

# **CARERS** look after family, partners or friends in need of help because they are ill, frail or have a disability. The care they provide is unpaid.

## **POLICY BRIEFING**

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### Lesbian and Gay Carers

**Date**            October 2003

**Relevant to:**    UK

#### **1.    Background**

Carers UK are highlighting the issues that face particular groups of carers, which mean they may have particular additional service, or information needs. These include: lesbian and gay carers, minority ethnic carers, disabled carers and rural carers, young carers and carers on a low income.

Gay and lesbian people suffer from the same disabilities and illnesses as anyone else and are just as likely to suffer from Parkinson's Disease, or mental health problems. Lesbian and gay carers have the same needs for support, services and information as any other carers, but prejudice and lack of legal recognition means that they face the extra barriers of social isolation and inappropriate services.

Estimates for the numbers of gay and lesbian people vary from 5% to 13% of the population. Even this lowest figure would mean that of the 6 million carers in the UK<sup>1</sup> approximately 300,000 carers in the UK are gay or lesbian.

#### **2.    The Current Situation - Problems**

**Homophobia** – Professionals may have a lack of understanding about the lives of gay and lesbian people and some are judgmental about their sexuality, particularly in accepting their partnerships. Expressions of homophobia by service staff, other professionals and other users, can have a profound impact on gay and lesbian service users. "They can become isolated, depressed and suicidal."<sup>2</sup>

Homophobia can either be direct (discrimination, physical and verbal attacks), institutional (lack of inclusive policy, poor staff training) or by simple ignorance (not considering that someone may not be heterosexual or that their needs are different).

**Isolation** - Caring for a person can be an isolating experience. This can be exacerbated by homophobia and the fear of homophobia and some gay and lesbian carers feel unable to access existing services and carers support, feeling that they may face discrimination.

**Having to come out** – Gay and lesbian carers often find that they have to ‘come out’ to many professionals - doctors, social workers, care assistants and nursing home staff - who have become involved in what may previously have been a very private relationship. Carers of same-sex partners many find they have little choice but to reveal their relationship to many professionals, but this can leave them feeling vulnerable and exposed at an already stressful time, particularly if their relationship has previously been hidden. It is particularly important that service providers have effective policies to ensure that staff respond in an appropriate manner.

**Non-recognition by professionals** – because same-sex partners are not recognised as the ‘nearest relative’ either in law, or by many professional staff, a partner can often become excluded from the care of that partner in a hospital, or nursing home. Carers tell us that they have been denied visiting rights and access to information to the same-sex partner, often against the express wishes of the patient. Staff may also overlook same-sex partners when seeking advice on consent to medical intervention and deny information to that partner. Gay and lesbian parents are also often denied visiting rights to their partner’s child.

**Residential care** – Carers tell us that it is never easy to make the decision that a partner, relative or friend should move into residential accommodation. This can be even harder for gay and lesbian people, as it is rarely possible for them to access residential services as a couple, and many are afraid to ‘come out’ in this situation through fear of discrimination. In addition, the transfer of a person into residential care often involves making decisions and arranging financial matters that can involve negotiation with family members, which can be difficult if their same-sex partner is not recognised as the ‘next of kin’.

**Inheritance** – when a married partner dies, money and property that is transferred to the remaining partner is exempt from taxation. When a same-sex partner dies anything that the remaining partner inherits is liable to inheritance tax.

**Intestacy** – if a person dies without leaving a will same-sex partners do not currently have any rights to the estate or to administer the estate.

**Confidentiality** – not all lesbians and gay men feel comfortable being defined in those terms and some will have concerns about such information being documented on file, particularly where they have experienced discrimination in the past. Health and social care staff should record the name of the carer without the patient having to declare the nature of their relationship, what matters is the caring relationship.

**Benefits** – The benefits system does not recognise same-sex relationships for claims. This means that claims for contributory benefits where an allowance may be claimed for an adult dependent discriminate against same-sex relationships. Widows and widowers of same-sex partners are not able to claim bereavement benefits, which are only available if the widow(er) was legally married.

