The National Health Service is changing; patient involvement has become far more a part of everyday life. The message about what patients and their carers want is clear. They want to be respected and fully involved in discussing, agreeing and providing their treatment and care plan. They also want professionals, agencies and specialists to work together.

Involving patients and their carers has to happen at all levels — it is no good having patients on boards or involved in staff recruitment if, at an individual level, they do not feel consulted and fully involved in their own treatment. It is important to recognise and support family carers not only as a principle but also because families provide the bulk of health and social care. If we do not support and engage with them, we have not only lost an opportunity but also may find treatment and care plans inadvertently undermined. Most importantly, patients want the best treatment possible — but “best” on their terms, taking into account personal preferences on issues like pain and the way they live their lives. The challenge is for professionals to fit the patient, to make the service patient-shaped, remembering that patients are not all the same shape.

CHALLENGES

From the patient’s perspective there are some challenges for pharmacy. Patient organisations still report that too few patients receive information about their medicines that they can understand and use, in particular about possible side effects.

A hospital discharge project that I have been involved in identifies a mixed picture. On the one hand, there is a more patient-centred approach, where pharmacists work on the ward and provide a longer-term prescription so there is no delay to discharge. On the other there are examples of people waiting several hours for prescriptions before they can go home. We must not underestimate the impact on patients of those waits. Discharge is not just leaving the ward — it is going home. For many patients and their carers it is going home to a changed situation, involving anxiety and confusion for both parties. Minimising the additional anxiety caused by delay maximises the health outcomes. A patient-shaped service recognises that what to the professional is a number of points on a treatment pathway with a clear distinction between community and hospital, to patients is just one blurred aspect of a much bigger picture — their lives.

In the patient and carer movement we talk about empowerment: our jargon for patients and carers feeling in control of the situation by asking questions and using information. It is not about a stereotype of the unjustifiably angry and difficult patient — generally such people are those who have been disempowered. It is about patients feeling their perspective is listened to and understood — these patients are better able to take a full role in their own recovery.

Researching for a recent presentation led me to discover that “empowerment” has its counterpart in pharmacy practice — concordance. This concept fits into the modernisation agenda well. It places the patient, not the professional, at the centre. It emphasises a holistic approach because medicine-taking is as important, if not more so, than medicine-prescribing. This approach is only possible within a patient-shaped service that listens to, engages with, and tries to understand patients and the factors affecting their desire and ability to understand and follow a regimen. This flow of information from patient and carer to professional is more likely to lead to a flow of adequate and appropriate information and advice from professional to carer.

Concordance emphasises that in order for medicine-taking to be successful the professional must understand the patient’s experience and attitude to the disease and treatment; the patient must know how and why prescribed medicines should be used, and “know” in a long-term, thorough way, not just to have barely understood a string of words only to forget them. It may be important to set aside preconceptions of “common sense”, because no sense is truly common to everyone involved. Professionals may find it difficult to comprehend why patients cannot understand the difference between their prescription before inpatient treatment and after, because it is “common sense”. But then patients would say a system lacks common sense, too, if records held by general practitioners are not automatically and adequately updated for changes of prescriptions during a hospital stay. It also appears “common sense” to ensure people leave hospital with 14 days’ worth of medicines — how can a recuperating patient with only a hard-pressed family carer visit a pharmacy shortly after discharge?

Changes in professional practice and demarcations are essential if the treatment and service is to suit the patient rather than the patient suit the treatment and service. An important step towards patient-shaped services is, of course, allowing patients to help shape the service. Patients’ and carers’ voices need to be included in planning groups — innovation is not always in itself a good thing, and we need to keep the patient at centre-stage. However, examples I have come across of ward-based pharmacy, of self-administering schemes and of patients using their own drugs, are all examples of improvement from the patient’s perspective.

Not all patients have access to the same service in the first place. Modernisation has to be about recognising and overcoming inequality issues, including patients whose first language is not English and whose experience of health care is still one of disadvantage. This means working carefully with representative groups to find ways of understanding and overcoming problems. Information is not only passed from health care professional to patient; it is also passed within and through communities and we need to work creatively with that.

NEW WAYS OF THINKING

Patient and carer involvement can lead to new ways of thinking. A year ago I was involved in a conference for older people and their carers about the National Service Framework for Older People. Carers were clear that they wanted to be seen as partners in care and believed, in particular, that they had a clear contribution to medicines management and falls avoidance. This idea was taken by carers into planning groups and led to Bristol South and West Primary Care Trust working with carers to develop a leaflet aimed at them, from their viewpoint. I know from comments at carers groups that this has impacted on the ability of carers and patients to understand and use their medicines. It sends a clear signal that carers and patients are valued.

There are many other such examples. However, sometimes involvement does not work well, because professionals do not understand how to make meetings user-friendly, or how to work with community organisations to support and involve people. A sole patient representative who has no outside support may find it difficult to push for change through a formal committee structure. Patient involvement has its own expertise, but modernisation means that good practice is increasingly being recognised and developed, through Patient Advice and Liaison Service schemes, through PCTs and through partnership with patient and carer organisations.

In conclusion, from a patient perspective, modernisation is changing things and leading to better health outcomes. Many of the structural changes are in place but for the individual patient the proof will come with an improved experience. It comes down to imagination, seeing the world from the patient’s viewpoint and communication. It means really listening to patients.

Carol Watson says that changes in professional practice are essential if treatments and services are to be patient-centred.

Carol Watson is chief executive of Bristol and South Glos Carers Centre.