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Networked patients set the pace

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Recently I joined a webinar flagged by the cancer Facebook group I belong to. Framed as an “experts talk at patients” meeting I asked if we could send in questions in advance, and did so, with little expectation that they would be answered. But my cynicism soon waned. This was a conference organised and moderated by patients—and it showed.

A patient and her daughter (her carer and committed patient advocate) opened proceedings. The patient emphasised how fortunate she had been to be managed by a specialist with expertise in adeno-cortical carcinoma (ACC)—a highly heterogeneous cancer affecting fewer than 1 in a million people. Most patients are not managed by specialists with expertise in this area, and diagnostic delay and suboptimal treatment are common.

Both of these problems were illustrated in the short opening video in which a wide range of patients talked movingly about their patient journeys. One reported that her doctor had described her as an “anomaly” and said he couldn't treat her because he didn't know what to do. This immediately prompted her “to find someone who does.”

She was young and assertive. Many of us are neither. And as the patients talked I reflected on my own journey with this tricky cancer, and how long it has taken me to become empowered.

The invited speakers, medical oncologists and surgeons, were chosen by the patient organisers for their specialist interest and experience in treating patients with ACC. They pitched their talks well and did not talk down to their audience. Their commitment to improve the outlook of a condition which has a dismally low five year survival rate was evident. And it was heartening to hear them flag the importance of patient empowerment and activism to help advance understanding of this orphan cancer, where first line drug treatment (a toxic drug called mitotane) has not changed in over 60 years.

“I tell my patients that knowledge is power,” said Jaydira Del Rivero, an oncologist who works at the National Cancer Institute at the National Institute of Health in the US. “They should ask why their doctor is recommending one treatment over another” as well as about risks, benefits, and side effects. The same goes for participation in a clinical trial, she said. You should ask what questions it seeks to answer and what the outcome measures are. Not only what it entails for trial participants.

As she talked she put up slides listing questions to ask and how to pose them. She later shared her email and encouraged those with more questions to contact her. A hugely generous gesture given the large number of patient attendees from around the world.

While the surgeons diverted us with gory intraoperative videos, patients lobbed questions into the chat box. By the end of the session I had been given the name of three UK specialists with an interest in ACC, pointed to new resources, put in touch with a UK researcher conducting qualitative research on ACC patient's “journeys,” and been warmed by a global community of friends I didn't know were out there.^{1,2,3}

A common message was how isolated ACC patients feel. I have certainly felt very alone and lost count of the number of consultations starting with “I have no experience of treating patients like you but ...” It's not inspired hope or confidence.

When I developed liver metastases less than a year after major thoraco-abdominal surgery to remove a 19 cm invasive tumour it looked like my trajectory would prove par for the course. A second round of heroic surgery was recommended followed by high dose abdominal radiotherapy. Not because there was evidence it would help, but in my NHS specialist's belief that “it halts most cancers in their tracks.” It was gruelling.

So far so passive. But when lung metastases were detected three years later and more thoracic surgery recommended I hesitated. My BMJ work had made me aware that the evidence base for surgical metastasectomy of lung secondaries from abdominal tumours was being questioned. Would it not be better to keep out of hospital and “seize” what days were left to me?

The power of patients

Repeat scans documented an increase in size of the metastases and I took to googling, as most of us do. I “met” a fellow ACC patient this way. His clinical course had been similar to mine. He told me about the adrenal cancer research centre he had funded and the international patient community he had set up. I no longer felt alone. He gave me the resolve to undergo further surgery.⁴

I have learnt more about what effective patient advocacy and leadership can achieve since then. Not least from the patient and carer advocates who helped develop and continue to inform *The BMJ's* Patient and Public Partnership Strategy.⁵

I have also learnt to live with cancer as a chronic disease alongside several other longterm conditions. The combined experience has extended my knowledge about practice variation and the many downsides of “too much medicine.”⁶ Topics *The BMJ* repeatedly returns to.⁷

In 2015, adjuvant chemotherapy before major abdominal surgery for a recurrence in the caudate lobe of the liver was recommended. I declined and

“researched” less invasive options. This taught me salutary lessons about the pros and cons of seeking “out of the box” advice about cutting edge tests and treatment. I found out that nanoknife ablation might be an option and pursued it. My cancer hospital had not heard of it then but it offers it now.

As a lucky 19 year survivor of ACC despite presenting with histologically aggressive Stage III disease, I’ve mulled over how I can help others. But while I have only pondered, others have been proactive. The webinar was a tour de force. A great example of the power of networked patient communities and professional and patient partnership.

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- 2 YouTube. ACC connections. https://www.youtube.com/channel/UCtLH2E_5S5nC3s2KPLIF_XA
- 3 ACC connections. <https://linktr.ee/ACCcommunity>
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