LA TROBE UNIVERSITY

AN EXTRA DEGREE OF DIFFICULTY

An evidence based resource exploring the experiences and needs of older LGBTI carers and the carers of older LGBTI people



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Val's Cafe

VIC Carers AUSTRALIA

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Section 1: Introduction

There are currently 2.7 million unpaid carers in Australia, 39% of whom provide more than 40 hours of care a week (1). This caring comes at a cost to carers – on average they have poorer wellbeing than the broader community and their wellbeing declines as the hours they spend caring increases (2).

Little is known about older LGBTI carers in Australia. However, we do know that older LGBTI people are more likely to be carers and rely on intimate partners and friend carers (3). This is attributed to the facts that older LGBTI people have limited contact with biological family (4) and they are less likely to have children (5). It has also been attributed to their historical experiences of discrimination – which for many has contributed to delays accessing formal services due to fear of discrimination (3, 6, 7).

The importance of understanding the experiences and needs of older LGBTI carers and the carers of older LGBTI people has been highlighted in a number of research projects undertaken by Val's Café for many at the Australian Research Centre in Sex, Health and Society (ARCSHS), La Trobe University. This research has documented the experiences of same sex partners caring for a person with dementia (8, 9, 10), the role of trans carers as advocates (11) and the experiences of an intersex carer (12). However, to date there has been no research exploring the experiences of older LGBTI carers.

This resource draws on research conducted by Val's Cafe in partnership with Carers Australia. The aim of the research was to document the experiences and needs of older LGBTI carers and the carers of older LGBTI people. The research took place in 2015 and gathered data from 54 carers - 49 completed an online survey and 5 participated in in-depth interviews. The Human Research Ethics Committee at La Trobe University approved the research. Key characteristics of the participants are following.

Survey participants

The key characterises of survey participants, presented as percentages:

- Number of participants: (49)
- Sexual orientation: gay (52%), lesbian (23%), heterosexual (14%)
- Gender identity: male (53%), female (38%), trans (4%)
- Intersex: (5%)
- Location:
    - New South Wales (38%)
    - Victoria (33%)
    - Queensland (16%)
    - South Australia (7%)
    - Western Australia (2%)
    - ACT (2%)
    - Northern Territory (2%)
- Relationship to care recipient:
    - Partner (42%)
    - Friend (20%)
    - Child (11%)
    - Parent (7%)
    - Lover (2%)
- Older LGBTI person that was/is caring for someone: (76%)
- Primary carer: (73%)
- Age range: 29 – 74 years (mean age: 60 years)

Interview participants

Characteristics of interviewees as numbers, rather than percentages

- Number of participants: (5)
- Sexual orientation: gay (3), lesbian (2)
- Gender identity: male (3), female (2)
- Location:
    - Victoria (3)
    - New South Wales (1)
    - South Australia (1)
- Relationship to care recipient:
    - partner (2)
    - partner and daughter (1)
    - parent and child (1)
    - child (1)
- Older LGBTI person that was/is caring for someone: (5)
- Primary carer: (5)
- Age range: 56 - 73 years (mean age: 61 years)

Legislative and policy reforms

In recent years there have been significant reforms recognising the rights of older LGBT Australians (6). These include an amendment to the Aged Care Act (Commonwealth Government of Australia, 1997) to afford older LGBTI people special needs group status and the development of a *National LGBTI Ageing and Aged Care Strategy* (13).

The Strategy describes the Government's commitment to ensuring the needs of older LGBTI people are understood, respected and addressed in Australia's aged care policies, programs and services. In regard to carers, the Strategy refers to principles of:

> INCLUSION: the rights and needs of older LGBTI people, their families and carers are included in the development of Australian Government aged care policies and programs
>
> EMPOWERMENT: older LGBTI people, their families and carers are supported with the knowledge and confidence to maximise their use of the aged care system

A number of goals outlined in the Strategy also refer to carers. This includes ensuring information on the needs of carers in aged care related publications and information (1.1); supporting geographically isolated carers (1.5); developing policies and organisational processes that promote inclusion of carers (4.1) and empowering carers (5.1). The current resource provides an evidence base that enables the needs of carers to be reflected in aged care related publications and information and enables service providers to understand what is required in the development of LGBTI inclusive services for carers.

Following on from these reforms the Federal Government allocated funding for community visiting schemes, or programs to provide visitors for socially isolated older LGBTI people. These community visitors provide the opportunity to support older LGBTI carers.

About this resource

This resource has five sections. In the following section a summary of the key issues arising from the survey and interviews with older LGBTI carers and the carers of older LGBTI people is presented. It draws on concurrent research at ARCSHS where the experiences of older LGBTI carers were identified (8, 9, 10, 11, 12) and identifies strategies to address each issue. Section 3 includes a summary of the results from the survey. Section 4 presents stories from 5 carers. In the final section a list of additional resources and suggestions on how to use this guide for educational purposes is presented.

