
Dementia, Lesbians and Gay Men

Alzheimer's Australia
Paper 15
October 2009

Heather Birch



CONTENTS

ACKNOWLEDGMENTS

FOREWORD

ACKNOWLEDGMENTS **5**

Introduction **8**

How many lesbian and gay seniors are there? 8

What's different about lesbian and gay ageing? 9

Ageism and social isolation 10

The Legislative Context **11**

Decriminalisation of male homosexuality 11

Relationships recognition 11

Equal opportunity legislation 11

Human rights 12

Centrelink 12

Advanced care planning issues 13

Superannuation 13

Wills 14

Families and Caregivers **15**

Issues for Service Providers and Care Workers **17**

Assessment 19

Community care 19

Residential care 20

Accommodation payments 21

Aged Care Accreditation Standards 22

Other residents 22

Intimacy and relationships 23

Special issues for transgender people with dementia 24

Late stage care issues 24

Where to Get Help **25**

Alzheimer's Australia 25

Alzheimer's Society UK 25

Rainbow Carers 25

Legal rights 26

Useful community organisations 26

Further reading 27

Other publications	28
Glossary of terms	29
References	33
ALZHEIMER'S AUSTRALIA PUBLICATIONS	36

ACKNOWLEDGMENTS

This paper was prepared by Heather Birch, former Chair The ALSO Foundation Seniors Project Advisory Committee. The views expressed in this paper are the views of the author and not necessarily those of other organisations.

Alzheimer's Australia wishes to acknowledge the contribution of those who generously contributed and reviewed this paper.

We particularly wish to thank Justice Michael Kirby, former Judge of the High Court of Australia for commenting on the draft report and preparing the Foreword.

Thanks is also extended to:

Delys Sergeant AM, Andrew Burry (AIDS Action Council of the ACT), Graham Lovelock (GLBTI Retirement Association [GRAI], Western Australia), Catherine Barrett (Australian Research Centre in Sex, Health and Society La Trobe University) members of the Alzheimer's Australia National Consumer Committee (Lucille Bloch, Marianne Gevers, Margaret Baulch, Sally Garrett), Dr Jo Harrison (School of Health Sciences, University of South Australia), Matrix Guild Inc, Anne Kelly (Alzheimer's Australia Tasmania), Anne Eayrs and Claire Brown (Alzheimer's Australia), Kathryn Cunningham (Alzheimer's Australia South Australia) and Ruth Leslie-Rose (Alzheimer's Australia NT).

Editorial comment by Dr Danielle Clode.

Project management by Jack Sach, Alzheimer's Australia Vic.

© Alzheimer's Australia 2009
ABN 796 2558 2771

FOREWORD

Hon Michael Kirby AC CMG

In the past, Australian gay men and lesbians, bisexuals, transexuals and other members of sexual minorities (GLBTI), commonly hid their sexual orientation. This was a burden on their relationships with their birth families, their neighbours, their work fellows and the world at large. There was a rule to live by: 'Don't ask. Don't tell'.

The result of that rule was sometimes that members of sexual minorities were absorbed, more or less, into the majority heterosexual population. Some even married and had children, although their relationships frequently suffered because of the internal conflicts. Others pretended, although frequently observers of their lives would whisper behind their backs and often in a nasty and critical way.

Fortunately, the twentieth century witnessed a rise in enlightenment. This came about, in part, through science, following the research of Dr Alfred Kinsey and others into human sexuality. And, in part, through changes to the law reflecting and stimulating changes in social attitudes, many of them coming about following the Wolfenden Report in England in 1957. Science and law can change as much as they like but attitudes of prejudice will frequently remain. Sadly, some such attitudes of prejudice are caused by religious instruction. Fortunately, this too is changing in many quarters.

The first generations of Australians who lived through the new discoveries of science and the changes of the law and social attitudes, are now arriving at the ages when problems of dementia and Alzheimer's disease begin to affect members of the human family. These conditions do not discriminate. They fall equally upon heterosexual, homosexual and bisexual people.

Some things are new. Most people in Australia are living longer. Australia's population is ageing, with all of the health consequences that this produces. As well, many of those now beginning to face problems of dementia and Alzheimer's disease, represent the first generation of people living openly, or semi-openly, without shame or undue fear because of their minority status. Law reforms are being proposed and adopted to remove many of the residual legal disadvantages faced by sexual minorities. However, discriminatory attitudes and some discriminatory laws still remain. Alzheimer's Australia is to be congratulated for examining the particular impact of dementia and Alzheimer's disease on GLBTI minorities.

It may be hoped that, in the future, many of the problems described in this paper will be removed as prejudicial social attitudes and discriminatory laws give way to more just, equal and accepting approaches to members of the GLBTI minorities. In the meantime, our society has a number of problems on its hands. Some of these arise because of injustice in the law. Some derive from the predominant role that religious organisations play in many retirement and health facilities. Yet others exist because of residual fears in the minds of GLBTI people, left over from the times in which they grew up. This paper seeks to address all of these concerns and to do so in a short, readable account of where the problems lie; what can be done about them; and who can be contacted to help those in special need.

Special needs may be traced to the much higher levels of loneliness suffered by sexual minorities. One figure in this paper suggests that 46% of GLTBI people in Australia live alone, as compared to 23% of the general population. Living alone is specially difficult for a person facing a journey into dementia and Alzheimer's disease. Having no children or supporting family can also make the predicament worse. But even for those who live with

partners, the problems of making wills, protecting superannuation entitlements, demanding human respect and showing human affection present difficulties addressed in this paper.

It is a mark of the improvement in our society that the present investigation has been undertaken. Packed into its few pages is a lot of wisdom and practical advice. In a sense more importantly, there is also kindness, acceptance and recognition that we are all basically one. True spiritual values require that we recognise and respect this fact and accept that people are different in various respects - in gender, race, intelligence, beauty and also human sexuality. Yet these differences are insignificant beside the features we share in common. And in today's world, those features include the challenges of dementia and Alzheimer's disease.

A handwritten signature in black ink, appearing to read "Michael Kirby". The signature is fluid and cursive, with a prominent dot above the 'i' in "Kirby".

Hon Michael Kirby AC CMG

1 October 2009

Introduction

This paper was commissioned by Alzheimer's Australia to promote an informed discussion about the issues affecting lesbians or gay men with dementia or caring for someone with dementia. It addresses the issues associated with the interaction between service providers and lesbian and gay men with dementia and their family carers, including the complexity of family relationships and barriers that may affect care provision and quality of life.

The focus of this paper is on lesbian and gay seniors, including their same-sex partners. Not all people with dementia are seniors; however younger lesbians and gay men living with dementia may have a number of similar concerns and needs to those of lesbian and gay seniors. This paper also includes information about the needs of younger lesbians and gay men who are supporting a heterosexual family member living with dementia.

Some issues and concerns identified in this paper are shared by transgender people, as well as additional specific issues such as the impact of medical interventions on ageing, including surgical changes and hormone treatments over a long period of time. This paper encompasses the needs of those members of the transgender community to the extent to which they identify themselves as gay or lesbian, but does not address the specific needs of transgender people.

Dementia is a term used to describe the symptoms of a large group of illnesses that cause a progressive decline in a person's functioning. It is a broad term used to describe a loss of memory, intellect, rationality, social skills and what would be considered normal emotional reactions. There are different types of dementia with different implications for people living with dementia and their families and carers.

The impact of dementia is unique to the person, their family and carers. However, some generalisations can be made. For a gay or lesbian senior there may also be additional factors affecting the experience. This paper seeks to contextualise the issues involved and inform readers by way of discussion and case examples.

How many lesbian and gay seniors are there?

Australia lacks comprehensive data about the actual numbers of lesbian and gay seniors. The Australian Study of Health and Relationships (2003)¹ found that while only 2% of the population identify as non-heterosexual, up to 15% have experienced same-sex attraction or had sexual contact with someone of the same-sex. Older people may not identify as non-heterosexual, particularly if they have previously had a heterosexual relationship including marriage or if they do not have a current same-sex partner.

