Making the unbearable bearable: a relative’s tips to clinicians

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As most of us know, life feels rather different when it’s your ‘nearest and dearest’s’ health on the line, as opposed to your patient’s. It’s possibly even worse than if it were your own health at stake. I made this discovery again recently when someone close to me had a serious health problem. For a start, my anxiety levels have been through the roof, whereas as with patients, I am usually good at containing my, and my patients’, anxiety. How challenging it was to find myself in the relative’s position—the shoe on the other foot. Not only do you have to retain the appropriate boundaries to support the person you’re accompanying through the medical minefield, but you also need to ensure the patient remains the patient during their consultations. In my experience as a relative, this was not always easy.

When I’m the clinician, I usually find it helpful to know if my patients are doctors themselves or if they come in accompanied by a relative who is medically trained. Where they are, there’s a challenge—I try not to use jargon, but it helps to not use language which might be too simplistic. I don’t want to run the risk of my patient feeling patronised and I also don’t want any medical relatives to end up feeling they have to explain things to my patient after they’ve left the consulting room. My recent experiences when I attended hospital appointments as a medically trained family supporter left both of us sometimes feeling frustrated. It might have also frustrated the doctors we consulted. Next time I may decide not to reveal my medical status.

Becoming part of the great hospital machinery felt both a relief and frightening at the same time. A relief because once we were ‘in the system’ and the patient became a known entity, the waiting in limbo anxiety dissipated a bit. On the other hand, when I wanted to push and check-up that things hadn’t got lost, and referrals had been made, I had to learn to sit on my hands. The person I was supporting didn’t want to run the risk of upsetting anyone, so didn’t want me to start ‘interfering’. Other friends and relatives have learnt that ‘chasing up’ is often what’s required. I had to learn to wait longer than I wanted.

There’s also been a knock on effect on my own practice as a GP. Partly this has been a direct result of experiencing life on the other side, and partly because I realise giving patients ‘permission’ to take action themselves can be useful. It gives them permission to retain some control over what is otherwise a rather disempowering situation to be in. It’s a bit like urging patient to take time off work facilitated by a sick note. It helps patients to do what they need to do to look after themselves.

So now I take the time to give much clearer directions about how long things will take and how long it will be before appointments come through. I offer a reality check so that the ideal pathways, as described by the hospital healthcare professionals to my patients, are tempered by the reality of how long letters actually take to be typed up and sent out, and how long it is actually likely to be before a bed becomes available or a test report will be acted on.

It’s the small things that make the reality of a frightening health scare more bearable. Like telling the truth in concrete and trustworthy terms about time scales, rather than making vague statements. When a doctor had said ‘we’ll get this sorted in 3 months’ time’ but a hospital administrator says ‘actually it’ll be 6 months by the time the tests are back and a bed is found’, it’s far easier to cope with daily life and manage expectations. So without casting aspersions, I now find myself offering up reality checks to my patients. I think that’s almost as important as making the referral to the hospital in the first place.

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