Part of

UNHEARD IN HEALTHCARE

Kaleidoscope's first ever live storytelling event. Read real stories from all parts of health and care.

A house call for a sore throat

“Patients always wanted antibiotics for a sore throat, but 70% of throat infections are caused by viruses, and therefore antibiotics are pointless.”

Sore throat **was the only information written next to this request for a house call. I was a trainee GP at the time, just out of hospital, and fresh with ‘hospital acquired’ prejudices about patient behaviour.**

Seeing this request, I thought: who needs a house call for a sore throat? In fact, who needs to see a doctor for a sore throat at all? Patients always wanted antibiotics for a sore throat, but 70% of throat infections are caused by viruses, and therefore antibiotics are pointless. This patient needed to be educated on two fronts: house calls and antibiotics!

It was a beautiful crisp winter's day. I walked up to the large bungalow, past two cars, thinking: they have transport, why didn't they come to surgery?

A cheery, middle aged woman answered the door. Not the patient. I knew from the details on the front of his records that he was a 15-year-old boy.

She was very polite and expressed her gratitude for me coming out to see her son. She would normally have brought him to the surgery but… a long list of reasons why she hadn't been able to do this followed.

Excuses, excuses, I think.

> *"Patients, mostly, try not to ask for anything from the NHS unless they really need to, and are usually very grateful."*

She led me into the plush sitting room. The sun shone in through the sweeping bay window onto her son, who reclined on a large armchair surrounded by cushions.

I was startled by him. He had severe cerebral palsy. His arm and leg on one side of his body were small and contracted due to spasm.

He was almost blind, his hearing was okay, but his speech limited.

Despite his difficulties, through his mother, he expressed thanks to me for coming to see him.

I examined him; we had a nice chat and the boy made a few jokes. I think I gave him a prescription for penicillin, but I can’t be sure.

My main memory is what I learned from meeting this boy and his mum: patients, mostly, try not to ask for anything from the NHS unless they really need to, and are usually very grateful.

It’s a cliché, but I learned as much from my patients as I ever taught them.

In those days, patient records were kept in Lloyd George envelopes. The notes were very sparse and did not have a summary of the patient’s illnesses.

Soon after this, all records had to have a summary card at the front of the envelope, and a little later the records were computerized.

Asthma patient experience

“It occurred to me that I had been stripped of my individuality, not by individuals knowingly practicing this but by an under maintained machine, that was built in a different age.”

When I thought about writing my experience of general hospital, it struck me that this is exactly how the health service perceived me, one of millions of patients with an experience I liken to a cup of water poured into the sea. A sea of experience, they periodically dip and test to declare variables like salinity and temperature in statistical terms, with individual experiences lost in the vastness of the whole.

I arrived through urgent care presenting mild asthma attack. The receptionist asked,

“Are you struggling to breathe my love?”

“‘Yes” I answer, “I’ve taken a whole inhaler and it isn’t working.”

“Okay my love, I’ve put it as urgent” was the reply, in a patronising tone.

“Please can I confirm your address and telephone numbers.”

I struggle to confirm my details while concentrating on not being able to breath and take a seat in the waiting area. Quietly continuing with my asthma attack, I am called for triage after 30 minutes. The nurse, a friendly guy, takes my vitals and informs me my ‘stats’ aren’t good, but not to worry, he’s put me as urgent on the computer.

I return to the waiting area, to sit with my ever-worsening asthma attack. Another 20 minutes goes by and I am called by a second nurse. By this time, I am barely able to talk. The nurse appears concerned and calls a doctor, she immediately puts me on a nebulizer followed by another, before wheeling me on to the assessment ward in a wheelchair.

From this point onwards, I felt myself being quickly assimilated into the system. A system that will strip my rights, devolve my opinion and know me not by name, but by hospital and bed numbers. I was moved from ward to ward, with no notice or explanation.

> *“A system that will strip my rights, devolve my opinion and know me not by name, but by hospital and bed numbers.”*

Mornings would arrive, marked only by the change of food and staff. I would sit wondering if I would see a doctor that day or not. I asked questions to the nurses, but was told with a robotic smile, to save them for the doctor.

Around the tenth day, I felt a change. I was seen by a young doctor, who for the first time explained some of the decisions that had been taken without me.

She explained the plan for my recovery and discharge for the first time in over a week. I started to feel more human again, more empowered and understood as an individual.

I continued to make steady progress until I was at the pre-agreed stage that was sufficient for me to be discharged. In the final days of my stay, I sat reflecting on the experience. I could not fault the clinical expertise of the staff I met. I felt grateful to be in receipt of care, without needing to fund the stay.

Yet I was left with an odd feeling of having experienced trauma. It occurred to me that I had been stripped of my individuality, not by individuals knowingly practicing this act but by an under maintained machine, that was built in a different age, A machine that had been stripped back to its core functions.

A machine that cannot be remodelled, for the enormity of the task is too great for most to undertake. A machine that despite having received new parts, was fundamentally constructed in a way that it could only produce the psychological output that I was now experiencing.