The Australian Census of Population and Housing collected limited information about same-sex relationships in 1996, 2001 and 2006. Almost twice as many people stated they were living in same-sex relationships in 2001 than in 1996 with an increase from 10,214 to 19,596 couples reporting their same-sex domestic partnerships. The 2006 Census figures reveal a further increase of 25.9% with 24,683 couples indicating a same-sex household relationship.²

Australians were not asked census questions about sexual orientation and gender identity in general. If an individual identified as gay or lesbian and was not living at the same address as their partner, did not have a partner, or was cautious about providing personal information due to concern about privacy, the individual was assumed to be heterosexual. The Australian Bureau of Statistics acknowledges that the number of same-sex couples is underreported³ and notes "a reluctance to identify and lack of knowledge that same-sex

relationships would be counted ... some people will worry about privacy, such as not feeling comfortable revealing that information in smaller towns where the Census Collector would be known to the person".⁴

Access Economics estimates an increase in the number of people with dementia from 227,360 (2008) to 465,460 (2030), an increase of 238,100 people. This expected increase is entirely due to demographic factors.⁵ If we assume that 8% of people with dementia may be non-heterosexual, a midway estimate between the 2%–15% findings by the Australian Study of Health and Relationships, by 2031 we could be looking at providing services to over 37,200 people who are not heterosexual.

What's different about lesbian and gay ageing?

A brief history

In many ways, the challenges faced by lesbians and gay men living with dementia will be no different to those of other people in a similar situation. However, it is important to recognise some of the issues and concerns raised when needing to seek help.

Many lesbian and gay seniors became adults in a time when homosexuality was considered to be unnatural, wrong, deviant and the basis for societal discrimination. They may have been accused of being sinners and encouraged to repent and see the evil of their ways. They may have been forced into therapy to cure their "mental illness" which frequently included aversion therapies. They may have lived in fear of "discovery" in case they were sacked. Some employers checked the daily media for the names of men arrested for "lewd acts" in public toilets. Both lesbians and gay men risked being dismissed from their employment based on their sexuality.

For many older gay men, the laws forbidding their expression of their sexuality shaped their younger years. Being oneself only with friends and 'closeted' to the rest of the world was about survival. They may now find themselves again in an atmosphere that is not supportive and even perhaps hostile.

A gay man aged 80 today may have developed his sense of identity and self-worth in a secret world where people like him hid their identities and maintained a very different public persona. He would have been 44 when the American Psychiatric Association declassified homosexuality as a mental disorder in 1973. He would have been 50 when the first Lesbian and Gay Mardi Gras was held in Sydney. When he was in his mid to late 50s he would have heard about a disease that killed many of his friends, and when he was almost 60 he may have feared identification and discrimination based on the Grim Reaper advertisements aimed at preventing the spread of AIDS screened on TV and in newspapers in 1987.

It was not uncommon for lesbians and gay men to enter into heterosexual relationships for cover as a form of 'passing' as a heterosexual or in the hope that 'it would all go away'. There may be previous spouses of the opposite sex and adult children for whom the person's current sexual identity is either unknown or an issue of contention.

Lesbians and gay men may make decisions several times in a day about whether to be 'out' or 'in the closet'. This may be a simple thing such as use of a pronoun when referring to a partner. It may be a decision about whether to refer to a partner, current or past, as 'my partner' or 'my friend' or 'my brother or sister'. Many daily activities and conversations don't require people to make a statement about their sexuality. But when lesbians and gay men begin to interact with services and support systems, this can become an issue.

Lesbian and gay seniors and partners may have concerns about confidentiality, uncertain about who may have access to their personal information? This fear may be based on

experiences or on a perceived likelihood of abuse. They may be very familiar with having to make day-by-day decisions about whether to be 'in' or 'out'.

Once lesbian and gay men reach old age however, they may find themselves dealing with services such as community care and residential aged care where staff may not understand their specific needs. Services may be based on the assumption that people using their services are heterosexual. Lesbian and gay seniors are often invisible. A person whose 'identity' is defined in some sense by their sexual orientation not only challenges assumptions about what is normal sexuality, but also our assumptions about ageing.

While behaviour may have been modified outside the home, most lesbian and gay seniors would have felt that they could be themselves inside their homes. Dementia and age-related disabilities may mean that previously carefully guarded behaviour may be forgotten and an individual inadvertently reveals his or her sexuality to others. The person with dementia may also identify a partner who has been discreet about their relationship for work or family reasons.⁶

For some older lesbian and gay seniors, home may have been the only safe place for them to be themselves, both when in a relationship or as an individual. Dementia means that others will come in to this private place, not just once, but on a regular basis. If uncertain about a service provider's attitude, older lesbians and gay men may try to retreat into invisibility hiding photos, books, paintings, and record, CD, video or DVD collections before each home visit.

Some older lesbians may have spent many years developing and maintaining their independence (from men) at a time when women were assumed to be dependent on others. They may be greatly challenged by the loss of independence brought about by age-related disabilities and dementia.

Ageism and social isolation

Some lesbian and gay seniors may face social isolation and ageism within the community including within the lesbian and gay community. This can be a particular problem for gay men who find themselves isolated and lacking social support. Research conducted for The ALSO (Alternative Lifestyle Organization) Foundation found that the experience of ageism for gay men "is embedded in the dominant character of social relations in the commercial scene, and many gay men feel that they have nowhere else to go".⁷ A culture which values youth and the body beautiful, and considers older gay men as predators looking for a young partner to boost their self esteem, can be very alienating. The research found that some lesbians also experience ageism; however the lesbian community was more accepting of older women.⁸

Many older gay men have survived as their friends and peers died from AIDS related conditions in the 1980s and 1990s. This loss of a source of friendship and the ageist attitudes of both younger and sometimes older members of the gay community can mean that older gay men are isolated and lonely at a time when they need support and validation of their identities.

Reduced access to networks of gay or lesbian friends, gay or lesbian interest or social groups and to the broader lesbian and gay communities can contribute to reduced health outcomes for lesbian and gay seniors. Social isolation and loneliness are commonly associated with depression, which is a common outcome of personal stress, and the mental health of lesbians and gay men is considered to be substantially at risk as a consequence of discrimination in societies in general.^{9 10}

The Legislative Context

Lesbians and gay men living with dementia and their families and carers are recognised and protected by a range of legislation in Australian States and Territories which cover antidiscrimination and recognition of same-sex relationships.

Decriminalisation of male homosexuality

South Australia became the first Australia jurisdiction to decriminalise some homosexual acts in 1972, followed by further reforms in 1975 and 1976. This was followed by law reform in the Australian Capital Territory (1976), Victoria (1980), Northern Territory (1983), New South Wales (1984), Western Australia (1989), Queensland (1990) and Tasmania (1997).

Relationships recognition

In Australia, the *Marriage Amendment Act 2004* (Commonwealth) inserted a definition of marriage into the *Marriage Act 1961* (Commonwealth) so that marriage is “the union of a man and a woman to the exclusion of all others voluntarily entered into for life”.¹¹

Same-sex relationships are recognised in various ways in Belgium, Canada, Netherlands, New Zealand, Spain, the United Kingdom and some states in the United States of America. Even if a same-sex couple is legally married under the law in another country, this marriage is not recognised in Australia.

However Australian States and Territories have acted to remove discrimination against same-sex couples through law reforms enacted between 1999 and 2006. Legislation recognises same-sex domestic partners as the next of kin. For example, Section 37 of the *Guardianship and Administration Act 1986* (Vic.) gives a list of the people who can consent to medical treatment for a 'disabled person'. The person's domestic partner (who does not have to be living with them) has the same status as a spouse and takes precedence over their nearest relative. Other States and Territories have similar legislation eg, *Guardianship Act 1987* (NSW).

Non-heterosexual couples in Tasmania can register a Significant Relationship with the Registry of Births, Deaths and Marriages. This is defined as a relationship between two adults who have a relationship as a couple, who are not married to one another, not related by family and where both people live in Tasmania.¹²

The Victorian State Government introduced legislation in late 2007 to establish a similar relationships register.¹³ The Queensland State Government is also considering introduction of a register.¹⁴ Civil partnerships can be registered in the Australian Capital Territory.¹⁵

Equal opportunity legislation

All States and Territories have equal opportunity legislation covering discrimination on the basis of sexuality. The actual terms vary, and include sexual orientation, sexual preference, sexual identity, lawful sexual activity, gender identity and transexuality. This legislation covers services including aged care.

Case study 1

Ann was living at home had a worker assisting her to shower because her partner Mary was no longer able to help her. Last week the worker asked if they were lesbians. Mary denied that they were because she was concerned that Ann would receive a lesser standard of care. However, one morning the care worker noticed they had both been sleeping in the double bed. The care worker refused to touch Ann in the shower. Mary was concerned because Ann needed a lot of assistance and she couldn't understand why the care worker wouldn't help. Ann was confused and distressed and Mary thought about ringing the service provider to make a report, but she didn't know what she should say.¹⁶

Human rights

Australian States and Territories are approaching the question of a human rights charter with different outcomes to date. Currently the Australian Capital Territory and Victoria have additional human rights protection through legislation.

