Patient comment: delivering person-centred care in long-term conditions

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As patients, we also have a responsibility for looking at new ways of working with our clinicians. Person-centred care for long-term conditions (LTCs) offers us an excellent opportunity. Around 40% of the UK population have LTCs, accounting for 70% of inpatient bed days, 78% of GP appointments and 70% of health and social care spending. The figures are stark.

Multimorbidity is on the increase. Most people with multimorbidity are younger than 65 and, in the 65–84 age group, 65% of people have two or more conditions. These figures are on the increase.

Limited resources and economic arguments concentrate the mind and present a challenge to us all. How, as patients, can we do things better? How, as clinicians and healthcare specialists, can you support us in different ways?

Dr Eaton¹ elucidates ways in which patients and doctors can work more effectively together to manage LTCs. The phrase, ‘the clinician could be considered as the expert around the disease with the person as the expert on their lives’, rings true. And, ‘holistic care – viewing the person as a whole rather than a disease or body part’, is something every patient applauds.

Fortunately, I have had good health and no experience of LTCs. However, for the last 18 months I’ve had polymyalgia rheumatica (PMR) and the concomitant effect of steroids have introduced me to the complexities in the health system: rheumatologists, osteoporosis consultants, orthopaedic surgeons, X-ray departments and MRI scans plus the usual plethora of blood tests and diagnostic tools. I imagine my reactions were similar to those of a person newly diagnosed with an LTC, and I read this article through my personal prism. In addition, with my professional hat on, I applied my communication consultant and journalist’s eye.

Once the shock of a diagnosis has been accepted, alongside the expectation of high-quality medical care, there is the wholly new aspect of ‘living with it’. The challenge is ensuring that what is discussed and offered is centred round what the individual considers important and what they want to achieve. In my case (apart from restoration of health), it was to resume scuba diving. This is still in my sights and my doctors know this.

Communication is key to delivering person-centred care. Figures show that people with LTCs spend only a few hours each

year with their clinicians and healthcare services and 99% of their time managing their conditions. It is crucial that valuable time with medical experts is used efficiently and constructively.

People with LTCs are often ‘on their own’ struggling with daily life. It can be a difficult, frightening and lonely place. If they are going to find the strength to self-manage their health effectively, they need to have knowledge, skills and confidence to work with clinicians and follow their personal care plan.

Knowing they have an ‘annual review’ is a reassuring factor. If the patient understands this is part of their long-term care plan, it can act as an incentive. A review provides an opportunity for two-way conversation about future hopes, action plans and goal setting. It’s also a conversation in which they can expect, if appropriate, to be challenged. Ideally, there should be four elements to this review:

1. Preparation
2. Discussion
3. Review
4. Documentation

Preparation

It is in the best interests of everyone for the patient to be ‘prepared’ for the review. The practice of sending results to people before appointments is one to be encouraged. For patients, who are feeling vulnerable, this allows them ‘thinking time’ prior to the consultation. They can consider their options, preferences and highlight possible problems. This helps to overcome any shades of passivity!

Discussion

This might include tailored information, advice regarding resources, education, skills training, access to new technologies, and peer or community support. Evidence shows that people who are ‘involved’ and feel they are active in their health management are more likely to have better health outcomes and care experiences. The good news is that this in turn leads to better use of resources.

Review

Ideally, an agreement is reached on what has been decided, a date fixed for the next review, and a contact found for any necessary support in the interim.

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Documentation

Agreed outcomes are summarised and put into the new personal care plan. This is the patient's, is recorded in their clinical records and shared with other relevant healthcare professionals.

One major challenge, not to be overlooked, is ensuring that people with lower motivation, poor health literacy or those in difficult social circumstances receive the individual support they need. Sometimes these barriers can be overcome with a different style of communication from the clinician. Here, I would make a plea that clinicians always use simple and straightforward language. As Dr Eaton highlights, it is all too easy to resort to confusing medical jargon in reports and in discussions with patients.

Good communication is fundamental to shared decision making and central to delivering care to people with LTCs. The last decade has seen remarkable strides on this front but there is still room for improvement. A good clinician encourages people to tell their, often complex, story. He uses a variety of communication skills: open questions, paraphrasing and summarising. He listens and hears, expresses empathy and finally checks with the patient that he has heard their story correctly.

All patients deserve person-centred care, and academic and exemplar programmes show evidence of the benefits of this approach: clinicians report better patient relationships and positive outcomes; patients gain confidence and are able to take responsibility and engage more fully in their cycles of care. In addition, improvements in the use of resources lead to consequent lower healthcare costs. This is something none of us can afford to ignore.

Dr Eaton states that "The underpinning principles require a different mindset for clinicians and support for people ... to participate in their health more effectively."

This sounds like a partnership that we, as patients, fully endorse. ■

Reference

1. Eaton S. Delivering person-centred care in long-term conditions. *Future Hospital Journal* 2016;3:128–131.

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