Section 2: Key issues and strategies

In this section key issues that relate specifically to older LGBTI carers and the carers of older LGBTI people are presented.

Caring for biological family

A number of participants described caring for biological family members who were homophobic. This created additional carer stress – eroding self-esteem and placing pressure on same sex relationships. Participants also reported that heteronormativity in carer support groups meant they had limited opportunities to be supported through these challenges. *Information needs to be provided to LGBTI carers so they understand how to locate LGBTI inclusive supports and to ensure they have sufficient opportunities for respite and debriefing.*

Caring for partners

Several participants reported their intimate partner was reluctant to access aged care services because of the fear of discrimination. In these cases the responsibility for care rested solely on the intimate partner, adversely affecting carer wellbeing. *Service providers need to undertake a self-assessment using the LGBTI Self Assessment and Planning (SAP) Tool (15), implement strategies to provide LGBTI inclusive services and then communicate their inclusivity to LGBTI communities. This will assist older LGBTI carers to navigate safe and inclusive services for both themselves and their partner.*

Social support

Connection with other LGBTI people was described as an important aspect of carer wellbeing. Social networks provided spaces where older LGBTI people could 'be themselves' and 'speak freely' in a world that was often experienced as homophobic or transphobic. However, carers described how these important networks were difficult to maintain alongside their caring responsibilities and reported feeling socially isolated. *LGBTI communities need to support older LGBTI carers. There is also an opportunity to link older LGBTI carers with LGBTI specific Community Visitors Schemes (CVS) where these exist and ensure that CVS programs make links with mainstream carer groups.*

Grief

Grief was expressed in relation to the loss of companionship the loss of a partner, changes in relationship dynamics, the discrimination and difficulties encountered, the lack of recognition by families of origin and the loss of LGBTI community connections. *There is a need to recognise the layers of grief that may be experienced by older LGBTI carers and to provide access to psychological support. The development of LGBTI specific carer groups and carer counselling could assist in achieving this. Support is also needed following the death of an intimate partner, or friend.*

Carer groups

A significant number of participants reported that heterosexual carers in carer support groups didn't understand the historical or contemporary issues they encountered. Consequently a number withdrew and requested the development of LGBTI specific carer groups. *There is a need to develop LGBTI specific carers groups. There is also a need to ensure that facilitators of carer groups have the necessary skills and information to ensure LGBTI carers are welcomed by all participants of the group.*

Lack of information targeting LGBTI carer

Several participants expressed frustration at the lack of information specifically for LGBTI carers. *Carer services need to provide LGBTI inclusive services and promote their inclusivity to LGBTI communities and organisations. LGBTI communities also need to promote information about carer supports throughout their networks.*

Acknowledging carers

Intimate partners and friends caring for an older LGBTI person described having a unique bond - carers provided safe spaces where diversity was understood and affirmed. However, same sex relationships and LGBTI carers were not always acknowledged by service providers. This created additional stress, particularly where there was conflict with families of origin. *It is important that service providers recognise and respect the important role that older LGBTI carers play. This includes ensuring carers are involved in decisions about care and that documentation is LGBTI inclusive.*

Living in rural and remote areas

Several carers articulated difficulties related to the lack of support services in rural and remote locations, which meant having to uproot themselves from networks where they felt safe as an LGBTI person. *There is a need for services to identify creative ways to support LGBTI carers living in rural and remote locations. LGBTI communities in these locations need to provide support for LGBTI carers.*

Staff values and beliefs

LGBTI carers reported being adversely impacted by service provider's prejudicial values and beliefs about LGBTI people. This lead to barriers to services access, compromised quality of care, or refusal of services. A

number of carers also reported some service providers believed they were exempt from providing services to LGBTI people because they had a culturally diverse workforce or were a faith based service. In addition, many more participants expressed fear that faith based services would discriminate. These experiences created additional carer stress and exacerbated carers fears of discrimination. *Further education for the service sector needs to occur to ensure staff understand the impact that their values and beliefs have on the delivery of LGBTI inclusive and culturally safe services (16). Organisations need to provide clear leadership to staff and other service users to communicate their commitment to LGBTI inclusive service delivery. Staff education must include information that there are no exemptions from LGBTI inclusive service provision and that it is unlawful to refuse services on the basis of sexual orientation, gender identity, or intersex status. Respectful dialogue about workforce diversity and LGBTI inclusive practice must occur. The cultural diversity of the aged care workforce and the provision of services by faith based organisations ought not be seen as obstacles to the provision of LGBTI inclusive services.*

Service responses to LGBTI staff

A number of carers described concerns about LGBTI staff experiencing discrimination in aged care services. Therefore this was seen as evidence that services would not welcome LGBTI clients and contributed to further reluctance to access services. *Service providers need to understand that the provision of LGBTI inclusive services requires organisational leadership to ensure LGBTI staff are recognised and values. Strategies to welcome LGBTI staff could be promoted to demonstrate LGBTI inclusive services for carers.*

