

This week in the Patients Association Weekly News:

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Patients Association AGM 2019



Our CEO Rachel Power and our Volunteer Membership Officer Elspeth Evans welcome people to our AGM

We had a very successful Annual General Meeting this week, with many engaged members joining us in person, or online via the live-stream*.

Our Chair, Lucy Watson, took a moment to remind us of the values, goals and mission of the Patients Association - to listen to and represent patients. She explained that while we've seen an increase in calls to the helpline, we would like to reach an even more diverse range of patients - that's one of the reasons why we decided to make membership free.

Rachel Power, CEO, spoke of the importance of engaging people at grassroots levels, enabling and empowering people to take action for change. Projects such as the [Nutrition Checklist](#) and the [Care Home Charter](#) aim to empower people to get more involved with their treatment and care.

Head of Income Generation, Sarah Reilly, gave an update on all the work that has been done to update and improve the strategies and governance around our finances, and enable us to bring in more revenue, including from new funding streams. She also reported that despite concerns that our income could fall when membership fees were scrapped, we actually saw a small increase in revenue, thanks to generous members who made donations in place of the fees. Thank you!

John Kell, Head of Policy, talked about the huge number of issues that the Patients Association has been working on, with a list of consultations and policy papers that we have been actively involved in so long that it needed more than one slide! These included work on access to medicines, patient safety, organ donation and complaints processes.

The Patients Association is continuing to grow and we thank our members, Trustees, and friends for all their support. We are pleased to announce that Isaac Egberedu was elected Treasurer, Dave Taylor was re-elected as a Trustee, and we give a warm welcome our newest Trustee, Suzanne White.

If you weren't able to make it to the AGM you can still [watch the meeting online](#), on our website.

* This is the first time we have attempted to live-stream the meeting and we would love your feedback on whether you found it useful. We have heard a couple of people had issues with the connection in the second part of the meeting (apologies), but you can watch the meeting in full by clicking on the link below.

[Watch now](#)

A Passionate Panel on Patient Experience



The culmination of our AGM day was a fascinating and inspiring panel discussion, in which we heard from people with a variety of lived experiences, and heard further contributions from audience members in the room.

We were joined by: Kirit Mistry, a patient with diabetes and Co-Chair and Trustee of the National BAME Transplant Alliance; Cyrilene Cullen, who cares for her son Fergus, who is living with Lennox-Gastaut syndrome; and Yvonne Coghill CBE, OBE, FRCN, Director for Workforce Race Equality Standard Implementation at NHS England, and Deputy President of the Royal College of Nursing.

Kirit began by talking about the importance of patients creating their own opportunities to make change, as he had to do when he encountered a lack of culturally sensitive support and information in Leicestershire for people of South Asian backgrounds with diabetes. He encouraged everyone to be 'passionate patients'.

Cyrilene shared the story of her son Fergus, who has a rare and incurable epilepsy syndrome. She outlined how a personalised care approach really changed their experience: "It's all about choice and control and flexibility," she concluded, sharing lovely images of Fergus enjoying life to the full.

Yvonne spoke about both her passion for nursing, the importance of improving inclusion within both society as a whole and the NHS in particular, and the links between the two. With 44,000 nursing vacancies in the NHS, and black and minority ethnic nurses more likely to move from NHS staff roles to agency work, she argued forcefully that a more inclusive NHS would benefit everybody.

We're hugely grateful to all our speakers for such a rich and informative discussion. Anyone who missed it at the time can still [view it online](#).

Patients Association in the news



This week we have been featured in The Guardian commenting on [the difficulties patients with Parkinson's face in hospital](#), our Chair Lucy Watson [spoke out against fees for GP appointments](#) in a report in The Sun, and we have also commented today on the number of patients who are still being admitted to mixed-sex wards (article still to be published).

Do you have knee problems? We KNEE-d you!



We'd like to hear from you if you currently have knee problems and are considering surgery, are waiting for a procedure or have recently had an operation. We're working with the University of Oxford to produce new patient information about the recommended

treatment options for meniscal problems of the knee and we're looking for people to pilot a new approach to creating guidance that will help to inform and empower patients. Can you help?

Participants will need to attend a meeting in Oxford on **Thursday 7 November from 1.30 to 4pm**. Travel expenses will be reimbursed and participants will also receive a gift voucher to thank them for their time. If you are interested in taking part please contact Heather Eardley on heather.eardley@patients-association.com.

As well as working with the University of Oxford, the project is also supported by the NHS 'Getting It Right First Time' programme and the British Association for Surgery of the Knee.

[Sign me up](#)



 the patients association

Calls to our helpline are now free of charge!

We've launched our new 0800 number, making it free for people to speak to our expert advisers:

0800 345 7115

From the helpline

The helpline took a call from Evelyn* about the distressing experience of her father, who had been admitted to hospital with terminal cancer. He was in a very great deal of pain, and the family were struggling to get staff to respond to the emergency buzzer to attend

to him. Evelyn described how her father removed his oxygen mask as he could no longer stand to be in pain. She tried to get him to put the mask back on, and eventually a nurse arrived, but he wouldn't let them replace the mask, and died soon afterwards. Staff attempted resuscitation before Evelyn reminded them that a 'do not resuscitate' order was in place.

The family were understandably traumatised by what happened, and unhappy with the cause of death that the hospital listed on the death certificate, as they believe he took his own life. Evelyn called us for advice on how best to raise a complaint.

The helpline team gave Evelyn information on how to contact the complaints team at Cardiff and Vale University Health Board, shared our leaflet 'How to make a complaint', which contains advice on how to draft a formal complaint, and suggested that she might like to report what happened to the Healthcare Inspectorate in Wales. We also signposted her to her local Community Health Council, so that she could seek to obtain support from an advocate. Evelyn got back to us to let us know that she had arranged an appointment for the following week, and had started drafting her letter of complaint.

*Name has been changed.

If you need health or care advice, call 0800 345 7115 between 9.30 and 5pm on weekdays, or email helpline@patients-association.com. You can also visit our website to find out more about our helpline, and visit our advice and information leaflets [here](#).

[Contact our helpline](#)

What our team is reading this week

Contaminated blood: New papers show senior medics allowed scandal to continue

NHSE reviewing patient transport contracting after string of failures (£)

Brexit: What will happen to European Health Insurance Cards?

How putting NHS staff first is making hospitals better

'Unacceptable' delays in diagnosing secondary breast cancer

About Us

Our vision is that health and social care will be delivered in a way that meets every person's health and social care needs.

Our mission is to give effect to the patient voice, to improve patient experience and support people to engage fully in their own care. Find out more about our values on our [website](#).



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