

Patient participation in palliative care

A Voice for the Voiceless

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Preface

Developing a creative alliance with the *person* beyond the *patient* is a core tenet of effective palliative care. This book explores the meaning, purposes, value and delivery of person-centered palliative care. In creating St Christopher's Hospice in 1967 and thereby launching the modern hospice movement, Dame Cicely Saunders drew on the strength of the voices of so many who had until then remained voiceless, the dying. As Professor John Hinton (1967) observed at around the same time 'the dissatisfied dead cannot noise abroad the negligence they have experienced'. Saunders' hundreds of meticulously documented tape recordings of patients discussing their individual experiences made sure that this situation did not continue. Paradoxically although many of today's governments themselves now issue demands for user involvement in healthcare, as settings multiply along with their associated experts, treatments and technologies, the need for a better understanding of how to develop active partnerships between service users and professionals has never been greater. This book examines progress thus far and attempts to delineate future challenges.

The book places the modern hospice movement in a context characterized by the need for instant information, a better-informed public more able to criticize and with greater expectations of choice and solutions, a multi-cultural society and a tension between the roles and rights of the traditional specialist expert and the individual user. All of these factors interact within an expectation that users will be involved actively. Part 1 considers the political and philosophical evolution of current developments in user involvement in palliative care, continuing by addressing specific key areas such as quality, education, the role of culture and bereavement care. In Part 2 various professionals give a perspective of how the particular value base, knowledge and practice of their profession attempts to maximize person-centred and user-involved work.

There is sometimes confusion over the use of different terms such as person centred and user involvement. Part of the richness of palliative care

is that these concepts are in evolution. We are using person centred to relate to the individual in the holistic model of total care. Being person centred is a dynamic two-way process. Indeed patients and professional staff repeatedly testify to how much they receive from one another. User involvement is concerned with the means of achieving a person-centred service and the meaningful participation and consultation of service users—the people who are the patients, clients and carers of palliative care—in the planning, evolution, evaluation and education of services from their own unique perspective.

Professionals in palliative care settings often somewhat glibly state that the patient is, or should be, at the centre of care. There have been few attempts to examine how to keep them there without professional needs and protocols crowding them out. This book asks how we listen and why we listen. As Relf reminds us in her chapter, listening is not a neutral activity and we need to develop a much more sophisticated understanding of the differing filters of conceptual frameworks that can get in the way of effective dialogue between service user and service deliverer. Having listened we must also seek appropriate ways to act upon what we hear, supporting and promoting the voices that emerge.

Small and Bradburn pursue this theme, exploring how to develop alliances that deal with power imbalances and that ensure that users become not just commentators on services but actively involved in their development and implementation. They examine the best structures to ensure that users can organize to put relevant pressure on healthcare planners. Napier continues this examination by reminding us that very ill people are not sovereign consumers able to pick and choose freely in the market place. Their choices are inevitably limited and they do need the support of experts, particularly since most users of palliative care services are unaware of what would constitute a good service until they actually need it. Gilbert sounds a warning about the dangers of suppressing the shared professional values of healthcare workers, which must remain a fundamental part of what is offered to patients and their families. Speck, Davie and Noble provide a reminder that professionals can be too quick to classify service users as vulnerable and that many of them readily see the personal benefits of participating in research and education, provided explicit conditions of support are met.

Finally, there are of course, the ongoing challenges that palliative care faces in reaching out vigorously to advocate for those excluded from good care; the disenfranchised, disadvantaged and discriminated against. When we are working with patient, family and friendship networks, whose choice

matters most? How do we make sure that those with rare conditions or where death comes very quickly, or those who leave no one grieving for them, or who have only professional carers in institutions, also have their voices heard? How do we ensure that our efforts to find representative voices do not diminish important differences in class, gender and ethnicity?

Small remarks that there is 'an impetus for innovation that comes from the memory of things done badly, a perception that things can be done better, an idea of how to achieve this and a picture of what a better system could look like.' The voices of users, patients, carers and professional stakeholders are vital to the process of understanding and achieving shared and relevant quality agendas. The end product of user involvement and person-centred care is to offer the best possible experience in palliative care. As the thoughts of the service users that end this book demonstrate, both done well can enhance energy, choice and the value of individuals everywhere.

We thank all who have contributed to the ongoing debate about the nature of person-centred palliative care and the part user involvement plays within it. In particular, thanks to Jan Stone for her painstaking typing of repeated drafts of the text and to the numerous people with whom we have worked, patients, carers and colleagues, who continue to inspire and challenge us.

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Part 1

The role of the patient in palliative care

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A voice for the voiceless

Dame Cicely Saunders

Nurses, social workers, doctors and other professionals hear different questions and comments from patients. As they begin to fear that their illness is not responding to treatment, people will sometimes test staff they know cannot give them answers. These staff can only suggest that the question be put to those who, certainly in the past, may have been seen as guardians of an unpleasant truth. No one *wants* bad news but uncertainty and constantly dashed hopes are often harder to bear. A much admired Ward Sister, referring to a demanding patient, said to her staff one evening 'That man needs to talk' and went to open an exchange which manifestly relieved much overwhelming and previously unaddressed anxiety. This was indeed bold when, during those War years, so little information was given. Because of that restriction, a junior nurse was often treated with an easy camaraderie by patients and who knows how much ease that gave to both parties. Having no responsibility can be frustrating but can also avoid much tension and lead to a relaxed banter. Memories of those pre-antibiotic days when pharmacopeia was limited and when there was nothing to offer but meticulous nursing and the often intimate relationships that developed, are an important part of my own therapeutic journey (Saunders 1996).

