Communication in health and social care

Participating in power

Ann Brechin
Roger Priestly was diagnosed with multiple sclerosis twenty-five years ago. Soon after the diagnosis, Roger became increasingly effected by the motor-inhibiting features of the disease, and this resulted in him needing to access additional support and services. Roger describes his early experiences.

Roger Priestly
When I was first ill, it was a case of asking and asking and asking, until you found out what was available, and even then, there were occasions on which I didn't find out things, until after the time at which I could first have used them. The gateway to health and social service provision is generally regarded by the authorities as the family doctor. In fact, my problem, and I think this is a fairly common problem is, that the family doctor knows very little about the facilities which are available. The trouble is therefore, you've got to do so much of the work of finding the right direction yourself. In fact, your general practitioner will probably have very little knowledge of the local support groups, or the national support groups, or the sources of help in terms of mechanical aids, and support through social services. So you've really got to try and make your own contacts with the sub-sections of the health assistance area.

Ann Brechin
The difficulties associated with MS, and the unpredictability and complexity of this degenerative condition, have resulted in Roger developing his own expertise. Here, he tells us about how he has become his own advocate.

Roger Priestly
You've got to duck and dodge, you've got to be a bit of a Del Boy, in hopefully the nicest way! When accessing the various services, I personally found that it was necessary to adopt a very carefully decided attitude with each person or service you encountered. Often you will find, that if you are polite, not obsequious, as long as you are firm in your understanding of what your wants are, or of what advice you need from them, then they are only too happy to help you, and they like to deal with people who are understanding of their problems, who are polite and who are friendly and happy.

The average professional provider of services, comes across a lot of very grumpy, very bad-tempered people, and this is perfectly understandable, because I am tempted to be grumpy and bad-tempered. But the one thing I have learnt over twenty-five years, is the advantage of being able to be humble, to have humility, but, underneath that, to have a steely determination. It is therefore necessary not to take the first answer you are given, but to work out whether that answer is in fact the one that you want, and if the answer is ‘no, that service is not available’ then ask and ask again, and be prepared to be determined to demand the service – but always with politeness, and this is the great advantage of a background like mine, because I worked in an office, I wrote letters as part of my job for thirty years, and I was used to talking to people on the telephone and face-to-face, and not being automatically cowed by, or ready to accept at face-value, what they said to me.

Ann Brechin
So the skills that Roger highlights are partly skills he transferred from his job. He's learnt to modify these skills with what he calls ‘humility’. He offers an example of how he's been able to access the resources that he needs.

Roger Priestly

If you can find out what you want, it is best, often I have found, not to go to the GP and say, ‘could I do this?’, or ‘could I do that?’, because that demands that they spend more than the ten minutes they've got allowed for your appointment. But if you can write a letter to them saying, you understand that X or Y is available, but that you need their introduction, and it is even better if you can say, it would be nice, general practitioner, if you could write to X or Y perhaps along the lines of the attached draft letter. You will often find, the doctor is so relieved to be saved the work, that he will sign your draft letter, and that saves you a problem, it saves him a problem, but it does mean that you have got to be prepared to work at your writing skills, and equally, you've got to be prepared, in conversations, not to accept the answer which is first given to you.

Never forget that for most of the financial assistance which is available to people with long-term invalidity, there is an appeal procedure, and very often, anything up to fifty percent of appeals succeed. So do not be afraid to appeal, and appeal again. If you go high enough, you can get your voice heard. You might not achieve what you want, but you often do get better satisfaction. But it can be a long and hard road.

Ann Brechin
It sounds as if Roger has had to work hard to convince professionals like his GP that he understands his own needs.

Roger Priestly
There does tend to be an imbalance of power between the providers of services and care, and the users of service and care. The providers of service and care, always think they know best, and this is understandable, because in many cases, they are dealing with patients who really do not know what they want or need, and do not understand the wants and needs, particularly the needs, of the service-providers.

Ann Brechin
Roger goes on to explain how things can be improved, when you build personal relationships with service providers.