### 3. Case Studies

Andrea, who has mobility problems, cares for her and is cared for by her partner Janet. She complains that services provided by public authorities are inflexible and often inappropriate. *"There isn't just one way to be a disabled person, or a carer. We are all human beings, and we come in many difference guises. With local authorities if there is anything that's slightly out of the ordinary, then they can't deal with it ... we can't all fit into the same strait-jacket."*<sup>3</sup>

### 4. Lesbian and Gay Carers and Work

**Carers' Leave** – is not always granted to a worker whose same sex partner becomes ill, even though it is available for carers of an other-sex partner. Likewise the provision of childcare leave may not be available to same-sex parents. A 1999 TUC survey found that 44% of lesbian and gay trade union members suffered discrimination because of their sexuality.<sup>4</sup> Staff should be able to access special leave provisions without necessarily having to come out to their manager.

**Pensions** – Most occupational pensions offer a death in service lump sum and a dependants' benefit. However, only half of these schemes pay dependants' benefit to same-sex partners<sup>5</sup> and less than half of schemes paying lump sum benefits to unmarried survivors treated same sex partners the same as opposite sex partners.<sup>6</sup>

### 5. Civil Partnership Registration (England and Wales)

The Government's consultation paper, *Civil Partnership: a framework for the legal recognition of same-sex couples*, proposes setting up a civil partnership registration scheme through which same-sex couples would be able to obtain a formal legal status for their relationship and the attached rights and responsibilities. A copy of the consultation document can be downloaded from: [www.womenandequalityunit.gov.uk](http://www.womenandequalityunit.gov.uk).

Under the proposed legislation a registered partner will have the same rights as married couples in respect of making financial decisions on behalf of adults with mental incapacity. It is hoped that the new registered partner status will help bring about a culture change in the recognition of same-sex couples by health and other professionals. Registered partners will also:

- Be treated as a single family unit for income related benefits purposes.
- Have the same state pension rights as married couples once entitlement for husbands and wives has been equalised in 2010.
- Have the right to register a partner's death, the right to be notified about an inquest into their partner's death and have rights in relation to the burial, exhumation and cremation of their partner.

- Have entitlement to bereavement benefits if their partner dies.
- Have a right to inherit where a partner dies without leaving a will.
- Have the same tenancy rights as married partners, including the right to succeed.
- Be entitled to claim bereavement damages in respect of a death that occurs as a result of another person's negligence and the right to claim compensation for the death of a partner under the Fatal Accidents Act.
- Members of public service pension schemes will earn entitlement to survivor benefits for registered partners in the same way as for married partners.

### **Concerns**

Carers UK welcomes the proposed legislation. However, the changes to benefits that will result from the legislation will mean that some families will face a drop in income and it is important that any changes are publicised widely in advance to ensure that same-sex couples entering a civil partnership are aware of all financial consequences.

## **6. Other Legislation and Guidance**

**The NHS Action Plan 2000** sets out the new key principle of commitment to challenge any discrimination in service provision on the grounds of sexuality.

### **European Council Directive (2000/78/EC) 2000**

Gives employers a new duty to promote equality in the workplace on the grounds of sexuality, to be implemented in all EU countries by December 2003.

**Employment Equality (Sexual Orientation) Regulations 2003 (England, Wales and Scotland)** – proposes new laws to protect lesbian and gay workers come into effect from 1 December 2003 to meet the requirements of European Employment Directive. The regulations will make it illegal for any employer or training provider to discriminate in respect of any aspect of employment, on the grounds of a worker's sexual orientation. Separate Regulations are anticipated shortly for Northern Ireland.

**Civil Registered Partnerships (Scotland) Bill** – is a Private Members Bill currently going through the Scottish Parliament, which would give same-sex partners the right to register as a Civil Partnership and gain similar rights to those proposed for England and Wales.