Social workers were among the first to keep detailed observations of the inadequate provision available for end-of-life care. One seminal article from Boston was published in the *New England Journal of Medicine* in 1945 (Abrams *et al.* 1945). Four social workers plotted the course of 200 patients and noted a serious gap in communication as well as in service provision. Further studies by social workers illustrated the journeys they shared with their dying patients and their families as they tried to help them discover their own strengths (Saunders 2001).

It was as a Lady Almoner (medical social worker) that I met David Tasma from the Warsaw Ghetto, a patient in the large teaching hospital I was

working in during the summer of 1947. He could only be offered palliative surgery and, knowing that he faced a relapse, I kept in touch with him after his discharge and during his admission to another hospital for terminal care some months later. During the following two months I was virtually his only visitor and, in an increasingly deeper relationship, discussed with him the possibility of founding somewhere more suited to his need (he was then a patient on a busy surgical ward of some 60 patients). This need was not only for better symptom control, but also for an opportunity to come to a sense of fulfilment of a solitary life, ending as it was at the age of 40 in a foreign land. Speaking of his legacy to me of £500 he said, 'I will become a window in your Home.' He thus became the founder of the modern hospice and palliative care movement. On another occasion he asked 'for something to comfort me.' I repeated several psalms to him that I knew by heart and then suggested I might read to him. 'No. I only want what is in your mind and in your heart.' He had become an agnostic, he had told me earlier, but added 'I like you too much to say I believe just because I like you.' Before he died, he told his most understanding Ward Sister that he had come back to the faith of his fathers (his grandfather had been a Rabbi). After his death I felt a strong assurance that he had made a quiet journey to peace in the freedom of the spirit.

His phrases, challenging us to openness, to the match of scientific learning with a relationship of person to person and to that essential inner spiritual freedom, have maintained their place as the founding myth of a now worldwide movement. Such principles have been interpreted and practised in very different cultures and resources.

Patients continue to present us with challenges. Three years after the death of David Tasma, I was working in an early unit for patients with far advanced cancer as a volunteer nurse. It was here that I first observed the effectiveness of regular four hourly giving of oral morphine, established there some years previously by the nursing team. Following the advice of Mr Norman Barrett, the thoracic surgeon for whom I was working at the time, I went on, three years later, to read medicine to learn more about pain.

Whilst working at St Joseph's Hospice in East London with the Irish Sisters of Charity, where I spent seven years on an extensive study on *The Nature and Management of Terminal Pain* (Saunders 1967), I began making tape recordings of many of my patients. The following was presented as part of the annual report of the teaching hospital run by the Sisters in Dublin. I was probably the only Protestant on the staff but had their eager co-operation in the introduction of four hourly opiate

oral medication. The patient, Mrs H, was interviewed a week after her admission:

What was the pain like before you came here?

Well, it was ever so bad. It used to be just like a vice gripping my spine—going like that and would then let go again—and I didn't get my injections regularly—they use to leave me as long as they could and if I asked for them sometimes, they use to say, 'No, wait a bit longer.' They didn't want me to rely on the drugs that were there, you see. They used to try and see how long I could go without an injection ... I used to be pouring with sweat, you know, because of pain ... couldn't speak to anybody I was in such pain ... and I was having crying fits—I mean I haven't cried, I think I've only cried once since I've been here, that's all—well over a week. And I was crying every other day at the other hospital. I was very depressed, ever so depressed; but I'm not at all depressed here, not like I was there.

Since you've been here and I put you on regular injections, what's the difference?

Well, the biggest difference is, of course, this feeling so calm. I don't get worked up, I don't get upset, I don't cry, I don't get very, very depressed—because I was getting awfully depressed, you know, really black thoughts were going through me mind, and no matter how kind people were, and people were ever so kind, nothing would console me you see. But since I've been here I feel more hopeful as well. I feel that I'm getting better and I'm going to go home. Whereas there I didn't, you see. And no-one would tell me that I was either. I kept asking various people, and nobody would give me a clear answer. But since I've been here, I don't feel that desperate need to ask 'Am I going to get better, am I ...' I mean, I want to know.

But you don't feel that desperation?

No, I don't feel that hopelessness.

A much shorter recording was used as part of a Good Cause Appeal on BBC Radio in 1964. Mrs M said:

Before I came here the pain was so bad that if anyone came into the room I would say, 'Please don't touch me, please don't come near me.' But now it seems as if something has come between me and the pain, it feels like a nice thing wrapped round me.

