

## The Review

# Patients with long-term conditions, their carers, and advocates

The e-mail popped up announcing a government-sponsored consultative day-conference entitled *Developing Services for People with Long-Term Conditions*. Chronic disease is what GPs do; this looks good for the CPD portfolio, it's a day out, and it's free.

It turned out not to be what I expected. I was the only GP present and there was not a single clinical thought all day. In true civil service style it was multidisciplinary and inclusive across the natural boundaries of health and social care: managers and policy makers, patient groups, and community organisations. There was an independent chair, minute takers, catered breaks, and lots of 'break out into your small groups and report back on ...'. To my surprise I learned much, and came away with copious notes and the outline of a Reflective Learning Diary concerning things I had little prior appreciation of, such as community work and self-help organisations.

Government and health trusts place much emphasis on the 'voice of the consumer'. They show the kind of attentive respect that provoked wistful thoughts in this GP. In turn, the bodies that represent the interests of patients demonstrate a grasp of the politics of service provision and a commitment to their 'community of interest' despite their mutual competitiveness. I was impressed with the depth of work that is going on at community level. The constellation of disease-specific organisations for self-help have found that forming a federation gave them a voice, an informed and informative network that filtered every public document for implication, threat, and opportunity. This Long Term Conditions Alliance links with other bodies at a national level that network information and experience about what works elsewhere. They draw on a wide skill-base of people who live with long-term conditions: business people, politicians, media personalities, teachers, academics, community developers, and articulate individuals of no particular professional background. They came with confidence gained from knowing what they are talking about, that their experience has validity ['we are experts by experience']. They were not afraid of plain speaking.

Yet vulnerabilities were demonstrable in their sensitivities about use of language in discourse: 'people, not patients', long-term

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conditions rather than diseases; service-users rather than clients; disability rather than handicap; medications rather than drugs. At the same time there were hints of consultative fatigue, expressed as '... another talking shop and still no mention of a strategy; ... but there is no new money; ... they expect us to find ways to work smarter as well as harder with what there is'.

They had gone beyond the point of discovery that all long-term conditions share common ground. It is clear to those who attend day-centres and self-care programmes that the other attendees have different diagnoses but that they share concerns over a majority of issues. They quote a figure of 80% of common ground in the care pathways of all chronic conditions (live discussion from conference). This leads them to conclude that services and programmes of care must be generic, although with flexibility to take account of specifics and complex need. 'Specialists may be special, but all patients are generalists', as one said. They have moved from a base that is condition-specific towards the generic understanding of long-term conditions at the same time as shifting their strategy from competition to cooperation between voluntary organisations and beyond, towards the Federation model. Naturally they have not abandoned or coalesced their individual power base which is the local, disease-specific support group. That would serve to weaken the voice and validity they have gained. They know the dangers of fragmentation of effort and they know what it is like to receive fragmentary care.

### WHAT IS IT THEY ARE REPRESENTING AROUND THE NEGOTIATING, POLICY-MAKING TABLE?

Underneath a veneer of assertiveness, the professional patina that representatives need to adopt, an array of emotions were

detectable ranging from a diplomatic conciliatory voice to anger that verged on aggression. They acknowledge and 'own' the full range of expressions from negotiation and advocacy to denunciation. They freely admit that people with illnesses are not always at their best (who is?), and often not easy to satisfy. They cannot afford to bask in a glow of complacency that progress is being made. Their membership will not for long tolerate a passive, time-serving representative. In this sense they are political, sceptical about 'progress without change' and consultation without product.

Oscar Wilde defined cynics as those who know the price of everything but the value of nothing. Representatives of patient organisations are not cynics. Costs they understand; values are at the core of what they do. With no profit incentives, their goal is to bring a sense of normality to groups of individuals, many of whom feel stigmatised, alienated, and marginalised. They appear to be highly motivated to promote their community of interest.

### WHAT PEOPLE WITH LONG-TERM CONDITIONS WANT

People with long-term conditions want to feel normal, to live ordinary lives, and to participate in family life and the life of their community. Clearly their respective long-term conditions (mainly cardiovascular, respiratory, or neurological diseases, diabetes, cancers, sensory disability, and mental illness) impinge on life in characteristic ways. That is the 20% or so of their agenda that is disease specific, the remainder being the common ground. Among the challenges they face are:

- Persisting, recurring problems of symptom control: pain breathlessness, weakness, and fatigue.
- Uncertainty about the future that ranges

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from life expectancy to the timing of a weekend break.

- Lifestyle restriction: the limitations imposed by their condition, such as the ability to move around their home, timing and use of drugs, dietary restrictions, and communication problems.
- Impact on family life through relationship stress, impaired sexual performance, contraction of the social circle, participation in family roles, and activities that were once taken for granted.
- The sense of dependency on care-givers, primarily the family and kinship circle.
- Care needs that stretch the patience of the patient: they experience convoluted clinical pathways (especially where there is comorbid disease); they spend a lot of time waiting ... for appointments, for the district nurse to turn up, for the spouse to come back from work.
- Guilt at loss of ability to carry out productive roles as bread-winner, parent, or employee.
- Impoverishment: more than half of all those with significant disability live below the average household income due to loss of earning capacity and the increased living costs associated with their condition, such as heating and laundry.
- Stigma: the feeling or perception that they are seen as different or to be pitied,

and thus deprived of respect, opportunity, and inclusion.

- Despondency: the diminished sense of hope, actual mood disorders like anxiety and depression.
- Non-disease-related complaints include sleep disorder, diminished energy, accident proneness, and constipation
- Loss of self-esteem: self-efficacy, self-worth, impaired body-image; loss of respect and privacy especially regarding hygiene and intimate bodily functions.

Disempowerment results from many of the above factors. when all sorts of things get done to you, with regimens prescribed for you, your world begins to shrink. From this emerges the 'Big Birthday Present List' (Box 1), those attitudes, activities, and services those with long-term conditions would like to receive from a compassionate and supportive society.

At the end of the workshop as we went our separate ways, all the words having ebbed away, I was left with strong images of what it is like to be a patient. It was the first time in a career of over 30 years as a GP that I had given space in a focused way to this area. There was no rocket science, but I had learned much. Lasting impressions were encapsulated in a few whimsical sayings, a folk-wisdom that kept re-emerging mantra-like through the day and whose truth shone through any apparent triteness:

### Box 1. The big birthday present list

- To be treated with dignity and respect, as 'people not patients'
- To live as normally as possible, and to be treated accordingly
- Empowerment, especially towards self-care
- Ownership; of their own condition
- Information about their condition[s]; the right input at the right time and signposting to services available
- Services that are accessible and user-friendly
- Engagement on the part of professionals
- Streamlining of services and episodes of care; seamless pathways of care
- Poverty support; welfare rights advice
- Employment support
- Lifestyle support
- Emotional support
- Youth support; for young chronic sick and under-age carers
- Contribution; the sense that they have something to give in return to society, to fellow-sufferers, some aspire to be Expert Patients

### ADDRESS FOR CORRESPONDENCE

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*'Added life to years rather than added years to life.'*

*'We are people not patients.'*

*'I just live one day at a time.'*

*'Today is the first day of the rest of your life.'*

*'I may not have any degrees but I do know about sore joints and disjointed clinics.'*

*'The best time to plant a tree is 20 years ago; the second best is now.'*

To which I mentally added a few lines, perhaps as a 'memo' to self:

*'If you don't really want to know, don't ask; if you don't want to listen don't sympathise; if you don't want to do something don't make promises, and don't promise things unless you intend to deliver.'*

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### Provenance

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