I said my goodbyes to any staff I saw on my way out, as the ward manager reached for the phone to have another bed 8 replace me. I had clinically recovered from my illness, but it would take time to recover from the experience.

Diabetes– a family affair

“If there’s one
thing I can share
from experience,
it’s that diabetes
is a family
disease and
should be treated

I can’t quite remember when I realised my mum had type 1 diabetes, but I always realised my mum was ‘different’ in some way. The way she became enraged and completely irrational sometimes when she had a hypoglycaemic attack.

The way she sometimes started to shake and sometimes fall down, and the figure who normally protected me suddenly seemed so helpless.

The way I always used to sneak sweets into my mum’s handbag, just in case IT happened.

My panic and fear I felt when I was alone, when I was alone with her and IT happened.

One day someone told me 'You better be careful how many sweets you eat, or you'll end up diabetic like your mum.' The fear that overtook me then overwhelmed me for months.

> *"She once yelled at me and made me stay in the backyard because my draw wasn't tidy."*

As I moved to my teens. I grew more resentful towards my mum because of the way she would shout and be unreasonable when IT happened. A few times it happened in front of my friends, which was just too embarrassing for words. She once yelled at me and made me stay in the backyard because my drawer wasn't tidy.

What infuriated me the most was when I tried to help her and give her sugar she sometimes refused to take it, spitting it out or getting angry at me. I was sure she was just making things difficult. Sometimes I lost it and started shouting back, which then made her cry and made me feel terribly guilty.

I felt so burdened by responsibility. I normally spent sleepless nights staring at her sleep scanning for signs of hypo.

Now aged 24, I look back with sadness at the anger I built up towards my mum. I wonder what will happen if my dad isn't around anymore, will she be able to live alone? What would it be like if she was alone all day? Who is going to be there to help when she starts shaking, slowing down? I'm the only one left in the family. I also want a career.

Looking back, I feel it would have been really helpful if a healthcare professional had taken the time to explore what I thought about my mum's diabetes and explained my misconceptions and fears.

> *"Who is going to be there to help when she starts shaking, slowing down? I'm the only one left in the family."*

If someone explained type 1 and type 2 differences that would've really prevented a lot of anxiety and fear. It could have prevented a lot of resentment I built towards my mum as a kid, maybe even provided me with more insight about how they could have helped my mum control her diabetes more effectively. I could have been guided a bit more, avoiding my many-a-rant about cards.

If there's one thing I can share from experience, it's that diabetes is a <u>family disease</u> and should be treated as one.

F4 Doctor

“Confirming death is a massive duty that has an air of ceremony that is usually straightforward.”

I don’t know when I picked up the habit. The family slowly leaves me to it.

“Hello Hazel.”

“I just need to listen to your heart, check your pulse and look into your eyes.”

She doesn’t reply.

The slow ticks of the clock whilst my stethoscope lies on her chest hearing…nothing. Okay, she has died.

I’ve done the checks.

“Goodbye Hazel.”

As I close her eyes, lingering in the moment half captivated by death and half out of respect.

The silence broken only by the clock.

Perhaps I talk to you for some slim hope you reply. I know your voice. But it’s gone. You’ve gone.

A tremendous duty sits on the 23-year-old F4 and, as I carefully document in my finest handwriting, I realise this is the last note you’ll have.

Jeesh. And you got me?

I sign the bottom faintly nodding in respect.
“Goodbye Hazel”

So, I talk to dead patients, right? (I am talking to sound more endearing than detached so I hope that comes across.)

Confirming death is a massive duty that has an air of ceremony that is usually straightforward. Facts.

Usually.

Once we were wrong.

She didn’t reply to my starter hello nor the quick check. But as I squeeze her hand she screams.

I’m not sure if you’ve spent time around many dead people, but the one thing is they are dead. She wasn’t.

And don’t ask how awkward the family chat after was.

[redacted]

Mother of a patient

[redacted]

"The Government talks about joining up health and social care, but they can't even get a pharmacy to talk to a surgery in the same building."

Yep. I took my son's prescription to the pharmacy yesterday. Women looks at it and says sorry, nurse has written it wrong. I'm like oh okay. So, what do you suggest. Take it back to the surgery.

So, I explained at the surgery. Receptionist says I bloody hate pharmacies. 45 mins sitting in the waiting room. Receptionist calls me and says, "here you go, I got it changed."

So, I'm supposed to be grateful that the nurse corrected the script she wrote wrong after waiting 45 mins.

But I still said thanks.

The thing is, we are brainwashed. If you were to make it private overnight, suddenly people would start kicking off saying it's not good enough.

They were both in the same building, the receptionist and the pharmacist. But they hate each other so much they send messages about patients rather than talking.

The Government talks about joining up health and social care, but they can't even get a pharmacy to talk to a surgery in the same building.

New radiographer

“I genuinely believe that some people I know would have had fewer than 20 words said to them a day, over an eight-hour shift.”

I started my radiotherapy university course pretty optimistic & hopeful, in that I was doing something good in order to help people, even if a lot of people have no idea what radiotherapy is. I had a long-term girlfriend and things were ticking over nicely.

