



special articles

Psychiatric Bulletin (2005), 29, 266–267

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Partners in care

Being equally different: lesbian and gay carers

The images of other people we see on a daily basis in the media invite us all to compare ourselves with, identify with, or aspire to be like whoever is shown. Mostly this activity is of little significance and hardly touches our lives, but the further we know ourselves to be different from the norm then the more challenging those differences become to us.

Ten years ago my partner was diagnosed with presenile dementia; he was 56 years old and I was 52. By nature I am a 'joiner' and so it was a natural thing for me to join the Alzheimer's Society, not merely because it seemed sensible but I thought I might need more help from such an organisation later on. As a gay man, that image issue soon hit me in the same way that it has done over the years in so many other ways. Month by month, as I read the Alzheimer's Society magazine and looked at its other literature there seemed to be an assumption that the disease only affected married couples or those with supportive families. The focus seemed to be on heroic husbands or wives, married for scores of years, who were now entering a supremely challenging phase in their relationship; or it was on devoted families who now needed to consider how they could meet the needs of parents suffering from this most dreadful disease. I found it difficult to identify with such images or to incorporate them into my new experience as a carer. I had been in a relationship with my male partner for over 20 years, so there was some connection, but I wanted to know whether there was someone else out there who was caring for someone they were not married to or who was gay like us? I also thought about the increasing number of single people (some of whom would more than likely be gay) coping with the disease alone and possibly with not another person available to support them in their hour of need. At this point I could have resigned from the Society on the pretext that it was not an organisation for people like me; but I didn't! I wrote a simple letter expressing these thoughts; after all, I thought, one simple letter might also call attention to the fact that as a gay man I did not feel particularly welcome. I was not overwhelmed by replies, but there were sufficient to make it possible to create a network of helpers who could be contacted by phone and who might use their experience and skills to give other 'gay' callers that

tremendous feeling of relief which comes from knowing you are not alone. We also wanted to affirm that our experience as gay carers was as equally valid as that of our heterosexual counterparts and worthy of the same quality of support that others were receiving.

The feeling of how powerful 'negative' imagery can be for us as 'gay' people also started to be increasingly recognised by health and social service professionals when they also began to contact us, usually with an admission that it had not previously occurred to them that lesbian and gay carers might have unique and unmet needs. This has led to a significant number of invitations to speak at group meetings and conferences, and the resulting changes in practice and awareness have been extraordinary. In some cases it has also led to literature used by various groups being evaluated to determine just how 'gay'-friendly it really is.

A yet more fundamental experience also led to the formation of our Lesbian and Gay Carers' Network. Some people said to us, from the outset, 'Surely the world has changed in its attitude towards you, and the law has followed suit. Why do you need something special when society is already more sympathetic?' Certainly the life of the 'gay' carer is easier than it was, but as older gay men and lesbian women we bring with us to this task of caring a significant amount of baggage from a previous age. The men remember all too clearly being 'illegal' and being victims of police harassment. The women similarly know about that kind of society and also one where people hardly believed that lesbians actually existed. All of us have a past knowledge of beatings, murders and discrimination in the workplace and, over the years, we have consequently learned to build protective walls around our lives making us relatively anonymous and giving us the maximum possible feeling of safety. But should the time come when we are suffering from a life-threatening disease, have a requirement of long-term healthcare, have the need to get help from social services, and possibly require residential care, then all those carefully constructed defences are immediately at risk. In short, a new and threatening world suddenly arises for the 60-year-old gay carer at the hospital, the doctor's surgery, or on the phone to a social worker, when he is told that he has no automatic next-of-kin rights, or has no automatic

The Lesbian and Gay Carers Network – Alzheimer's Society can be contacted via the National Helpline of the Society on 0845 300 0336 or visit http://www.alzheimers.org.uk/Gay_carers.



right to know about the medical circumstances of his partner, or has to face the prospect of receiving essential domiciliary visits provided by workers who do not think to use the same understanding they would employ with their heterosexual clients. This all happens at a time when the pressure, emotion and isolation of being a carer can be at its greatest. The Lesbian and Gay Carers' Network exists so that we can be at the end of a phonenumber during those times of extreme need, and it is not surprising that tears are shed, frustration is expressed and deep anxiety exhibited as individuals tell their stories. There is also a considerable amount of gratitude expressed for our existence.

The Alzheimer's Society has taken these issues on board in a most impressive and heartwarming way. Its policy of social inclusion has made us feel that as 'gay' carers we belong and, although we may be different, we are equally different. There are five of us who serve the network by having dedicated phonelines in our homes. We are not inundated with calls, but in a society where up to 700 000 have dementia, and where it is estimated that 5% of the adult population are 'gay' we recognise with some trepidation that the real demands for our work are only just beginning. With that prospect in mind, the Society received an award from Comic Relief in order to fund a full-time worker to serve its Lesbian and Gay Carers' Network for 2 years; that appointment was made in 2004. In time, we hope other national charities will take similar steps.

One of the network's distinctive services is the provision of information relevant to 'gay' carers through its own pages on the Alzheimer's Society's website (<http://www.alzheimers.org.uk>). Our section of the site receives hundreds of hits per month and is almost unique in providing a comprehensive collection of published material on the topic of 'gay' carers of people with dementia; there are other pages containing news and views. We learned early on that the psychological and social significance of our mere existence was not to be underestimated, and that would have been true had we received just a single call.

There remains a deep need within the health and social service sector, and indeed in the residential home sector, to learn more about us as 'gay' people, to learn how to empathise so that we feel safe to talk about our relationships and our needs, and to encourage us to request help without feeling threatened. When society achieves that then the need for us as a network will decrease, but we all know that we are a long way from that goal at present.

Declaration of interest

The author is a volunteer for the Lesbian and Gay Carers Network – Alzheimer's Society.

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