

EDITORIAL

The Caring Community

The pioneers of palliative care made an impressive early impact on health care in focusing primarily on comprehensive symptom management for dying individuals, a focus which, sadly, was quite unusual at that time. As palliative care matured into a recognized discipline, its field of activity extended to include matters of family support, staff counselling, bereavement care and community education. Much of the energy which fostered the growth of palliative care came from the non-government sector of society with impressive efforts at the community level to raise funds and establish hospices. Only later did palliative care achieve a measure of respectability within the established canon of medical specialties, and come to be seen as a proper recipient of a moiety of government funding for everyday health care.

The acceptance of palliative care within medicine and by government bureaucratic responsibility has not been viewed universally as a positive development. It is seen to have detracted from the volunteer spirit which motivated so much of the first efforts to improve the care of dying persons; it has been accused of 'medicalizing' what was a remarkable grass-roots social movement. But the desirability of continuing or re-establishing a committed community support for palliative care services is still recognized, and has become a concern for palliative care advocates within professional bodies and governments alike.

That concern is illustrated in the national palliative care strategy adopted by the peak body for Australia, *Palliative Care Australia*, which lists as one of its primary objectives:

To improve the knowledge and skills of families, carers and community groups so that they can better support relatives, loved ones or individuals within the community who are dying, and work optimally through their bereavement.

To achieve such a broad objective, the strategy advocates education for local community groups to enable their informed participation in care. The advocacy is supported by an Australian Government initiative under the heading *Caring Communities*, which has advertised funding for projects which inform, activate and support community action in palliative care.

To encourage the 'caring community' requires some agreement on what constitutes a community, and just

what is the 'caring' being asked of it, and how does one promote 'the caring community'.

Community is variously defined, drawing on aspects of co-location, sharing of resources, organization into a political or social entity, or common allegiance and values.

There are considerations of space and time, solidarity, significance (a sense of belonging) or commonality (the sharing of property, ideals or activities) (1). A community will generally be regarded as successful if it is able to remain in existence over a considerable time.

I once lived for 6 years in a very well-defined community – a village in Papua called Pari. Its population of just over 1000 persons, virtually all related to each other by intimate or distant family ties, was held together also by a common history, close-built housing, a single religious affiliation, shared understandings of complex rules governing their interactions and communal activities. What that experience taught me was the immense amount of effort that is required to keep a community together. Throughout most hours of the day and the evening, I would be aware of all sorts of meetings and exchanges taking place along the village street, a complex sharing of sea and garden produce, meetings to arrange group activities such as fishing expeditions, cricket matches, church services or the gathering of funds from the extended family for a bride price. Community has to be built, and has to be maintained, by considerable effort, effort generated within the community itself.

Care, of course, is at the one time an attitude of interest and concern, and also a process of responsive activity directed at supporting the welfare of another. The palliative care literature suggests that when care for individuals with a terminal illness is conducted within a community setting, it is largely carried out within a family (2). A family often will be able to draw upon informal assistance from relatives and friends, and a wide range of physical and emotional supports from professional bodies and from associated trained volunteers. But if there is to be a caring community, it will be more than merely the sum of what particular families and their assigned carers are doing; it will be a concern and practice expressed more broadly within the structures and the resources available to the community.

If a community is to fulfil its potential as a resource for sustaining good palliative care services, it will need to understand what is involved in palliative care and to feel at least some comfort with the concept that death is a part

of life and deserves a mindful attention. It will need also to achieve a sense of competence and responsibility in its advocacy and support for care.

How feasible is the hope to promote the caring community?

Interventions to improve community health have been classified into two major kinds:

- 1) *There is community betterment, which involves groups and individuals in issues and activities seen as important by health agencies and health professionals, who look for their desired outcome in improvement in particular behaviours of relevance to health.*
- 2) *Conversely, there is community empowerment, which starts with issues of concern to community groups and individuals, and seeks as its outcome an improvement in the overall power or capacity of those participants (3,4).*

That distinction may be relevant to whether and how a caring community may be built. In past decades, community empowerment for palliative care was demonstrated in many communities and in several countries where groups formed with a spontaneous enthusiasm to create resources and facilities for situations where previously there had been neither concern nor effective relief for the sufferings of the dying. Communities were inspired by the opportunities to pioneer and build, and to better their local world through improved outcomes for dying persons, and they overcame all sorts of inertia and stifling regulation.

Such a corporate initiative is itself a significant encouragement for the health of its community, and a programme of health promotion. Kelleher has maintained that palliative care is an important component of health promotion, bringing to a community a greater confidence in the face of terminal illness, a greater willingness and readiness to engage in care of all kinds (5).

Heady pioneering initiatives can rarely be maintained for long, and for palliative care the promotion of the discipline's concepts and practice has increasingly come under the guidance of the expanding numbers of its dedicated specialist professionals. Whether empowerment can be recaptured will be difficult to predict and will differ from community to community. It can start from examinations of the threats to care which stem from the operation of local structures and attitudes and hierarchies (6). It may seem to require unsettling change, and a need to upset established authority, and so

calls for emotional strengths (7). Better care for suffering dying persons is unlikely to be fostered by nicely-framed displays in the marketplace or mall, or by talks on local radio. It can surely be helped through sensitive encouragement by concerned professionals who have grasped the concept of empowerment, who work in local settings to hear what really concerns community members, but they will do well to refrain from overt leadership and helpful suggestion.

A potential will have been demonstrated first, perhaps, in the formation of a strong corps of volunteers, open to being trained and deployed in clinical settings alongside the paid professional staff. But there also needs to be – at some distance from the care focus in hospital, hospice or home – an opportunity for tradesmen to offer their skills, accountants their expertise, lawyers their advice, and managers their insights. The caring community remains a worthwhile vision; while its central image is the bedside of the dying patient, it can gather into a network of responsive acumen and energy a diverse and admirable coalition of the willing, one likely to bring health and healing to all its participants. Writing years ago about blood donation, Titmuss coined the phrase 'the gift relationship' (8). The caring community will depend greatly on the co-ordinated gifts of its members, and in working to support the care of the dying they will do much to augment the sum of love in their environment. And love, as Titmuss noted, is a scarce resource, one which deserves to be husbanded and used well.

References

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