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How to keep the customer satisfied*

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I wear two different hats – one as a health professional and one as a consumer. I spent 35 years in the health care business, in the nursing service, nursing management and, for the last 10 years, at the Royal College of Nursing – in the real politik! I retired on health grounds in 1989 – it's strange how we say "health" when we mean "ill health." It seems to have become politically correct. Have you noticed that psychiatric units have become mental health units? Political correctness is hitting health in a big way now, though it doesn't make the problems go away. The fact is that I have probably learned more about some of the vital aspects of health care in the past four years than I did in the previous 35. It is true what they say – there is nothing like first hand experience.

We all remember patients who inspired us and whom we admired. They usually feature early in our careers. A child; someone who dies in great pain; the many, many people who showed great courage and bravery. I personally remember a man called Alfie Lomas. I expect he was in the latter half of his fifties and, of course, I thought he was old! He had emphysema and had to struggle to breathe nearly all the time. But he was the sort of chap who made the doctors and nurses (and patients) feel better. He explained to newcomers the ward rules – the need to keep the beds tidy and to lie in bed at attention. He explained the vital importance of the consultant's round, and also that, important though it was, the Matron's round was even more important!

I learned a lot from Alfie Lomas, but I remember thinking what a gap there was between the quality of his life and mine. I was in that young age group where I thought there would be a cure for death before it got to be my turn. I played tennis and sprung about like Zebedee of "Magic Roundabout" fame, but nevertheless I'd always been a chesty kid and somehow *knew* even then, deep down, that emphysema was to be important in my life.

I want to have a look at how things have changed, and perhaps how they haven't, since Alfie's time. Some specialties have changed beyond recognition in 40 years, but many long term lung conditions haven't changed all that much, or rather, the quality of life of the people with them hasn't. When Alfie was in his

early to mid fifties the NHS was not yet 10 years old and patients were mightily grateful for it. If they ever made the slightest squeak of a complaint it was invariably about something inanimate – like the old red waterproofs they used to have to lie on, or the food. They would say: "The doctors and nurses were wonderful but the food was terrible." That has changed somewhat over the years but is changing even more rapidly now. I hope health professionals will feel able to welcome the new consumerism. It is not, in my view, based on negative views of treatment and care and those who provide it, but is simply of a different time and a society which wants, wherever possible, an equal partnership in the scheme of things. Already one hears less of "Whatever you say doctor" and more of "Let me just see what I'd written on my list, to make sure I've discussed everything I need to." In any case, difficult though it may be to accept, the solution to many of *your* problems may lie in the new consumerism.

The British Lung Foundation, as you know well, exists to raise money for research into lung disease. I'm proud that its Council and Executive Committee so readily agreed to the setting up of a consumer arm and voice in the shape of Breathe Easy. We now have nearly 8000 members of the club and my aim is to achieve 100 000 by the end of this century. What has surprised many is the fact that Breathe Easy people want to raise money for lung research just as much as all the fit young people who generously ride bicycles for us. Breathe Easy members are making an increasing contribution to our income.

They also write to us telling us what life is like for them and how they think it could be improved, with lots of constructive suggestions and ideas. From these we have developed an agenda and it is mainly this list of issues which, as we address them and make progress with them, will help to keep the customer satisfied. The main items on the agenda are air pollution; smoking and the guilt often felt by smokers about having done it, as well as the agony of watching people smoking now; the frequent lack of support in the life struggle; the provision of liquid oxygen, or rather the lack of provision, which impedes mobility outside the home; the problem with getting nebulisers (and I mean where they are prescribed); 'flu and whether they should be vaccinated against it; and social issues like the availability of disability living allowance and worries about

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the impending imposition of VAT on fuel bills. These issues are matched by hundreds of letters full of positive, helpful advice about how to improve quality of life – from breathing exercises and yoga to the value of blowing up balloons, and – yes – alternative or complementary therapies.

I want to pick out just one issue from this list: that of the lack of support. Huge numbers have written and included phrases like “the doctor told me there is nothing that can be done.” That phrase is used to people over and over again. One of my preoccupations is the language we all use and one of my ambitions is to dissuade health professionals from saying “there’s nothing more that can be done.” Apart from the devastating effect it has on people, it is simply not true. What is meant is that there is no cure, no magic, *but there is always something that can be done*. This isn’t just political correctness, but goes to the core of what we need to be addressing.

As we move towards the end of this century and into the next and people live to be older, this situation will be increasingly highlighted. Symptom relief, palliative care, and different health care partnerships have to be high on the agenda for all of us, whichever hats we wear. Just to go back to language for a moment, you’ll notice I’ve committed perhaps the most cardinal sin – I’ve been talking about people with lung disease, not patients. Of course I’m a patient when I’m with my doctor or when I’m ill, but most of the time I’m not a patient suffering from lung disease but a person living with it. When we’re fighting battles for more resources or working together to raise money for this specialty we’re doing it for people. Believe me, it is about living. People seem to be as terrified of dying as ever. But having a long term condition is not about dying – that only takes a few minutes or less – but I’ve been struggling to breathe for over 20 years and I’ve been living a lot and suffering as little as possible. It is true, though, that you have to have significant resources and in some ways be very strong to cope with any long term condition.

Another area of support in which we are becoming interested is that of peer group support. My own profession has recently set up a Respiratory Nurses Group within the RCN and I’m delighted about this; they have even set up a Nurses Against Smoking Group and I hope that particular charity begins at home – nurses still have one of the worst records, as an occupational group, in failing to give up smoking. But the big thing in respiratory nursing now is “patient education.” Nurses, of course, have a significant contribution to make in

assisting and supporting people and patients, but I would prefer it if they enabled and facilitated peer groups to help themselves. Breathe Easy now has eight or nine local groups and a really thriving one is the Dorset Group which was started by a wonderful nurse called Jane Baker who now takes a very passive role as the members run the show themselves. In any case, this might be a better use of professional nursing time.

The answer to the question of how to keep the customers satisfied is therefore fairly simple – we need to get closer to each other, the health professionals and the customers, and to share more with each other. My plea is to let the customers in. We need to unite on issues like smoking (and the progress the libertarian lobby has been making while we haven’t been looking) and, above all, to press for more research into preventing lung disease and improving the lives of people who have it now. To do that we need to raise the public profile of the lung even more than has been managed so far. Society needs to know that we are united and passionate about all these issues.

These are troubled times for many in the health service. Last week the Audit Commission issued yet another of its reports about the health service. I get as riled as you must to see a body like this telling us what’s what. I am bound to say, though, that I get even more riled at the fact that they’re usually right. This latest missive is about information and is entitled “Listen more to patients.” Health professionals are besieged from all sides with pressures as well as advice. It’s a new world in health care in this country. Alfie would not recognise it. I’m not sure Bevan or Beveridge would either! NHS Trusts are nothing if not challenging (I serve as a non-executive member of a Trust Board) and in many parts of the country 1994/95 means doing more work for no more or even less money in many specialties – where does all that extra money politicians keep talking about go to?

If health professionals are experiencing low morale and having to fight harder than ever for their specialty, then part of the solution lies in a strong partnership with consumers. In all the areas where real progress and a higher profile has been achieved it has been done in this way, often, indeed, led by the consumers.

Our concern is about the very air we breathe into some of the most delicate and sensitive organs in the body. Maybe our turn has come; the issues are relevant and important and timely enough. Let’s breathe new life into getting change and improvements for people with lung disease – and those who care about them.