

Enduring Symptoms

From patient voices to
solution-driven care

Wednesday 24 June 2026

The Royal College of Physicians, London

A one-day hybrid, CPD-approved conference



Royal College of Physicians

Bringing patient experience, clinical insight and research together to explore more coordinated, compassionate care for people living with enduring symptoms.

HYBRID CONFERENCE

London + online

3 PROGRAMME PARTS

Perspectives to
solutions

PATIENT VOICES

Central to the discussion

WATCH AGAIN

16 recordings linked

Conference Overview

The programme brought lived experience into dialogue with clinical, ethical and service perspectives. Speakers examined diagnostic uncertainty, fragmented pathways, inequality, persistent pain, neurological symptoms and genomic medicine, alongside practical ways to improve support.

Across the presentations, recurring priorities were to take symptoms seriously, keep diagnostic thinking open and build care around the person's life and goals.

Themes Explored

Diagnostic uncertainty

Patient stories

Ethics & trust

Equity in care

Persistent symptoms

Joined-up services

Genomic medicine

Shared decisions

Session Highlights

Part 1 | Setting the scene
Opening perspectives and diagnostic uncertainty

Welcome

Professor Dame Lesley Regan

An opening perspective on health across the life course and the organisation of care for people with enduring symptoms.

Key points

- The welcome highlighted a life course approach to health.
- Integrated services and person-centred support were central to the opening message.

Takeaway: Consider the person and their changing needs across life when designing services.

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Terminology and the importance of diagnostic doubt

Dr Adrian Tookman

A challenge to the language and service structures used when symptoms persist without a clear explanation.

Key points

- Terms describing persistent symptoms should not close down further clinical thinking.
- Short appointments and rigid processes can leave complex accounts unheard.
- Clinical practice needs room for reflection, discussion and uncertainty.

Takeaway: Keep an open mind and make space for uncertainty throughout the diagnostic journey.

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Session Highlights

Part 1 | Setting the scene
Patient voices and patient-clinician relationships

The patient journey: what stories reveal

Dr Pip Hardy

How first-person digital stories can bring the realities of illness into education, reflection and service improvement.

Key points

- Personal accounts reveal priorities and experiences that numerical measures may miss.
- Stories can prompt empathy and reflection among staff, students and decision-makers.
- The Patient Voices examples connected listening with changes in learning and care.

Takeaway: Use patient stories to inform reflection and practical improvements in care.

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Navigating the patient-physician dynamic through antiphospholipid syndrome

Dr Minha Rajput-Ray & Tracy Jallow BEM

Patient and clinical perspectives on the demands of chronic illness and the relationships needed to navigate complex care.

Key points

- The DETTOL framework considers demands, environment, timeline, teamwork, ownership and leadership.
- Understanding the full history helps connect experiences across appointments and specialties.
- Planning together requires trust, continuity and recognition of the patient's knowledge.

Takeaway: Build next steps together, with responsibility and support shared across the care team.

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Session Highlights

Part 1 | Setting the scene
Lived experience and the ethics of care

When does the patient story go wrong?

Christianne Forrest

A comparison of one person's experience of breast cancer care with the search for recognition of a rarely diagnosed condition.

Key points

- An established cancer pathway contrasted with fragmented care for hypermobile Ehlers-Danlos syndrome.
- Separate specialty assessments can obscure a pattern affecting several body systems.
- Access, communication and the ability to advocate for oneself can shape the diagnostic journey.

Takeaway: Look across the whole history and remain curious when the usual pathways do not fit.

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Ethics of care for people with enduring symptoms

Associate Professor Chantal Patel

The ethical responsibilities of care when clinicians cannot yet name, explain or cure a person's symptoms.

Key points

- The presentation considered ethical communication and the credibility given to patient accounts.
- Improving daily life remains a meaningful goal while a diagnosis is uncertain.
- Continuity, staff education and joined-up support can reduce repeated handoffs.

Takeaway: Respect and sustained support remain essential throughout diagnostic uncertainty.

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Session Highlights

Part 2 | Finding solutions
Reassessment and practical support for chronic pain

Patient data and Jess's Rule: who will it help?

Richard Stephens

An assessment of the potential and practical limits of prompting a fresh look at symptoms after repeated consultations.

Key points

- The session explored reassessment as a way to challenge an early diagnostic assumption.
- Capacity, awareness and inconsistent application were identified as implementation concerns.
- Routinely collected patient data could help examine whether reassessment improves outcomes.

Takeaway: Pair the intention to rethink with evaluation of how it works in everyday care.

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The pain consultation and how to survive it

Dr Benjamin Ellis MBE

A practical discussion of chronic widespread pain, overlapping symptoms and conversations about living better with pain.

Key points

- Assessment can consider fatigue, sleep, cognition and other symptoms alongside pain.
- The slides explored hypermobility, neurodivergence and brain-body processing as relevant areas of enquiry.
- Planning can focus on activities, relationships, work and other goals that matter to the individual.

Takeaway: Agree useful goals and support daily life alongside efforts to understand symptoms.

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Session Highlights

Part 2 | Finding solutions
Equity, explanation and support for continuing symptoms

Enduring symptoms: an equity-focused psychiatrist's view

Dr Amrit Sachar

A psychiatric perspective that places inequality, clinical curiosity and compassion at the centre of care.

