Bridging the communication gap between health-care providers and patients' advocates

Sir,

'I asked a colleague to….advocate for me when things didn't make sense or when all the consultants involved didn't agree', wrote the parent of a seriously ill child (Gabbie, 2012), thereby highlighting the sense of powerlessness that patients (or parents of patients) experience when they are at their most vulnerable. The fact that the parent in this particular instance was, herself, an NHS consultant potentially magnifies the sense of powerlessness experienced by patients (or parents of patients) who are not health-care professionals.

This must have been the case in the instance of Alison Jackson (2009), who movingly wrote about her experience of exercising advocacy on behalf of her mother, who had been admitted to hospital with a fractured femur. In spite of starting off by acting with 'total respect towards the doctors and nurses' she became, over the course of time, 'appalled by the attitude of [the] consultant, who clearly regarded me as a nuisance and my mother as one of his less interesting cases'. Even when her mother's condition deteriorated and she wrote letters of complaint, she experienced frustratingly slow responses from the hospital, to the extent that 'Sometimes months would pass between one letter and the next' (Jackson, 2009).

Having an advocate mitigates the sense of vulnerability that compounds the distress attributable to the illness itself. In the context of the interface between primary and secondary care the patient's advocate is potentially a powerful ally to the GP, who is sometimes 'bombarded with letters that [make] no sense, full of contradictory diagnoses and plans' (Gabbie, 2012). In that scenario, a level-headed advocate might well be the one to cut across the confusion so as to identify what matters most to the patient on whose behalf he or she is acting. So as to optimize the role of the patient's advocate what we now need is an entitlement (enforceable by law, if need be) for the patient's advocate to receive timely responses to searching questions, and an entitlement, within reason, to an interview with the consultant in charge of the case.

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Gabbie S (2012) Lessons as a paediatrician-parent. *BMJ* **344**: e4392

Jackson A (2009) Written off by the National Health Service; A natural survivor's humiliating end. *Sunday Times News Review* **31 May**: 2

Sir,

I would like to thank Dr Jolobe for his interest and insight regarding my recent article, and for pointing out his views regarding advocacy.

As paediatricians we work in partnership with parents, expecting them to remain resident in hospital looking after their child in conjunction with the nursing staff. Particularly in regard to younger children who are unable to articulate their needs, parents are usually the best placed to know and interpret for them, alleviating some of the child's fears about the unfamiliar surroundings. This frees up the nurses and extended team to perform their job more efficiently and effectively.

At the other extreme of life it seems, from my observation, that we do not use families and carers to our best advantage. Many older patients may feel disorientated in hospital, and would appreciate having a relative accompany them. The carer would know the patient's usual routines and preferences, and help look after basic daily needs.

However, instead of expecting this, we actively seem to discourage it by enforcing rigid visiting hours, schedules and timetables. Perhaps embracing the relatives, or in those with no such individual, finding an advocate, would alleviate some of the pressure on the multidisciplinary team?

By empowering relatives more, we could relay information more effectively and have support in ensuring that patients understand to the best of their capacity, thus enabling them to make informed decisions about their care.

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If you would like to comment on any of the articles in *British Journal of Hospital Medicine,* or any issues which are relevant to our readers, please write in no more than 250 words to:

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