During 2006 the Federal Human Rights and Equal Opportunity Commission (HREOC) conducted the National Inquiry into Discrimination against People in Same-Sex Relationships: Financial and Work-Related Entitlements and Benefits. Public hearings and community forums were held around Australia and the Commission received 680 submissions. The inquiry found that 58 federal laws breached the human rights of more than 20,000 same-sex couples in Australia.¹⁷ The report was tabled in the Federal Parliament in mid 2007.

In November 2008, the Australian Parliament passed laws that recognise same-sex couples in federal law, offering them the same rights as unmarried heterosexual couples in areas such as social security, taxation, veterans' affairs, aged care, Pharmaceutical Benefits Scheme and Medicare Safety Nets, citizenship and superannuation.

Detailed information about these reforms is available on the Same-Sex Law Reform page on the Australian Government Attorney-General's Department [website](#).¹⁸

Centrelink

From 1 July this year, Centrelink has recognised all couples, regardless of sexual orientation or gender of a partner.¹⁹

Benefits of this change include access to concession card benefits for some partners, bereavement benefits following the death of a same-sex partner, and exemption of the family home from being asset tested when one partner enters high level care and the other partner continues to reside in their home.

However, from 1 July 2009, same-sex couples on Centrelink payments are paid the lower couple rate, rather than the higher single rate. Where one member of a couple is still working or has a high retirement income, the Centrelink recipient may lose their pension and Pensioner Concession Card once the income and assets of their partner are taken into account.

This may be of considerable concern to some same-sex couples, who have lived and worked during a time when there was no expectation of legal relationship recognition. Many of these people have missed out on a lifetime of financial benefits that were available to heterosexual couples. These include income tax law, family law, health insurance, property rights, access to insurance and superannuation, laws of succession and employment benefits for partners

Some have entered into financial agreements based on what they believed to be their fixed income. Depending on their partner's status, this may now be considerably reduced, and they could find themselves unable to meet mortgage or rental payments.

The Federal Government has decided not to allow a 'grandfather' clause which would keep existing pensioners in same-sex couples on their current arrangements and only apply the new law to new applicants, as has happened with changes to Wife's and Widow's Pensions, and the qualifying age for Age Pension for women.

The legal requirement to declare a same sex relationship to Centrelink may cause stress and anxiety for individuals who have long standing concerns about revealing their sexuality to Government agencies.

Advanced care planning issues

Planning for the future is very important. Although same-sex relationships are recognised under various State and Territory laws, it can add extra stress at times of crisis if a partner has to 'prove' their interest in and association with the partner with dementia.

Some members of a family of origin may dispute property ownership and guardianship with the partner when dementia has progressed and there is a question of mental capacity. The family of origin may also try to exclude a same-sex partner from care of the partner with dementia.

Advanced care planning is not just about legal and financial matters, it is about whether the relationship is to be declared to service providers. There are two people in a relationship—each one has the right to decide whether to let others know about their sexuality. Discussion on this matter should be encouraged while both partners still have the capacity to decide whether or not they wish to let service providers know about the relationship.

Each State and Territory has different legislation and requirements covering decision making when a person loses the capacity to make their own decisions. So that everyone is clear about the wishes of each person, and to provide more formal evidence of a same-sex partnership, it is important that lesbians and gay men have current legal instruments, such as Enduring Powers of Attorney, Advance Health Care Directives and Enduring Powers of Guardianship covering financial decisions, medical treatment decisions and lifestyle and health care decisions.

Further information about advanced care planning, including details about the instruments specific to each State and Territory, is contained in Alzheimer's Australia's position paper on *Legal Planning and Dementia*, available on the Alzheimer's Australia website at www.alzheimers.org.au.

Superannuation

For superannuation purposes, the meaning of the word 'dependent' was widened with effect from 30 June 2004 to include a person living in an 'interdependency relationship' with another person. Often this will include people living in same-sex relationships.²⁰

However not all superannuation funds recognise same-sex partners as dependents. It depends on the rules of the fund.²¹ It is important that lesbians and gay men who have a partner check with their funds about whether the fund rules acknowledge same-sex partners

as dependents, and whether they are bound by Binding Death Benefit Nominations. To provide instructions to fund directors, lesbians and gay men of any age who have superannuation funds should complete a Binding Death Benefit Nomination form for each fund. This nomination needs to be confirmed every three years to remain current. Nomination forms are available from superannuation funds.

Tax treatment of lump sum death benefits also depends on whether or not the beneficiary is defined as a dependent.

Wills

Dying intestate adds additional stress for any surviving same-sex partners. When other family members may deny the existence or legitimacy of a same-sex partnership following the death of one of the partners, this adds to the grief for the surviving partner. Even though State and Territory legislation includes same-sex partners in its definitions of next of kin, the onus of demonstration of the relationship at a time of stress is substantial. It is essential that same-sex couples organise their affairs so that wills clearly state their wishes. If this has not been done, and there is still capacity to make decisions, completion of up-to-date wills should be encouraged.

Families and Caregivers

Families can be complicated at the best of times. 'Family' can be a concept fraught with complex emotions for lesbians and gay men of any age. Who is regarded as family can vary greatly depending on the personal situation and experience of each individual. Lesbians and gay men may refer to their 'family of origin' which may or may not be a part of their everyday lives, and their 'family of choice' which may include a same-sex partner and/or members of the lesbian and gay community.

There are many caring relationships involving a gay or lesbian senior, including:

- Lesbians or gay men providing care for a same-sex partner (living together or separately), a member of the lesbian and gay community, or care for heterosexual parents or other relatives,
- Lesbian, gay or heterosexual adult children providing care for a lesbian or gay parent or co-parent, and
- Heterosexual people providing care for an ex-partner, friend or parent who has 'come out' as lesbian or gay later in life

Lesbian and gay seniors may have been rejected by, or have rejected, their families of origin. This may be a long standing estrangement or may have happened more recently. For some, the rejection by their family may have happened when they were much younger and may have occurred in response to their 'coming out'. Others may have been 'come out' or been 'outed' by others as gay or lesbian later in life and been rejected by their adult children.

Many lesbian and gay seniors are less likely to have adult children who can provide support and care. Research on the health and wellbeing of gay, lesbian, bisexual, transgender and intersex people in Australia found that lesbian and gay seniors are much more likely to live alone (46% vs. 23% of the general population).²²

The family who rejected their gay or lesbian members may now find themselves in a position where they need to call for support. Heterosexual siblings may assume gay or lesbian family members have fewer responsibilities and ties and therefore are more available to provide care. They may be expected to, or offer to, provide care for a family member who has previously rejected them based on their sexual orientation.

Case study 2

Jason's mother has been diagnosed with Alzheimer's disease. She would be able to continue living at home if someone provided ongoing supervision. Jason's sister is married and has two young children. She thinks her unmarried brother should consider either moving back into the family home to provide care or having their mother move in with him. Jason originally moved out because his mother could not accept having a gay son. He feels torn between his concern about her and his own need to be himself.

A diagnosis of dementia may mean a resumption of, or increase in contact with, other family members who have not accepted, or may not know about, the same-sex relationship. The experience of living with dementia is different for each person and for their families and carers. Same-sex partners may have less support from their families of origin for their role providing care. As dementia progresses, the relationships with families of origin and families of choice may also change. These changes also affect people in heterosexual relationships. However there may be added pressure for same-sex partners who may be assumed to be a brother, sister or friend.

Case study 3

Two women who had lived together for some years were admitted to residential care and placed in adjoining rooms and treated as a couple by staff. Jean had dementia; while Sally, who had been providing care at home, was now physically frail. Then Jean's adult son demanded that staff separate the two as his mother 'was not a lesbian'. He also requested that they not be placed at the same dining table or sit together in the lounge area. The staff complied with his request. Both women were very distressed. Jean's confusion worsened and she became agitated.

Some lesbian and gay families may include children who recognise both adults as parents. This may apply when children have been planned by the couple and where one partner has entered the relationship with a child. For other lesbian and gay seniors, their family of choice may be friends or members of the lesbian and gay community. The strong community networks that have been established to support people living with AIDS related conditions, for example, have become 'family' for some gay men.

Issues for Service Providers and Care Workers

Society assumes that people are heterosexual and that their relationships with others are based on this. Generally there is no need to draw attention to an individual's sexuality. However lack of information and an understanding about someone's life experiences, cherished current and past personal relationships and associations with other family of origin members can impact on a service provider's ability to provide the best care.