Key points

- Gender, ethnicity, neurodivergence and learning disability can affect access and how symptoms are interpreted.
- Research evidence needs scrutiny for whose experiences it includes or leaves out.
- An individual formulation should remain open to revision, including the possibility of rare disease.

Takeaway: Combine a broad assessment with validation, attention to inequity and a plan developed together.

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Unexplained chest pain and possible cardiovascular symptoms

Dr Sanjay Gupta

An exploration of persistent symptoms, fear and the difference between addressing uncertainty and relieving discomfort.

Key points

- Symptoms may remain disruptive after investigations have reduced concern about dangerous disease.
- A clear explanation can help patients understand what results do and do not establish.
- The session emphasised function, confidence and a purposeful plan for continuing symptoms.

Takeaway: Explain findings clearly and address the ongoing impact of symptoms as well as diagnostic concerns.

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Session Highlights

Part 3 | Moving forward
Services and symptom science

KEYNOTE | Problems and solutions of care

Dr John Dean

A proposal to organise support around the whole person when symptoms span specialties or remain diagnostically uncertain.

Key points

- Services built around individual diseases can fragment care for complex presentations.
- Generalist expertise, continuity and multiprofessional working were central to the proposed approach.
- Education, peer support and personalised goals can complement ongoing clinical assessment.

Takeaway: Develop coordinated services that support functioning and wellbeing while remaining alert to changing needs.

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Enduring symptoms: disease indicators or problems in their own right?

Professor Chris Burton

A discussion of symptom science and the challenge of investigating disease while also treating the burden of symptoms.

Key points

- Symptoms can signal pathology and can also persist as substantial health problems.
- Brain-body signalling offers a framework beyond a simple physical-versus-psychological divide.
- Explanation and support can proceed alongside appropriate review for disease.

Takeaway: Keep investigating thoughtfully while helping people understand and manage their current symptoms.

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Session Highlights

Part 3 | Moving forward
Neurological perspectives and genomic medicine

Enduring symptoms: a neurologist's perspective

Dr Ania Crawshaw

Functional neurological disorder (FND), the language used to describe it and the importance of explaining clinical findings.

Key points

- The presentation described FND as a real disorder and distinguished it from deliberately produced symptoms.
- Positive examination features, rather than normal tests alone, informed the diagnostic approach discussed.
- Clear explanation and individually selected support were emphasised in management.

Takeaway: Communicate the basis of a diagnosis and develop support suited to the person's symptoms and circumstances.

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Should everyone with enduring symptoms undergo genetic testing?

Dr Ehsan Karimiani

The opportunities and limits of genomic investigation for people whose complex symptoms have resisted explanation.

Key points

- Genomic advances can uncover diagnoses with implications for patients and relatives.
- Clinical patterns and family history can help identify people likely to benefit from assessment.
- The presentation weighed potential benefit against uncertain findings, incidental results and other burdens.

Takeaway: Consider genetics where clinically appropriate, with assessment guided by the likely value for the individual.

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Session Highlights

Part 3 | Moving forward
Women's health and the closing discussion

Why are women disproportionately affected?

Dr Lynsay Matthews

How dismissal, stigma and gaps in knowledge can shape women's experiences of symptoms and healthcare.

Key points

- Examples from menstrual health and other conditions illustrated delayed or mistaken diagnoses.
- Research accounts described the consequences of having symptoms normalised or disbelieved.
- The presentation highlighted the interaction of clinical complexity, training and research gaps.

Takeaway: Listen carefully, validate the impact of symptoms and address gaps in knowledge and care.

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Panel discussion: how do we move forward?

Professor Bill Noble, Dr Lucy Foulkes, Dr Camilla Higgins & Dr Vadivelu Saravanan

An audience and speaker discussion focused on improving care for people living with enduring symptoms.

Key points

- The closing discussion brought together the four panellists and the audience.
- The recording offers the full exchange about moving care forward in practice.

Takeaway: Continue the conversation between patients, professionals and services.

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Key Messages From the Day

Recurring priorities across the published presentations

Hear the full story

Make room for the account of illness, its history and its impact on everyday life. Patient experience can reveal what a narrow diagnostic pathway misses.

Keep thinking open

Use terminology carefully and recognise that understanding can change. Support for current symptoms and thoughtful diagnostic review can proceed together.

Make care continuous

Reduce fragmentation between services. People with complex symptoms need coordinated assessment, clear responsibilities and ongoing support.

Explain and plan together

Discuss findings and uncertainty in understandable language. Agree next steps around what matters to the person, including function and quality of life.

Address unequal experiences

Consider whose symptoms may be dismissed, whose needs are overlooked and whose experiences are missing from research or professional education.

Turn discussion into better services

Bring patient knowledge into training and service design. Learn from existing approaches and evaluate whether changes improve people's experience and outcomes.

The conversation continues.

Explore FPOD's work and revisit the conference recordings and slides.

forgottenpatients.org/enduring-symptoms-2026

About this summary

Session highlights draw on the published conference slide decks. The welcome and panel entries use the event-page descriptions. The closing messages are an editorial synthesis of the presentations.