“Arranging care for my family laid bare the information gaps”

My immediate and wider family is getting older and I am increasingly being asked to help them make important decisions about care. As an experienced nurse, the terminology around care packages, care homes and carer allowance trips off my tongue. Nevertheless, when it comes to being the one to advise close family or organise care myself, this terminology is not so helpful, as a recent experience brought home to me.

I was asked by my sister-in-law how to go about arranging privately funded care, at home, for her cognitively impaired mother. She felt at a loss to go about this, despite being a diligent and caring daughter. She had been given a list of phone numbers and left to get on with it. Would I help, she asked? I agreed – and it proved to be a frustrating experience. The list provided by social services was not up to date: phone numbers were no longer valid, some agencies were not accepting new patients and others did not provide care in her geographical area. After eight wasted calls, it was a relief to get through to an agency that could help us.

As nurses, what can you do to help your patients, carers and relatives in a similar situation? First, do not rely on social services to have relayed all of the necessary information regarding the process of arranging private care – they will only give patients a list. Try to approach your advice as if it were for your parent. Explain the process; for example, initially a patient-focused needs assessment and risk assessment of their home will be carried out by the care agency before they agree to provide the care needed.

Most importantly, urge patients or their relatives to be prepared before making such calls. Advise them to consider in advance what they need support with. The agency will also need to know a little bit about the person, access, and their home circumstances or special needs. For example, on behalf of my sister-in-law, I asked the agency if it employed any carers with experience of caring for someone with mild cognitive impairment. Finally, it is worth asking if a meeting can be arranged to introduce carers to the patient before their first visit to deliver care. Forewarn that this process doesn’t happen instantly – it takes time to organise.

You might feel that giving advice on carers is solely the job of social services. It is not. If patients are responsible for privately funding their care, they will also be responsible for, and required to, navigate the labyrinth of services to arrange care, together with any issues that arise. While numerous factsheets are available, such as from Age UK, about legal and financial aspects of care, I found the simple information about how to approach agencies – which was crucial to relatives – was missing at a time when it was most needed.

Remember, your patients or their relatives are buying a service – one that may continue for many years. NT

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How patients can improve healthcare

There’s a lot of talk about involving patients in designing aspects of healthcare. But achieving this can be far from straightforward, particularly in acute care; patients’ views can be gathered through evaluations, but how do you involve them in long-term service design projects without overburdening them?

Our innovation article on page 16 reports on experience-based co-design, a method developed by the Point of Care Foundation to capture patients’ experiences in a way that can be used to improve the services they receive.

Interviews with patients are filmed to give staff insight into patients’ views. The approach also involves patients and staff working together to design and make improvements to their services, rather than simply taking patients’ views but giving them no influence over the changes made.

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