An examination of ethical dimensions of consultations involving medically unexplained symptoms, including epistemic injustice and medical gaslighting.

- Testimonial injustice can occur when patient reports are given less credibility because of bias.
- Hermeneutic injustice describes situations where patients lack accepted language or frameworks for their experiences.
- Ethical care requires attention to communication, bias, access and trust.
- Clinical pathways should allow concerns to be validated and appropriately investigated.

Takeaway: Addressing epistemic injustice is an important part of ethical care for patients whose symptoms remain unexplained.

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