Roger Priestly
There's nothing I have found that irritates the medical profession, of all kinds, than constant telephone requests for help, for assistance, for attention. It is better if you can establish some personal relationship with the person, and better if you can avoid too regular an attempt to enlist help with your perceived needs. Your perceived needs are often not real needs, they are needs which you have because you feel lonely, or you feel just against, the ‘why me?’ syndrome is a very easily understood, but absolutely purposeless, syndrome. It is no use saying ‘why me?’. It's like saying, ‘why does the sun rise in the east and set in the west?’ The doctor can't say ‘why you’, the nurse can't say ‘why you’, so for goodness sake don't keep on at them, effectively worrying away about your condition, your problems.

Ann Brechin
The people who care for him at home, provide an essential service, as Roger explains.

Roger Priestly
The main source of assistance while you're in normal domestic surroundings, are the district nursing service, and in my case, my district nursing service have been particularly useful to me in directing me to, occupational therapists, and as an example of this, the wheelchair service. I need a wheelchair, because I cannot walk or weight-bear, and my arms equally, are now after twenty-five years, lacking in any independent movement, apart from some small movement in my left hand. You need therefore to have a wheelchair adapted to your particular abilities or disabilities. In my case, because I don't have control of my hands, I cannot use the usual joystick control which electric wheelchairs use, so I have a wheelchair which is adapted for use with suck-blow controls, which means that I can move my wheelchair by means of sucking and blowing, and it means that I can get around a house on one floor.

Ann Brechin

Certainly, Roger's physical disability is severe, and the home care services are essential to his ability to stay at home. Roger tells us about the nature of the relationship with the nursing and social carers, and its reciprocity.

Roger Priestly
I have found that the district nursing services, that social service carers, enjoy coming to help me because, they know that they can always laugh at me, they can always make a joke at my expense, and I do not get upset with it. That I am always prepared to use equipment which is necessary, to save them from undue strain, from undue pressure, and because of this, the providers tend to be much more helpful, and they will often, go well beyond the normal limit of the services that they are obliged to provide you with. My personal experience is, that I get very, very well looked after by the district nursing team, which has charge of my care, and the social services carers, because I carefully tailor, to make sure that I do not put strain, which I can avoid, on that relationship. But equally, do not accept a carer or a nurse who will look down on you, because of your degree of invalidity. Make sure that you are assertive enough to let them know that you are not a vegetable, but the happier you can be, the pleasanter you can be, by and large, the better the service you will get from them.

Ann Brechin
Roger's relationship with his paid professionals carers does not revolve around his disability. There's also a shared experience that comes from living in the same town. Roger describes how he manages this relationship.

Roger Priestly
I have found that in obtaining services, and in my relationship with the providers of services, it is more helpful, if you can widen the relationship between yourself, as the service-user, and the service-providers, away from the immediate narrow boundaries of your particular need for care. It is helpful in my case for example, that having lived in the same town, having children going to local schools, that often with district nurses, and with other professional service providers, that I have relationships, and joint knowledge of things happening in the town, of children and schools, and this gives you a rather wider area to talk about than your particular problem, and it makes relationships rather easier. This does not entitle you to know about their other professional relationships with their other clients. Equally, you have to be conscious that you are at a level of relationship with them, which might cause you to expect more attention, more care, than they are able to, or authorised to, provide. You must not push the boundaries, because of a personal relationship.

Ann Brechin
Finally, Roger explains how he's had to learn to cope with the intimate side of personal care.

Roger Priestly
I am afraid, that when you become ill, to the point at which you are disabled, then you have got to be prepared to abandon embarrassment. I don't know how many times I have been exposed naked to the views of people I don't know, and even more, to the view of people I do know. But one thing I do try to do is to avoid getting my family involved in my personal physical care, apart from areas such as feeding – my wife feeds me, because I can't feed myself. But, as much as possible, try and avoid placing on them, the embarrassment of looking after you. Do not, in my view, expect your close family to provide you with the sort of personal service that best comes from professionals. If you are incontinent, and this is a common feature of many illnesses, you must be prepared to accept, the services of the nursing profession, the caring profession. You have got to be prepared to be exposed to the most apparently undignified situations, and undignified intrusions on your personal space, but if you don't, then you will not manage to cope with life, you will not manage to accommodate yourself to life, and you will shorten your pleasant relationships with people, and also, if you're not careful, you will shorten your own life.