Then the relationship broke up and that sucked. Then I had my 1st hospital placement in X. Compared to where I lived, X was really lacking in a lot of things I craved. There was no ‘alternative’ scene, and the staff in the department made the placement very difficult.

Most of the staff were younger than me. The age difference led to a weird dynamic. I was a student, yet older, putting me at the bottom rung of the ladder, which I don’t agree with, but I get.

My second thought is that I overthink why I had such a difficult placement.

But then, it really made me think how little effort most people put into socialising, and how bad people are at conversation. The staff at X were not good at including others, but they didn't consider themselves bad at socialising.

It's more that they find socialising easy with people who are like themselves. But if you aren't like these people, you'll have a hell of a time fitting in.

"This leaves me to conclude: most of the people at my placement, frankly would have bullied me if we'd been at school together."

I genuinely believe that some people I know would have had fewer than 20 words said to them a day, over an eight-hour shift. It's only because I'm ludicrously confident (with low self-esteem, but that's another essay/ monologue/ diary entry) that I managed to get involved in any conversations. It was a lot of effort.

They've never not had friends, and I can talk about stuff: Love Island, football, pop music, whatever. It was hard, and I don't think they ever tried to reciprocate with asking me about my likes.

This leaves me to conclude: most of the people at my placement, frankly would have bullied me if we'd been at school together. I even said to someone I used to work with that I think he would've bullied me if we were at school together. He laughed, agreed, and didn't think a second more about what that actually implied.

Every morning I'd say, "did you have a good night" to which the typical sentence was "yeah, alright". It would've taken practically nothing to say "yeah, alight. Your night?" Yet no one practically did this.

I'm sure they did this with each other, but very little effort was put into keeping up a pretence of a conversation for people not in the ingroup. This includes dozens of students every year.

So, I'm sure the staff I worked with patted themselves on the back as being "great to work with" and "gets on with everybody." But you don't get to say that about yourself if the only people you get on with are no different from yourselves.

The man with the metal plate in his head

"By day, this turreted building, with its spiral staircases, resembled a fairy-tale castle more than a hospital. At night, sometimes, it was a place of fantasy."

A hospital at night is a very different place from a hospital in the daytime.

In the late 1980s, I worked as a junior doctor in an old Victorian Hospital on the seafront. By day, this turreted building, with its spiral staircases, resembled a fairy-tale castle more than a hospital. At night, sometimes, it was a place of fantasy.

One particular night, I was called to the geriatric ward. 'The man with the metal plate in his head' was sneaking around the ward after 'lights out'. If he saw a nurse, he quickly hid behind a curtain.

The other patients grunted and snored in their sleep.

I gently pulled back the curtain to find a small, bald, elderly man, his eyes big like a frightened rabbit. He was barely recognisable from the pleasant, and completely lucid man I had seen during the day.

'He's trying to escape,' said the night nurse.

'Thinks he's in Auschwitz. He has done this every night he's been here.'

The man raised his arm. The night nurse nudged me to stand back. He wielded a kidney bowl at us, like a weapon. I could see the scar on his bald head where the metal plate had been inserted.

What must he have gone through all those years ago, I wondered?

> *"It is the night staff who witness and cope with these 'dark fairy-tale' episodes and often no one else ever knows they have happened."*

'He was in Auschwitz?' I said, shocked. 'How frightening for him to relive such a terrifying experience, over and over.'

The night nurse shook her head.

‘He wasn’t in Auschwitz. He spent the war in an English village, in Yorkshire,’ she said. ‘He was a historian, studied the war,’ she added, in a disparaging tone.

From his behaviour and appearance, this place was Auschwitz. It was vivid and real to him. He was hallucinating about something that had happened, but not to himself.

With much coaxing, the night nurse and I eventually persuaded him to go back to bed and he was soon asleep.

The two things: the metal plate in his head and him hallucinating about Auschwitz, had fitted together and I had imagined a different reality for him.

Anyone who is acutely unwell can become confused in hospital, particularly at night. It is the night staff who witness and cope with these ‘dark fairy-tale’ episodes and often no one else ever knows they have happened.

The metal plate in the man’s head was put in following an accident and nothing to do with the war, by the way.

About Kaleidoscope Health & Care

Kaleidoscope brings people together to improve health and care. We find new ways to overcome old barriers. We enable constructive conversations on difficult topics, using inspiring events to encourage clarity of purpose and rigorous problem-solving.

Our approach to collaboration is systematic, evidence-based and cost-effective. Our services enable you to collaborate with rigour. We provide everything required to support effective connections, conversations and networks, from design to management to events. We provide consultancy to help you resolve complex issues through practical, sustainable changes.

As a not-for-profit organisation, we seek to work with our clients in a spirit of kindness, trust, and openness. Our multi-disciplinary team includes clinicians, policy makers, managers, specialists in communication and digital technology, and more.

Could we help you to solve your problems? If so, get in touch, we'd love to hear from you.

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