The provision of quality care services requires a complete picture of a person's every day life and support systems. For lesbian and gay seniors, this means providing an opportunity to 'come out' by affirming sexual orientation and gender identity to health or home care providers.

Some lesbian and gay seniors may be reluctant to access services because of past negative experiences with institutions and people in authority. They may have needed to maintain strict privacy around their sexuality and gender identity. They may be very cautious about whether attitudes have really changed and to whom they can safely disclose information. Lesbian and gay seniors may evaluate the attitude of each new service provider and worker to consider whether to be 'out' or not in each situation. They may be concerned that, if they scratch the surface of what appears to be 'tolerance', things may not have really changed at all.

Workers come from a variety of cultures and backgrounds with varying levels of knowledge and experience and may be uncomfortable working in a situation they do not approve of or understand. Being a homosexual may have been a sin against nature determined by God, or a crime punishable by death. It may be a real challenge to provide care to a lesbian or gay man. Service providers need to be alert to this and how it may impact on an individual worker's relationships with lesbian and gay seniors and their families and carers, and the quality of care being provided. An atmosphere of silence can contribute to and maintain discrimination.

Case study 4

During conversation with her personal care worker, Lucy mentioned that the woman in a photo next to her bed was her previous partner. She noticed that the care worker began to spend less time making sure her skin was dried properly and provided minimal assistance with dressing. Lucy wondered if this was because of the conversation but she didn't want to 'make a fuss'.

In 2002, the Australian Medical Association noted that "Australia's aged care policies make no reference to the specific needs of (gay, lesbian, bisexual, transgender, intersex) older people, particularly in relation to institutional care. There is a need to recognise sexual and gender diversity within the aged care sector as this lack of recognition means that health needs of older people are not being adequately addressed with culturally appropriate care."²³

Service providers may believe that their services are open to all and everyone is treated the same. They may say an individual's sexuality is private and the service doesn't need to know. In an agency that values diversity, the goal is not to treat everyone as if they are the same. Policies and processes need to recognise the differences both among staff and service users, while ensuring that these differences do not impact on the quality of employment or service provision.

Australian research has found that fear of prejudice or discrimination sometimes causes some lesbian and gay seniors to modify their daily activities at home. This has been

associated with a possible renewed need to 'hide' when accommodation options change with age.²⁴

Lesbians and gay men living with dementia and their partners may believe that service providers and care workers will be uncomfortable with their sexual orientation. They may not trust in representatives of authorities, official organisations and institutions. They may fear physical or emotional abuse if their sexual orientation is disclosed. They may think a care worker will judge them, pity them, avoid physical contact, harass them, treat them as an object of curiosity, betray confidences, provide poor quality services or reject them. This is usually an even greater issue in rural areas where individual lesbian and gay seniors are more likely to be more 'closeted' and therefore less visible and more socially isolated.

In the early stages of dementia, some lesbians and gay men with dementia may become concerned and frustrated when trying to remember how much they have revealed to a service provider. Remembering the fictions that may have been created to prevent being identified as lesbian or gay becomes harder.

Case study 5

Wesley and Jim have lived together for 43 years. Wesley now lives in an aged care facility and Jim visits him every day. Each morning when he wakes, Wesley asks where Jim is. Jim has been diagnosed with prostate cancer and needs chemotherapy. He remembers a 'bad experience' with a service provider and doesn't want everyone to 'know his business'. He wants to make a recording of his voice to be played to Wesley to reassure him when Jim is not able to visit. He is not sure who to ask for help.

As dementia progresses, past relationships may be remembered and recognised more than current ones. If the past relationships have been heterosexual, a current same-sex partner may feel totally rejected and alone.

Lesbian and gay seniors may also not be used to mixing with the opposite sex.

Case study 6

Bob and Ken had been a couple since they met at a gay club in the 1970s. Ken has been providing more and more care for Bob as he forgets things previously taken for granted. Following some tests, Bob has now been diagnosed with Alzheimer's disease. All their social visitors at home have been men. If female service providers come to their home, Ken knows that Bob will be confused and may become agitated. Ken is very concerned about their relationship becoming 'public property'. He does not want his private world becoming something that others will scrutinise and judge.

In the mind of some service providers, non-heterosexuality may be equated with HIV positive status or AIDS. Ill-informed service providers may view lesbians and gay men as an infection threat and inappropriately take precautions, disrespectful of personal dignity and privacy and identifying individuals as a 'problem'. This may include requiring care workers to wear latex gloves whenever interacting with a lesbian or gay man or asking the person themselves to do the same.²⁵

Some people living with dementia will be HIV positive. This may be the case no matter whether the person is lesbian, gay or heterosexual. Some will have AIDS. Many will not. It is likely that they will be very familiar with the need to create their own reliable support networks and to be very cautious about who to trust with personal information.

Further information about AIDS related dementia, its cause, symptoms, diagnosis and treatment is contained in the Alzheimer's Australia Help Sheet *AIDS related dementia* available on the Alzheimer's Australia website at <http://www.alzheimers.org>

While some lesbian and gay seniors may not wish to be open about their sexuality, this approach may not be shared by the baby boomer generation which is the next cohort to move towards using aged care services. Baby boomers may be more likely to have been able to live more openly as lesbians or gay men. They may also be less likely to accept either community or residential care which is not sensitive to their needs and may discriminate against them. This has implications for how aged care and other support services are provided. When discussing this with younger gay people their response is often "Other people just have to accept me as I am!". This perspective is not generally shared by lesbian or gay seniors who may fear the repercussions if their sexual orientation is uncovered.

Assessment

Holistic assessment involves the people who matter most to the person being assessed. Assessment staff may find it difficult to determine who is next of kin. Determining the best interests of someone with dementia can be difficult. There may be adult children who demand to have their say. They may see a needs assessment as an opportunity to interfere in a same-sex relationship which they do not approve of.²⁶

Intake forms which provide an opportunity to declare a partner of either sex and brochures and other promotional material about a service which use inclusive images can help reassure people that a service accepts and acknowledges all significant relationships.

A person with dementia may not be able to insist that their same-sex partner be involved and consulted during an assessment.²⁷ A partner may be denied information. Listening to the language used by a person living with dementia or the person who may be with them can assist service providers to identify that someone is lesbian or gay. The words 'my friend' or 'my companion' may be more comfortable for older people than the words gay, lesbian or partner. It may be obvious to service providers that a person living with dementia and their family carer are a partnership.

Assessment workers need to demonstrate their own acceptance of whatever a relationship may be through use of inclusive language and creating a trusting environment for the person with dementia and their partner during the assessment. Even if there is not an explicit statement about the nature of a relationship, same-sex partners can be involved in care plan discussions as a significant person.

Community care

When dementia is diagnosed, what was previously a private domestic relationship now involves more people as medical, health care and aged care services become involved. It can be difficult for anyone to acknowledge that they need to use services to support them in everyday living tasks they once took for granted. Home is a private place into which other people generally only come if invited. Accepting support may mean that independence is threatened and personal privacy becomes a thing of the past. This may be more of a concern for lesbian and gay seniors.

Case study 7

Bill and Chris have been living together for 38 years. During the past few years, Bill has taken on more caring responsibilities and now Chris has been diagnosed with dementia. Bill's arthritis is making it more difficult to do the housework. The assessment team has suggested that he join a local carer support group and referred him to the local council for home help. Bill is worried about dealing with new people who may not understand his home situation. Will he have to hide their photos each week so the care worker thinks that his partner is just sharing the house? He wonders whether to pretend that Chris is female when talking with the support group.

Gay and lesbian seniors may be uncertain about their welcome at carer support groups. Some will feel the need to assess whether there will be negative reactions if they mention their partner's name. If they are caring for a heterosexual relative, they may feel that they cannot talk about the impact this has on their own lives and any current or potential relationships. They may be coping with insensitivity from other members of their family of origin. They may feel that their relationships are not acknowledged, accepted or valued by other group members.

A lifetime of 'passing' and being alert to possible negative attitudes may mean that lesbian and gay seniors are more sensitive to comments that may be made in jest which question their sexuality.

Case study 8

Ron's partner John was a gentle man who was well spoken, dressed well and enjoyed cultural activities. As John's dementia progressed Ron reluctantly agreed to take him to a planned activity group for two days each week so he could have a break. One day Ron overheard a worker ask John if he was a man or a woman today. Ron was upset and would not take John to the group again.

The response from other group members (and service providers) may well be positive and supportive; however the uncertainty can create considerable stress for lesbian and gay family carers.

