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Family matters

JOHN KEADY

PHYLLIS 'PENNY' BRAUDY HARRIS

Welcome to 2009 and to the eighth year of the *Dementia* journal. It only feels like yesterday since we received the first draft of Gloria Sterin's invited, inaugural article in *Dementia*, an article that reflected upon her life with dementia and the meaning that the word 'dementia' held for her. Needless to say, it was not a torrent of positive attributes! What the article did contain, however, was a message straight from the heart, a message that was accessible, vulnerable, engaging and immensely articulate. As Gloria said in that piece: 'People can cope with this disease. But you need time' (Sterin, 2002, p. 9). Arguably, if we constructed and delivered services based on the daily life observations of people with dementia and their families, it would improve the quality of their lives immeasurably.

We start this first volume of 2009 with an article written by a family carer, Muriel Weyl, entitled 'Love Song at the End of the Day: A Wife's Journey'. This article shares many of the qualities, attributes and life observations first seen in Gloria's article, and it reminds us that caring is a complex, ever changing, multi-dimensional and bi-directional phenomenon that stems from people's biography and their preceding relationship with the person (with dementia). Most of all, to be a carer is also to be a person; life is not wholly defined by the act of care-giving, it has a deeper, resonating meaning and shared set of values. As stated in the title of the article and from the ensuing dialogic, Muriel is first and foremost 'a wife', and her experience reminds us that everyday expressions of love and belongingness are an integral part of daily life for people with dementia and their families. Care-giving is not all about 'stress', 'coping' and 'burden' and is, perhaps, and more fittingly, about human commitment, care, warmth, love and devotion. Attributes that are at times, and dependent upon the stage of the journey through dementia, tested to the limit of human endurance – and sometimes beyond it – but nonetheless are present.

Recently, Roach and Keady (2008) reported that following an extensive review of the literature, they could only find one study where the researchers had commenced their study with the aim of looking at the experience of dementia as part of a family system. This exploratory, qualitative study by Garwick, Detzner and Boss (1994) reported on 38 multi-generational family interviews where the primary caregiver nominated the 'family members' to be part of the interview process (in the study as a whole this ranged from between 3–11 people), although it would appear that the person with dementia was excluded from the family interview process. Through this approach, the authors reported that families spoke little about the medical symptoms associated with dementia and, instead, focused their attention on 'how the disease disrupted the fabric of everyday family life' (p. 8). Searching for stability and meaning in the everyday for multi-generational families became a crucial marker in understanding and absorbing 'dementia' into the family identity; it was not one person's problem, but a collective responsibility that was mutually dependent on invisible strings of support within and between family members.

As we have reported previously (Harris and Keady, 2006), for some unknown and inexplicable reason, people with dementia have become separated from their family systems within research, practice and policy attention with the weight of these resources being targeted at individual or dyad based methods of support/understanding. One way to re-join people with dementia to their families is to reconfigure the way in which relationships are reported and conceptualized. For example, we may be able to learn from the nursing literature where, in the 1980s and early to mid 1990s, nursing put forward an alternative care paradigm based upon the concepts of family nursing which Claveirole, Mitchell and Whyte (2001) defined as follows:

The purpose of family nursing is to promote, maintain and restore family health; it is concerned with the interactions between the family and individual family members. In working collaboratively with the family through education and encouragement the nurse helps them to utilize their strengths and mobilize their resources to evolve a more effective level of functioning. (p. 1143)

Whilst family nursing was originally applied to children's services (Friedemann, 1989; Bradley, 1996; Whyte, 1997), there has been a recent call to broaden the scope to long-term conditions across the age-span (O'Sullivan Burchard et al., 2004) and some evidence that the approach exists within continuing care environments for people with dementia (see, for example, Bonjean and Bonjean, 1997). Whilst the evidence base for a family systems approach to locating dementia care services is yet to fully emerge, there does seem to be something more 'real' and 'connecting'

about studies that seek to reach beyond the person and their immediate primary care support and view life and need as it ripples through the family network (Keady and Keady, 2005). Perhaps the time has come to broaden our canvass of responsibility and re-construct the meaning of relationships in family and dementia care. We have been painting in pastel shades for too long when what is needed are bold strokes and a bright new vision of dementia care.

The *Dementia* journal remains committed to promoting, disseminating and embracing all perspectives on living with dementia; one voice is not more important than another, all have a place and a stake in developing new visions of dementia care. As *Dementia* rolls out in 2009, our third issue of the year, Volume 9(3), will be a special edition on palliative and end-of-life care. This special edition will be edited by Dr Louise Robinson (Newcastle University, UK) and Dr Liz Sampson (Royal Free and University College Medical School, UK), both widely respected figures in the field, and we are delighted that their expertise and that of their contributing authors will be shared with the readership.

Finally, we would like to thank you for your continued support of the *Dementia* journal and hope that you enjoy the contributions in this and our forthcoming issues in 2009, and beyond.

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Biographical notes

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