That same year, I quoted in an article in the *Nursing Times* (Saunders 1964) the answer to the simple question, 'Tell me about your pain.' Mrs T had said,

Well doctor, the pain began in my back but now it seems that all of me is wrong.

She gave a description of several symptoms and then went on to say,

My husband and son were marvellous but they were at work and they would have had to stay off work and lose their money. I could have cried for the pills and injections but I knew I mustn't. Everything seemed to be against me and nobody seemed to understand.

She then paused before she said,

But it is so wonderful to begin to feel safe again.

As I wrote then and many times since, what was being talked about was 'total pain'—'all of me is wrong.' Without any further questioning she had talked of her mental as well as her physical distress, of her social problems and of her spiritual need for security. Then, as now, I know that listening to a patient's own tale of their troubles can be therapeutic in itself. As another patient said, 'It seemed the pain went with me talking.'

One exchange with a particularly well known patient has been used many times in discussions and lectures about the responsibility of giving bad news. Mr A.M. asked directly, 'Am I going to die?'. I replied equally directly with a simple 'Yes' because anything other than such honesty would have been an insult to his dignity. 'Was it hard for you to tell me that?' he asked. When I replied, 'Well, yes, it was' he said, 'Thank you, it is hard to be told but it is hard to tell too. Thank you'. Such conversations should be hard. We should recognize that we are committing our patient to an exacting journey and either to accompanying him ourselves or making sure that other support is available.

Such stories, accompanied by the many photographs I took, were presented in many lectures alongside the increasing volume of statistics showing the lack of tolerance and drug dependence that the regime and the whole hospice milieu was achieving. There were 900 records analysed when this was part of a *Royal Society of Medicine Symposium* (Saunders 1963). I remember a physician remarking then, 'I always thought regular giving worked but didn't know why.' Patients' voices had provided the answer.

Enabling professionals and grant-giving charities to hear these powerful statements led to the opening of the first modern research and teaching hospice, St Christopher's, in 1967. By then, however, the 'movement' (still unnamed) had made considerable progress (Clark 1998). Other patients and frustrated, often despairing, staff had begun to join a mounting interest in a fresh look at end-of-life care. Systematic studies in the 1950s gave necessary breadth to the detailed stories of St Joseph's 1100 patients (Saunders 1967).

From the beginning, St Christopher's had a small number of long-stay patients. Gradually these beds became specialized in the care of patients with motor neurone disease. One such patient, looking at another who was more disabled, said to me 'If I ever get like that man I shall want to do something to myself.' But when he, too, reached that place he said, 'I can't see round the next bend but I know it will be all right.' He went on to suggest a title for a lecture to me. 'This is a "bringing together illness" patient with staff, patient with family.' I asked 'Do you always see it as that?' 'Yes' he replied, with his Police Sergeant look, 'and I'm a trained observer.'

Another patient with motor neurone disease, a former medical secretary, wrote to her brother not long before her death on being the wounded Jew in the parable of the good samaritan instead of the good samaritan himself. These are to me powerful answers to the desperate dependence of increasing paralysis, which people discover if they have supportive care.

Also, of course, only patients themselves can teach us of a patient's own responsibilities. Paula, a still glamorous blond, said to a nurse 'I try not to moan, I just don't want people to remember me as a nasty person.' On her last night, after months of keeping her own counsel on such matters, she suddenly began talking to her night nurse about any life beyond death and asked her what she believed. The nurse was able to say something very simple. Paula replied, 'I can't say I believe now, not like that, but would it be all right if I just said that I hoped?' When she said goodbye to the nurse in the morning, she took off the false eyelashes she wore day and night—'You can put those away, I won't need them any more.' It was as if she was saying, 'Well, I'm me and it's all right.'

Mr T H wrote an article entitled 'Patiently speaking' for the *Nursing Times* (Holden 1980) with the use of one of the early communicators, a Possum apparatus. In it he gives many hints to those who care for patients with motor neurone and other severely disabling diseases:

It seems illogical that the only people in hospital who have no training for the occupation are the patients. Would it not make sense to accept that anyone landed in a new and strange environment needs some sort of instruction to help him to fit in and take advantage of the enormous wealth of kindness, generosity and good will, readily given by all staff?

What the patient has to understand is that although these are rather special people they are people with normal human feelings and responses. They do a very demanding job, work lousy hours for scandalous wages and have their share of trials and tribulations in their private lives. All patients are grateful for the care they get but many do not realise how much their own behaviour can contribute to their and everyone's well-being.

When I suggest that patients could be taught I do not envisage anything overt but judicious, friendly chats could achieve a great deal. Every patient has the right to know the what, why and wherefore about everything from normal routine to his personal treatment and condition. No patient has the right to be constantly complaining, ill mannered, discourteous, jealous, selfish, thoughtless, all the petty things which make *us* so unattractive and will be counter-productive in our relationships with staff, relatives and everyone else. The basic lesson is simple, the greatest act of self-interest is to be as unselfish as possible.

Little needs to be added to these voices, which echo in my memory and which have inspired so many people around the world to listen in their turn. The patients are the founders of the now accepted development of the speciality of palliative medicine.

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