Residential care

The process of selecting a short/long-term care facility can be a difficult one. Often the decision needs to be made quickly and occurs within the context of strong emotions such as guilt, fear, and doubt. Aged care information may be based on an assumption that all people who use the service will be heterosexual, eg current agency brochures, assessment process and intake forms do not indicate openness to acknowledging a same-sex relationship.

Care standards may be compromised as a consequence of negative and ill-informed staff attitudes. Some staff may be hostile or dismissive. In the case of residential care, other residents may also share these attitudes.

Case study 9

Paul and Mark had been together for almost 20 years when Mark was diagnosed with dementia. When Mark went into a nursing home Paul felt that his world was torn apart. He wanted to tell the staff that his partner was not the same person that he met and fell in love with and how much pain he had that Mark didn't always recognise him. He wanted the staff to know that the pain of dementia didn't differentiate between a gay or heterosexual person. He wanted to tell them he had the same pain, trauma and grieving and that he loved his partner like heterosexual couples do. He didn't tell staff because he didn't know if they would understand.²⁸

Just because some staff may be gay or lesbian does not mean they will understand the specific needs of lesbian and gay seniors. Their life experiences may be quite different, particularly for younger staff.

Accommodation payments

Understanding the aged care system can be difficult. When people enter residential aged care, there are a number of fees and payments that may need to be paid. The details will depend on whether the facility is low care or high care.

The *Aged Care Act 1997* sets out how these fees and payments should be calculated. The following information applies to people admitted to residential aged care prior to 1 July 2009. Because of the definitions of 'partner' and 'member of a couple' and the lack of recognition of a same-sex couple as a 'real' couple, a person in a same-sex relationship can end up paying more than a person in an opposite-sex relationship. This applies to both de facto and married heterosexuals, where the value of the family home is exempted from the assets and income tests used to calculate fees and payments.

Information available from the Commonwealth Department of Health and Ageing states:

"The value of your former home will not be counted as an asset if, when you enter the aged care home:

- your spouse or dependent child is living there;
- a carer eligible for an income support payment has lived there for two years; or
- a close relative who is eligible for an income support payment has been living there for at least five years."²⁹

Department of Health and Ageing information notes that the home can remain exempt from being counted as an asset for up to two years after the person enters aged care and for an indefinite period while a partner of the opposite sex remains in the home.

The HREOC Inquiry found that the *Aged Care Act 1997* does not recognise same-sex relationships. Because partners are treated as two individuals, there is a likelihood of discrimination when one of the partners is admitted to residential aged care. The Inquiry identified the following inequalities:

- "A same-sex partner is more likely to be *liable for accommodation payments*, because the family home is not exempt from the assets test as it is for an opposite-sex couple.
- A same-sex couple will usually pay a *higher accommodation charge* than an opposite-sex couple.
- A same-sex couple will usually pay a *higher accommodation bond* than an opposite-sex couple."³⁰

If the person being admitted to residential care is leaving a home shared with a same-sex partner, the aged care provider can treat the former home as an asset where the same-sex partner who has been providing care is not eligible for an income support payment. This could mean that the newly admitted resident is expected to sell their former home two years after the admission to finance the accommodation payment and could leave their partner without a home.

The HREOC inquiry was told that many lesbian and gay seniors, whose partners needed to enter a high-level care facility, were potentially faced with having to sell their home to pay high fees.³¹

There has been room for discretion on the part of residential aged care service providers when deciding about accommodation payments. The issue for a same-sex couple will have been their willingness to declare their relationship to the provider and to seek similar treatment to a heterosexual couple.

From 1 July 2009, same sex and opposite sex couples will be treated the same way. More information is available on the Australian Government Attorney-General's Department [website](#).

Aged Care Accreditation Standards

Ideally the Australian Aged Care Accreditation Standard 3, relating to Resident Lifestyles, should enable a gay or lesbian person living in residential aged care to receive quality services that are appropriate to their needs. This standard requires that "Residents retain their personal, civic, legal and consumer rights and are assisted to achieve active control of their own lives within the residential care service and in the community."³²

The standard includes providing support to maintain independence, friendships and participation in the life of the community, including outside the aged care service (Standard 3.5). Service providers should be encouraged to look at ways to assist lesbian and gay seniors to maintain connections with their familiar communities. This may include ensuring that lesbian and gay literature and publications are available and that residents have access to private Internet access for connections to the lesbian and gay friends and community through email, chat rooms and on-line information.

Case study 10

Elizabeth was aged in her eighties when she was placed in a secure nursing home, where the staff presumed that she would wear dresses. When her ex-partner visited she was horrified as Elizabeth had always worn long pants. However she did not know how to approach the staff about this issue.³³

Other parts of the standard that are of particular interest to lesbian and gay seniors cover residents' rights to privacy, dignity and confidentiality; encouragement to participate in a wide range of interests and activities of interest and being able exercise choice and control over his or her life while not infringing on the rights of other people.

Information about how residential care service providers and care workers can comply with the Aged Care Accreditation Standards, particularly Standard 3 is contained in Alzheimer's Australia's *A Guide to Practice for Managers in Residential Aged Care Facilities*, and *Practice in Residential Aged Care Facilities for all Staff*, both available on the Alzheimer's Australia website.

Other residents

There are also potential issues of acceptance of lesbians and gay men by their fellow residents in aged care facilities. Recent research conducted for the Australia Institute looked at the extent of homophobia in Australia. Homophobia was identified with those who believe that homosexuality is immoral. The research found that 35 per cent of the population aged 14 years and above believes that homosexuality is immoral. When broken down by gender, nearly 43 per cent of men and 27 per cent of women take this view.³⁴

The research found that older Australians are considerably more homophobic than young adults; 53 per cent of people aged over 65 who were surveyed adopt this view compared to 26 per cent among 18 to 24 year olds.³⁵

Lesbian and gay residents and their partners and friends will need reassurance that their rights to privacy will be respected. Dementia may mean a reduction in the ability to conceal and self-censor behaviour and information disclosure. Other residents, with whom they share very little in terms of life experience or way of life, may demonstrate prejudice towards a non-heterosexual resident or their family of choice.

Case study 11

Judy had lived as a woman for 30 years before she was admitted to aged care. She had taken great care over her appearance. Sometimes staff did not have time to assist with applying her make up. One day a care worker's ring caught in her wig and it slipped, showing her balding head. Some of the other residents saw this happen and requested not to sit at the dining table with 'that man'.

Intimacy and relationships

There are difficulties relating to sexuality faced by lesbians and gay men living in residential aged care facilities. Lesbian and gay seniors may be very fearful of showing any signs of affection or any physical intimacy due to taboos against displays of same-sex affection.³⁶ Sexual expression and physical demonstrations of caring such as holding hands can be seen as a problem. Ageist myths and stereotypes related to sexuality and ageing may impact on care provided for lesbians and gay men as well as for heterosexual seniors.^{37 38}

Case study 12

Gary visited the hostel every weekend to see his partner Andrew. He was getting used to the aged care facility and the staff. Gary had told them that they were partners and none of the staff had made any negative comments. However, on a number of occasions, while Gary was holding Andrew's hand, other residents made derogatory remarks about homosexuals. Gary understood the other residents had dementia and thought of being more discreet but Andrew was more settled when he was affectionate. He thought about talking to staff but he wasn't sure he had their support.³⁹

Within residential care facilities there is high level supervision and support of people with dementia. This can exacerbate fear of 'discovery' by care workers and other residents, particularly for a same-sex partner. It can also prevent other family of choice members, particularly gay men, showing any physical affection in case this 'outs' the resident within the facility.

Case study 13

David and Doug met at a music appreciation group. They became good friends over many years and were part of a broader social network of older gay men. Doug was eventually admitted to aged care and David visited whenever he could. He was Doug's only contact with his life prior to admission. One day David overheard two staff members laughing and talking about the two old fags and wondering if they 'still did it'.

Dementia may mean that a resident is less able to self-censor expression of their sexuality. Management of sexual disinhibition for gay or lesbian residents is no different to management for heterosexual residents.

People living with dementia continue to need caring, safe relationships and physical touch. Service providers need to provide support to enable residents who do wish to have intimacy and/or a sexual relationship, either with other residents or with a non-resident partner to do this safely. Further information about how service providers can provide support is contained in the Alzheimer's Australia SA publication *Intimacy, Sexuality And Sexual Behaviour In Dementia* available on the Alzheimer's Australia website at <http://www.alzheimers.org>.