**The Adults with Incapacity (Scotland) Act 2000**, gives same sex partners the legal right to be consulted about the affairs of their partner if their partner becomes mentally incapacitated. Same sex partners can access the provision of the act, for example; power of attorney and guardianship. The proposed **Mental Health Bill for England and Wales** would also give same sex partners equal rights to be involved in decision making.

Section 75 and Schedule 9 to the **Northern Ireland Act 1998** place a statutory obligation on public authorities to carry out their functions with due regard to the need to promote equality of opportunity. Sexual orientation and persons with dependants (including carers) are amongst the specified groups where equality is to be actively promoted.

## **7. Good Practice and Solutions**

### **Support Groups**

The **Alzheimers Society** runs a **Gay and Lesbian Carers Network**, including a telephone helpline service staffed by gay men and lesbian women, that provides an understanding ear for gay men and lesbian women caring for a relative, partner or friend with dementia. There is also a dedicated gay and lesbian carers web page and members of the network have undertaken speaking engagements across the UK.

The **Islington Support Group for LGBT** carers of people with dementia was established in September by the Islington branch of the Alzheimers Society. The group meets each month, has the services of a professional facilitator and is developing a programme of activities.

**HIV-AIDS Carers and Family Support Group** in Scotland provide counselling and support to carers and their families through home and hospital visits and a telephone support service. They also provide a respite breaks service for members.

In Brighton and Hove, the **Lesbian and Gay Friendly GP Practice Scheme** was set up to ensure that all practice staff receive training in issues around working with lesbian and gay patients and their carers.

The **George House Trust** in Manchester provides support to people affected by HIV, including their carers. Services for carers include: telephone advice service, community support and an opportunity for carers to meet and chat to other carers.

The **Lesbian and Gay Advocacy Project** ran by MIND in Brighton provides information and advice to lesbian and gay mental health service users and their carers and training for mental health service workers on lesbian and gay issues.

The **Navajo Lesbian and Gay Health Strategy** for Preston, Blackpool, Fylde and Wyre has 50 local organisations, including health care services, signed up to a lesbian and gay friendly assurance charter mark scheme. The charter mark ensures equity of access to services and equality of employment and training.

## **8. Carers UK's Recommendations**

Good intentions are not enough, local authorities, health authorities and other service providers must ensure that practice is based on coherent policy. Local Authorities, NHS Trusts and PCTs should:-

- Establish mechanisms and procedures to identify and assess groups of carers who have particular information needs and for whom specific services may have to be developed; including lesbian and gay carers, minority ethnic carers, disabled carers and rural carers to name but a few.
- Provide written policy guidelines addressing practical issues concerning same-sex partners and their families.
- Train staff in dealing with lesbian and gay clients, avoiding making assumptions about people's sexuality.
- Ensure that written materials you produce uses language that is inclusive of carers that are not married.
- Be sensitive about the way information is requested from patients, be aware that you have lesbian and gay patients, and ensure that all paperwork uses language that is inclusive of lesbian and gay families.
- Ask patients/clients who information should be given to and ask who to consult in treatment decisions, rather than using the legalistic term 'next of kin'.
- Ensure that policies are in place to address prejudiced attitudes and behaviour of staff.
- Care home accommodation available to couples should be made equally available to same-sex couples.
- Encourage lesbian or gay carers of a partner with dementia or other mental impairment to set up an Enduring Power of Attorney. This legal document will give the appointed person rights to organise their partner's finances
- Alert lesbian or gay carers to the importance of both partners having made a proper will.

### **Employers should:**

- Have a written policy covering carers' leave and parental leave. Where these arrangements are left to managers' discretion the possibility of unfair treatment arises. Likewise promotion decisions should be transparent and based on competence related factors.
- Implement equal opportunities policies that specifically include lesbians and gay men.
- Staff should be able to access special leave provisions, including carers leave, without necessarily having to 'come out' to their manager.
- Ensure that occupational pension schemes give entitlement to survivor benefits for same-sex partners in the same way as for married partners.