Special issues for transgender people with dementia

The HREOC inquiry found that “Aged care services do not adequately cater for people with diverse gender identity...Transgender and intersex people are also particularly vulnerable to discrimination in aged care settings, to the point where they may avoid seeking assistance altogether. There is anecdotal evidence of denial of services, forcibly preventing cross-dressing and deliberate physical violence when people are revealed to be transgender. Transgender people may also have medical issues related to their original gender that emerge with ageing, such as osteoporosis or prostate cancer.”⁴⁰

Dementia may mean that a post operative transgender woman may forget that her external gender aspects have been changed and may be confused and distressed about how to go to the toilet. As with any other confusion based on memory loss, care workers need to reassure and assist her.

Late stage care issues

For lesbian and gay seniors, past experience with religious institutions may have been negative including condemnation, intolerance, rejection and expulsion and even coercive therapy to ‘persuade the sinner to repent their evil ways’.

Capital cities generally have a number of inclusive religious organisations and churches that can provide spiritual support for lesbians and gay men. These include the Metropolitan Community Church and a number of supportive mainstream parishes and groups associated with the Roman Catholic, Anglican and Uniting Churches. Information is available from state and territory community organisations listed below in this paper.

Some lesbian and gay seniors may never have had the chance to grieve the loss of a partner. They may have been prevented from providing comfort and support to a dying partner by others who denied their relationship. If their partnership was invisible to others, there may have been no acknowledgment of the significance of their loss.

It is important that care workers include and support any same-sex partner, or other family of choice if appropriate, as key people providing support for a lesbian or gay man who is dying. In the early stages of dementia, the primary carer or care workers should encourage the person with dementia to talk about who they want to be at their funeral. Some of these people may not be known to their partner or family.

Following death, members of the family of origin or adult children of the person who has died may try to take over without consulting the surviving partner. Service providers may need to be advocates for a surviving same-sex partner when dealing with other grieving family members.

Case study 14

When Rhonda was diagnosed with dementia, her partner Dawn provided care with the support of various aged care services. Rhonda’s son, James, was unhappy about this but as he lived on the opposite side of the city to his mother, Dawn’s care really helped make things easier. Dawn and Rhonda had talked about how they wanted their ashes to be taken to their favourite beach and sprinkled in the water. However when Rhonda died, Dawn was upset to find that James had arranged for a burial service. When Dawn questioned this, the funeral director said he was doing what Rhonda’s next of kin had requested.

Further information about end of life issues is contained in Alzheimer’s Australia’s (AA) Paper No 7 on *Palliative Care and Dementia*, available on the Alzheimer’s Australia website.

Where to Get Help

Alzheimer's Australia

Alzheimer's Australia is the national peak body for people living with dementia, their families and carers and provides leadership in policy and services.

To find out more, call the National Dementia Helpline on 1800 100 500 or search the website www.alzheimers.org.au

Services and support

Support can make a positive difference to managing dementia. Alzheimer's Australia is available to assist. Alzheimer's Australia provides a range of sensitive and flexible services to support people with any type of dementia, their families and carers:

- Information about dementia
- National Dementia Helpline on 1800 100 500
- Support groups for people who have been diagnosed with dementia
- Private and confidential counselling
- Other programs and services in the local area such as recreation activities for families, friends, carers and people with dementia

Service details may differ between State and Territory organisations.

Education and training

Education and training courses provide valuable skills and support, and complement our other services. Both accredited and non-accredited short courses and workshops are offered for service providers and care workers, families and carers, and people with dementia. Alzheimer's Australia offers timely skills and knowledge in a supportive environment. Educators and session leaders are highly qualified and are experienced in providing information and support. Refer to the Alzheimer's Australia website for details.

Alzheimer's Society UK

Website: www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200204

The Alzheimer's Society UK has a number of resources of interest and support. These include a Lesbian and Gay Alzheimer's Society Carer's Network and a Lesbian, Gay, Bisexual and Transgender Carers group, which provides a telephone support service for anyone who is lesbian, gay, bisexual or transgender and who is, or who has been, caring for someone with dementia. Other resources include a regular newsletter and inclusion pack.

Rainbow Carers

Carers Victoria provides a range of services for lesbian and gay carers including:

- Advice, resources, and referrals
- Emotional support and counselling
- Education and training workshops

Contact: Carers Victoria on (03) 9396 9500 and mention Rainbow Carers. The service is open between 8.30am and 4.30pm Monday to Friday, with the exception of Victorian public holidays.

Legal rights

Information about the legal rights of lesbians and gay men is provided by the Victorian Lesbian and Gay Rights Lobby, including *Over the Rainbow—A Guide to the Law for Lesbians and Gay Men in Victoria* available at <http://over-the-rainbow.org/>.

The Attorney General's Department of New South Wales also produces a similar guide, *Understanding your legal rights—a guide for lesbians and gay men in NSW* available from http://www.lawlink.nsw.gov.au/lawlink/cpd/ll_samesex.nsf/pages/samesex_equal

Useful community organisations

New South Wales

ACON

Website: www.acon.org.au

ACON is a community-based non-government organisation promoting the health and wellbeing of a diverse gay, lesbian, bisexual and transgender community, and a leading agency in HIV/AIDS policy development and program delivery.

Contact: 02 9206 2000 Email: acon@acon.org.au

Victoria

The ALSO Foundation

Website: www.also.org.au

ALSO (Alternative Life Styles Organisation) works to enhance the lives of Victoria's diverse gay, lesbian, bisexual and transgender communities through securing legal and social acceptance and to assist members of the GLBT community to acquire the skills and capacity to achieve equality and justice.

Contact: 03 9660 3900 Email: also@also.org.au

Queensland

LGBT Ageing Action Group

Website: www.qahc.org.au/seniors#lgbt

Developing strategies to support and address the needs for LGBT seniors and carers in Queensland in association with several community organisations.

Contact: 07 3017 1791 Email: pmartin@qahc.org.au

South Australia

The Gay and Lesbian Community Service

Website: www.glcssa.org.au

Offers information, counselling, referrals, accommodation and library. Can also provide information relating to the Northern Territory.

Contact: 08 8422 8400

Western Australia

GLBTI Retirement Association (GRAI)

Website: www.grai.org.au

GRAI fosters the creation of accessible and sustainable retirement living, aged care and community services that specifically cater for the needs of older people of diverse sexualities and gender identities.

Tasmania

Gay and Lesbian Community Centre

Offers information, support and counselling.

Contact: Email though website - www.glctas.org

Australian Capital Territory

AIDS Action Council of the ACT Inc

Offers information, support and counselling.

Contact: 02 6257 2855

Transgender information

The Gender Centre

Website: www.gendercentre.org.au

Sydney-based organisation offering a wide range of services and information to people with gender issues, their partners, families and friends. Their website has a range of information on many aspects of transition.

Contact: (02) 9569 2366 Email: gendercentre@bigpond.com

TransGender Victoria

Website: www.transgendervictoria.com

An advocacy group striving for justice and equity for those identifying as transgender, transsexual or cross-dresser, their partners, families and friends. Areas of involvement include education and legislative change. TransGender Victoria provides support and referral for a range of personal and family problems.

Contact: (03) 9517 6613 (voicemail) Email: transgendervictoria@yahoo.com.au

Further reading

Gay and Lesbian Health Victoria Clearinghouse

Website: www.glhv.org.au/clearinghouse

Provides accessible and up-to-date health information and resources based on the social model of health.

Psychology Review

Website: www.groups.psychology.org.au/glip/glip_review

Lesbian and gay Issues and Psychology Review Vol 2, No 2 (2006) Special Issue: GLBTI Ageing

Age Concern (UK)

Website: www.ageconcern.org.uk/openingdoors

This UK based organisation has a number of resources available about lesbian and gay ageing as part of its Opening Doors initiative. Information materials include:

- *Issues facing older lesbians, gay men and bisexuals* (2002) and *Opening Doors Conference 2002* conference papers available to download from the website
- *Opening Doors: Working with older lesbians and gay men* (2001) and *The Whole of Me: Meeting the needs of older lesbians, gay men and bisexuals living in care homes and extra care housing* (available to order from Age Concern)

LGBT Aging Issues Network (LAIN)

Website: www.asaging.org/networks/index.cfm?cg=LAIN

Part of the American Society on Aging, LAIN works to raise awareness about the concerns of lesbian, gay, bisexual and transgender elders and about the unique barriers encountered in gaining access to housing, healthcare, long-term care and other needed services. Their website includes links to a wide range of resources and information.

Other publications

Department of Health (2007) NHS Briefing 4 - *Older lesbian, gay and bisexual (LGB) people*, Department of Health, London,
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_078347

Gallagher, J, Mason, J and Beat Box Betty (May 12 1998) *Mothering mom – gay children face special challenges when caring for aging parent*, The Advocate
<http://www.highbeam.com/doc/1G1-20830597.html>

Gross, J, (9 October 2007) *Aging and Gay, and Facing Prejudice in Twilight*, New York Times
<http://www.nytimes.com/2007/10/09/us/09aged.html?hp>

Harrison, J (2001) *It's none of my business': Gay and lesbian invisibility in aged care* Australian Occupational Therapy Journal. 48(3):142-145, September 2001

Harrison, J (2004) *Towards the Recognition of Gay, Lesbian, Bisexual, Transgender and Intersex Ageing in Australian Gerontology* School of Health Sciences, Vol. PhD, Adelaide: University of South Australia.

Los Angeles Caregiver Resource Center, *Fact Sheet: LGBT Caregiving: Frequently Asked Questions*
<http://lacrc.usc.edu/caregiverissues/factsheets/lgbtfaq.htm>

MetLife Mature Market Institute, (2006) *Out and Aging; The MetLife Study of Lesbian and Gay Baby Boomers* <http://www.metlife.com/assets/cao/mmi/publications/studies/mmi-studies-out-and-aging.pdf>

Royal College of Nursing and UNISON - *Not 'just' a friend: best practice guidance on health care for lesbian, gay and bisexual service users and their families*
www.unison.org.uk/acrobat/14029.pdf

Ward, R, Vass, A, Aggarwal, N, Garfield, C and Cybyk, B (2005) *A kiss is still a kiss? The construction of sexuality in dementia care* in *Dementia*, 4 (1) 49 - 72

Glossary of terms

This is a list of terms that may assist to understand the lives, issues and concerns of lesbians and gay men and their families and carers.

Accommodation Bond

Low level care and extra fee high level care - an amount you may be asked to pay when you enter low level care or an extra service place. It is like an interest free loan to the aged care home and by law it must be used by the home to improve building standards, and the quality and range of aged care services provided. (Department of Health and Ageing Information Sheet No 16)

Accommodation Charge

High level care other than extra fee - a daily amount fixed from the date of entry into care that you may be asked to pay in addition to your daily care fees when you enter high level care. (Department of Health and Ageing Information Sheet No 15)

Advance Directive

An Advance Directive (AD) is a statement by a competent person expressing their wishes in relation to their future health care, if they are not able to do so themselves at that time. A legal term that may differ between the States and Territories.

Ageism

Stereotyping, prejudice and discrimination based on a person's age. This could include the expectation that people of a certain age cannot or do not act, think or believe in a certain way.

Bisexual

A person who is sexually attracted to both men and women, although not necessarily to the same degree.

Butch/Femme

Common terms used by lesbians during the mid 20th century to describe adopted roles traditionally associated with men and women. This may have included clothing and demeanour, with butches assuming masculine identities and femmes assuming feminine ones. By the 1970s, butch-femme roles had fallen out of favour and were widely perceived by lesbian feminists as oppressive.

Closet (In the closet) (Closeted)

Undisclosed sexual orientation or gender identity – the opposite to being 'out'. Individuals may hide their sexual orientation and gender identity from all others, or in specific circumstances, eg at work, from parents, from health professionals, in certain social situations.

Coming out (Being out) (Out)

Voluntarily acknowledging one's own sexual orientation or gender identity. An individual's own acknowledgement may be referred to as coming out to yourself. This precedes any

coming out to others. An individual may be out in some aspects of their life but not in others, eg with close friends but not with family of origin. A person can be involuntarily 'outed' by others, eg by a partner with dementia.

Community

Term used as an abbreviation for a subset of society composed of people who are not heterosexual. This could be any combination of gay, lesbian, bisexual, transgender, intersex people.

Cross dresser

A person who has an inescapable emotional need to express their alternate gender identity and be accepted in that role on a less permanent basis. An example is a man who feels the need to wear clothing usually designated as women's clothing, such as a bra (as defined by Transgender Victoria Inc www.transgendervictoria.com).

Enduring Guardianship

A person appointed as an enduring guardian can make personal decisions on another person's behalf, such as living arrangements, medical treatment and services. A legal term that may differ between the States and Territories).

Enduring Power of Attorney (Financial)

A person appointed under an enduring power of attorney can make financial decisions on another person's behalf, for example disposing of assets, such as a house, or operating bank accounts. A legal terms that may differ between the States and Territories.

Family of Choice

People who are chosen to be part of an individual's family, eg same-sex partnerships, community of trusted friends who provide support similar to that of a family.

Family of Origin

People related by birth or marriage, including parents, siblings, aunt, uncles, nephews and nieces.

Friend

A term which may be used to refer to a same-sex partner, eg this is my friend.

Gay

Term used to describe people who experience lasting romantic and sexual attractions for the same-sex.

Gender Identity

A person's own sense of being male or female, which may not be the same as the sex allocated at birth.

GLBTIQ

An abbreviation of Gay, Lesbian, Bisexual, Transgender, Intersex, Queer, used to refer to people who are non-heterosexual. May be abbreviated even more eg GLBT or G and L.

Homosexual

See 'gay' above.

Homophobia

Fear of or discrimination against people who are lesbian or gay (homosexual) which may be demonstrated through hostility, disapproval of, or prejudice towards homosexuals as individuals, or homosexual behavior or cultures.

Intersex

General term used for a variety of conditions in which a person is born with reproductive or sexual anatomy or chromosomes that do not seem to fit the typical definitions of female or male.

Lesbian

Term used to describe women who experience lasting romantic and sexual attractions for other women. (Note: some older lesbians may refer to themselves as a gay woman, rather than use the term 'lesbian'.)

Medical Power of Attorney

The title given to a person who is legally appointed to make decisions relating to the medical care of another. A legal term that may differ between the States and Territories.

Passing

The practice of a person pretending to be of a sexual orientation other than their real one. Often used to describe someone being assumed to be a heterosexual rather than identified as gay or lesbian.

Same-sex relationship

A relationship between two women or two men.

Straight

Heterosexual.

Transgender

An umbrella term used to describe all those whose gender identity is at odds with their biological sex. This includes Transsexuals and Crossdressers (as defined by Transgender Victoria Inc www.transgendervictoria.com).

Transsexual

Person who identifies as a member of the 'opposite' sex, i.e. other than their birth sex. Transsexuals usually seek hormone therapy and often surgery to bring their body into line with

their gender identity. May use the terms MTF or M2F (male to female) or FTM or F2M (female to male). (As defined by Transgender Victoria Inc: www.transgendervictoria.com)

Transitioning

Transitioning often consists of a change in style of dress, selection of a new name, and a request that people use the correct pronoun. This may or may not include necessary medical care like hormone therapy, counselling, and/or surgery (as defined in Aizura A. Z., Walsh J., Pike A. and Jak (2006) *Gender Questioning*, a joint project of Trans Melbourne Gender Project and Gay and Lesbian Health Victoria).

References

- ¹ Smith, A, Rissell, C, Richters, J, Grulich, A and De Visser, R (2003) *Sex In Australia Sexual Identity, sexual attraction and sexual experience in a representative sample of adults* in Australian and New Zealand Journal of Public Health. 27 (2) pp138 – 145
- ² Australian Bureau of Statistics (2007) *2006 Census of Population and Housing Table 1 Main ASGC States and Territories (UR) by Relationship in Household for Person Records (includes people of all ages)* on <http://www.coalitionforequality.org.au/2006census.pdf> , accessed 24 November 2007
- ³ Australian Bureau of Statistics (2005) *Year Book Australia, 'Same-Sex Couple Families'*, p142
- ⁴ Dennett, H: *Sydney Star Observer* , More Gays Stand Up In Census, - Issue 873 - Published 28 June 2007 - <http://www.ssonet.com.au/display.asp?ArticleID=6679> - accessed 14 October 2007
- ⁵ Access Economics (2005). *Dementia Estimates and Projections: Australian States and Territories* Commissioned by Alzheimer's Australia, p 5
- ⁶ American Society on Aging, *How Diverse Cultures View Dementia*, Live Well, Live Long website http://www.asaging.org/cdc/module2/phase2/phase2_4.cfm - accessed 20 December 2007
- ⁷ Chamberlain, C and Robinson, R (2002) *The Needs of Older Gay, Lesbian and Transgender Persons*, a report prepared for the ALSO Foundation, Melbourne: Centre for Applied Social Science, RMIT University. pp iii and 25
- ⁸ *ibid*, p iii and 22
- ⁹ McNair, R, (2003) Lesbian health inequalities: a cultural minority issue for health professionals in *Medical Journal of Australia* 178 (12): 643-645
- ¹⁰ Fyfe, M, *Depression rates higher for gays*, in *The Age*, 31 March 2006 – accessed 9 December 2007
- ¹¹ Australian Government Attorney General's Department website – Getting Married section – http://www.ag.gov.au/www/agd/agd.nsf/Page/MarriageGetting_Married#section8 – accessed 14 October 2007
- ¹² <http://www.justice.tas.gov.au/bdm/relationships> - accessed 13 December 2007
- ¹³ *New Register To Recognise Committed Relationships*, Office of the Attorney General media release 4 December 2007
- ¹⁴ Clasher, I *Registry tipped for Queenslanders*, Queensland Pride <http://qlp.e-p.net.au/news/registry-tipped-for-queensland-2005.html> published 30 May 2008 – accessed 5 July 2008