## **9. What Carers UK is doing**

- Raising awareness of the issues facing gay and lesbian carers.
- CarersLine – provides a free advice and information to callers throughout the UK (0808 808 7777, Wednesday -Thursday 10.00 – 12.00 and 2.00 – 4.00).
- CarersOnline website provides high quality national and local information and enables sharing good practice via the bulletin board.
- Responding to the government's consultation on civil partnership registration.
- Working with gay and lesbian organisations to help identify and support carers.

## **10. Research**

To date there has been little research on gay and lesbian carers, though three interesting pieces of work are currently being undertaken:-

Elizabeth Price at Hull University is currently undertaking an important piece of research into gay carers of people with dementia.

The Equality Network in Scotland is undertaking research into the treatment of same-sex partnerships by public services, including health and social work.

Gay Homes in Retirement are carrying out a survey into the housing needs of older and retired lesbians and gay men.

## **11. Recommended Reading**

**Sex and Relationships: A guide for care homes**, Counsel and Care, 2003

**Opening Doors: Working with older lesbians and gay men**, Age Concern, 2001

**Equality and Inclusion: A public services agenda for lesbians and gay men**, UNISON, 2001

**Lesbian and Gay Rights at Work: A TUC charter for equality**, TUC, 1999

**Supporting Inclusive Communities: Lesbians, gay men and local democracy**, Local Government Association, 2001

**Choosing Residential Accommodation: a guide for lesbians and gays**, The Alzheimers Society Lesbian and Gay Carers' Network, 2003. Available on [www.alzheimers.org.uk](http://www.alzheimers.org.uk).

**Living with HIV: a manual for carers**, Victoria McNeile & Jane Joyce, West Midlands Health Authority, 1996

**Planning for later life as a lesbian, gay man, bisexual or transgender person**, Age Concern Information Sheet, 2003

## 12. Useful websites:-

Carers Online - [www.carersonline.org.uk](http://www.carersonline.org.uk)

Alzheimers Society Lesbian and Gay Carers Network -

[www.alzheimers.org.uk/Gay\\_carers](http://www.alzheimers.org.uk/Gay_carers)

Scotland – Equality Network [www.equality-network.org/](http://www.equality-network.org/)

Scotland - HIV Family and carers support Group <http://www.hiv-aids-carers.org.uk/>

Body Positive (Strathclyde) <http://homepages.enterprise.net/bpstrathclyde/>

Stonewall - [www.stonewall.org.uk](http://www.stonewall.org.uk)

Age Concern's Opening Doors programme – [www.ageconcern.org.uk/openingdoors](http://www.ageconcern.org.uk/openingdoors)

AIDS Helpline Northern Ireland - [www.aidshelpline.org.uk](http://www.aidshelpline.org.uk)

Coalition on Sexual Orientation - [www.coso.org.uk](http://www.coso.org.uk)

George House Trust – [www.ght.org.uk](http://www.ght.org.uk)

## References

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<sup>1</sup> **Data from 2001 Census**, Office of National Statistics, 2003

<sup>2</sup> **Back in the Closet**, Community Care, 30 May 2002.

<sup>3</sup> **We're in This Together**, p. 72, Carers National Association (now known as Carers UK), 1999.

<sup>4</sup> **Lesbian and gay rights at work: a TUC charter for equality**, TUC, 1999

<sup>5</sup> **NAPF Survey of Occupational Pensions Schemes**, NAPF, 2001

<sup>6</sup> Ibid

## Training for Professionals:

We provide both in-house and training courses that incorporate these issues. For detailed information about courses and booking visit our website

[www.carersonline.org.uk](http://www.carersonline.org.uk). Alternatively, contact Chris Hockley on: 020 7566 7632 or e-mail: [training@ukcarers.org](mailto:training@ukcarers.org).

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