- ¹⁵ *How to enter into a Civil Partnership*, Department of Justice and Safety, Office of Regulatory Services http://www.ors.act.gov.au/bdm/WebPages/bdm_civil.html - accessed 5 August 2009
- ¹⁶ Barrett, C (2007) *Case study 1*, unpublished research conducted for the Matrix Guild Inc and Vintage Men Inc
- ¹⁷ *Simple changes could end discrimination for thousands of Australian couples*, Human Rights and Equal Opportunity Commission Media Release (21 June 2007)
- ¹⁸ Australian Government Attorney General's Department website - Same Sex Reforms - Overview of the Australian Government's Same-Sex Law Reforms - <http://www.ag.gov.au/samesexreform> - accessed 13 June 2009
- ¹⁹ Australian Government Centrelink website - Centrelink recognises same-sex relationships from 1 July 2009 - http://www.centrelink.gov.au/internet/internet.nsf/individuals/same_sex.htm - accessed 13 June 2009
- ²⁰ The ALSO Foundation (2006) *Superannuation and Same Sex Couples - Legislative Overview* - accessed 15 December 2007 (no longer available online)
- ²¹ The ALSO Foundation (2006) *Superannuation and Same Sex Couples - Some common questions and answers relating to your superannuation* – accessed 15 November 2007 (no longer available online)
- ²² Gay and Lesbian Health Victoria, *Private Lives research outcomes* – unpublished presentation by Assoc Prof Anne Mitchell 12 February 2006 to a Melbourne meeting of community representatives and researchers on lesbian and gay ageing
- ²³ *AMA Position Statement on Sexual Diversity and Gender Identity*, (passed by the Federal Council of the AMA October 2002) <http://www.ama.com.au/web.nsf/doc/WEEN-5GA2YX> - accessed 18 December 2007
- ²⁴ Pitts, M, Smith, A, Mitchell, A and Patel, S (2006) *Private Lives - A report on the health and wellbeing of GLBTI Australians*., p 64
- ²⁵ Harrison, J, *Discrimination and older gays: surviving aged care* – in Anti Discrimination Board NSW *Equal Time*, Number 61 August 2004, p 3 http://www.lawlink.nsw.gov.au/lawlink/adb/ll_adb.nsf/pages/adb_et61 - accessed 8 October 2007
- ²⁶ *Domestic partners and next of kin: dealing with illness and hospitals*, in *Over the Rainbow*, Victorian Gay and Lesbian Rights Lobby - <http://www.over-the-rainbow.org/case-studies.php#CS6> , accessed 17 November 2007
- ²⁷ Human Rights and Equal Opportunity Commission (2006) *National Inquiry into Discrimination against People in Same-Sex Relationships: Financial and Work-Related Entitlements and Benefits*, consultations (Murray Bridge) 26 August 2006.
- ²⁸ Barrett, C op cit, *Case study 2*

- ²⁹ Australian Government, Department of Health and Ageing, *5 Steps to Entry into Residential Aged Care*, June 2006, p 26
<http://www.health.gov.au/internet/wcms/Publishing.nsf/Content/ageing-publicat-qcoa-16info.htm> - accessed 17 November 2007
- ³⁰ Human Rights and Equal Opportunity Commission (2007) *National Inquiry into Discrimination against People in Same-Sex Relationships: Financial and Work-Related Entitlements and Benefits*, p 325
- ³¹ *ibid*, p 415
- ³² Department of Health and Ageing, *Standards for Aged Care Facilities - Standard 3*,
<http://health.gov.au/internet/wcms/publishing.nsf/Content/ageing-standard-facility-std3.htm> - accessed 16 December 2007
- ³³ Human Rights and Equal Opportunity Commission, *op cit*, Written Notes (Murray Bridge) 29 August 2006 -
http://www.hreoc.gov.au/Human_Rights/samesex/inquiry/MurrayBridgeForum20060829.html - accessed 31 October 2007
- ³⁴ Flood, M and Hamilton C (July 2005) *Mapping Homophobia in Australia*, Australia Institute Webpaper - <http://www.tai.org.au/documents/downloads/WP79.pdf> - accessed 18 December 2007, p 1
- ³⁵ *ibid*, page 10
- ³⁶ Ministerial Advisory Committee on Gay and Lesbian Health, Department of Human Services (2001) *What's the difference? Health issues of major concern to gay, lesbian, bisexual, transgender and intersex (GLBTI) Victorians* - unpublished background paper
- ³⁷ Nay, R and Gorman, D (1999) *Sexuality in Aged Care* in Nay, R (ed) *Nursing Older People: Issues and Innovations*, pp 194-210
- ³⁸ Bauer, M, McAuliffe, I and Nay R (2007) *Sexuality, health care and the older person : an overview of the literature* in *International Journal of Older People Nursing* 2(1):63-68
- ³⁹ Barrett, C *op cit*, *Case study 3*
- ⁴⁰ Human Rights and Equal Opportunity Commission, *op cit*, p 366

ALZHEIMER'S AUSTRALIA PUBLICATIONS

Quality Dementia Care Series

1. Practice in Residential Aged Care Facilities, for all Staff
2. A Guide to Practice for Managers in Residential Aged Care Facilities
3. Nurturing the Heart: Creativity, Art Therapy and Dementia
4. Understanding Younger Onset Dementia
5. Younger Onset Dementia: a practical guide

Papers

1. Dementia: A Major Health Problem for Australia; September 2001
2. Quality Dementia Care; February 2003
3. Dementia Care and the Built Environment; June 2004
4. Dementia Terminology Framework; December 2004
5. Legal Planning and Dementia; April 2005
6. Dementia: Can It Be Prevented? August 2005 (superseded by paper 13)
7. Palliative Care and Dementia; February 2006
8. Decision Making in Advance: Reducing Barriers and Improving Access to Advanced Directives for People with Dementia; May 2006
9. 100 Years of Alzheimer's: Towards a World without Dementia; August 2006
10. Early Diagnosis of Dementia; March 2007
11. Consumer-Directed Care: A Way to Empower Consumers? May 2007
12. Dementia: A Major Health Problem for Indigenous People; August 2007
13. Dementia Risk Reduction: The Evidence; September 2007
14. Dementia Risk Reduction: What Do Australians Know? September 2008
15. Dementia, Lesbians and Gay Men; October 2009
16. Australian Dementia Research: Current Status, Future Directions? June 2008
17. Respite Care for People Living with Dementia; May 2009

Reports Commissioned from Access Economics

- The Dementia Epidemic: Economic Impact and Positive Solutions for Australia; March 2003
- Delaying the Onset of Alzheimer's Disease: Projections and Issues; August 2004
- Dementia Estimates and Projections: Australian States and Territories; February 2005
- Dementia in the Asia Pacific Region: The Epidemic is Here; September 2006
- Dementia Prevalence and Incidence Among Australian's Who Do Not Speak English at Home; November 2006
- Making Choices, Future dementia care: projections, problems, preferences; April 2009

Other Papers

- Dementia Research: A Vision for Australia; September 2004
- National Consumer Summit on Dementia Communique; October 2005
- Beginning the Conversation: Addressing Dementia in Aboriginal and Torres Strait Islander Communities; November 2006
- National Dementia Manifesto 2007-2010
- National Consumer Summit, Younger Onset Dementia Communique; February 2009

These documents and others are available at www.alzheimers.org.au

Visit the Alzheimer's Australia website at

www.alzheimers.org.au

for comprehensive information about

- dementia and care
- information, education and training
- other services offered by member organisations

Or for information and advice contact the

National Dementia Helpline on 1800 100 500

(National Dementia Helpline is an Australian Government funded initiative)

Visit the Dementia Collaborative Research Centres website at

www.dementia.unsw.edu.au

for further information about the people involved and the research activities