A message of welcome

A number of participants reported the failure of services to send a message of welcome to LGBTI people. Several reported that information about local support services lacked LGBTI inclusive language and imagery. This included the language used at intake and assessment. Carers reported feeling reluctant to access services unless there was a message of welcome. *Service providers need to ensure organisational information communicates a message of welcome to LGBTI people. Government mandated templates and documentation need to be amended to ensure they are LGBTI inclusive. Service providers should identify creative ways of sending a message of welcome. These initiatives will assist in ensuring carers feel welcomed and safe accessing these services.*

Service development: extra degree of difficulty

While most carers experience challenges, the LGBTI participants in this research reported experiencing an extra degree of difficulty. This included caring for homophobic family members and the fear of discrimination by services. Indeed 43% of carers who completed the survey experienced discrimination in relation to their sexual orientation, gender identity or intersex status as an older LGBTI carer or the carer of an older LGBTI person. Not surprisingly 28% delayed accessing services because of the fear of discrimination. *The unique challenges experienced by older LGBTI carers need to be understood and considered in the development of LGBTI inclusive services to ensure equitable access for older LGBTI carers.*

Section 3: survey results

The following section outlines key responses from the survey. Comments from participants are presented in italics and in the own words of survey participants. To preserve the authenticity and essence of the survey results we have not edited the responses but have used [brackets] where we have added words to assist readability.

Characteristics of being a carer

- **63%**: indicated being a carer has changed the relationship with the person they care for
- **79%**: said life is very different now compared to before they were a carer
- **28%**: delayed accessing service they or the person they were caring for need due to the fear of discrimination relating to sexual orientation, gender identity or sex
- **43%**: experienced discrimination in relation to sexual orientation, gender identity or sex as an older LGBTI carer/carer of an older LGBTI person
- **38%**: reported accessing carer support services – including respite, counselling, home help, carers groups
- **18%**: felt very uncomfortable or uncomfortable accessing services as a carer

Personal Wellbeing Index

- **57**: mean score for Personal Wellbeing Index. Scores were calculated on a 10 point scale with higher scores being reflective of better health and wellbeing. This score is low compared with 58.5 for carers broadly or 73.4 – 76.4 for the general community (2).
- **12.5 – 100**: was the mean score range, indicating significant variation in self-reported wellbeing
- **18%**: scored less than a mean of 30, indicating a significant number had very poor wellbeing
- **10%**: scored more than a mean of 90

Changing relationships

79% reported that being a carer had changed the relationship with the person they were caring for. A small number noted positive changes such as becoming a more compassionate person or feeling closer to the person they were caring for:

- *It made us much closer*
- *Probably deepened our relationship*
- *Bought us closer together*
- *Shift from friendship to carer, new dynamic and grounds for connection*

In contrast, most participants reported that becoming a carer had an adverse impact on their health, wellbeing and relationships. Challenges reported included caring for parents who were homophobic:

- *It brings me in more contact with their catholic sanctioned homophobia*
- *I was a free person and could do what I liked and go where I wanted. [Now] I have to be around for my mother and be aware of her sensitivities around my sexuality.*
- *As a gay man with children who are now adult I often feel torn between responsibilities to them - helping them with careers relationships etc. and to my mother. My mother will needed increasing care as she is 91 and trying to stay in her own home. As I am the only single one and as I work for myself a lot of the care seems to default to me. ATM [at the moment] my biggest operational challenge is her frequent medical appointments the biggest emotional challenge is her homophobia and an endemic sense of disapproval that I haven't met her expectations which demoralizes and depresses me.*

Other impacts that were frequently cited included having less time, energy, money and social interaction:

- *Tiring*
- *Less time!*
- *There is no social life now, many past friends are no longer in contact. I no longer work full time and miss the interaction with people in the work place.*
- *Placed a serious strain on me*
- *I became more of a parent than friend...and managing their right to decide became very tricky*
- *It is very demanding and we seem to have role reversal [my] mother has become my child*
- *It is difficult now to go away on holidays and have weekends that are genuinely free. It is the same with preparing meals and overall home duty coordination. My ageing parents in law are very dependent on us both. My partner is unable to work full time due to her caring role but I have too for financial reasons.*
- *… i couldnt get any charity organizations to help i was on the dsp [disability support pension] and now owe 14000 on my mastercard*

Participants in same sex relationships also reported that becoming a carer to their partner changed the nature of their intimate relationship:

- *38 years with my partner I no longer consider him as my partner and am now his carer*
- *I am his everything where before we were individual identities*
- *I feel more like a servant*
- *We no longer [function] as a couple. Even though I still refer to us as partners this is no longer the case. There is no longer any intimacy in the relationship. To sum it up we are now more like brothers and my partner depends on me for many things*
- *Neither of us work any more and so we are dependent upon a combination of superannuation and government pensions, in my case aged pension and in his case Disability Pension. Our differences in personality are perhaps brought more sharply into focus and this can generate tensions that need to be worked through. Sometimes we lose sight of who is care for whom, until we re-find the realisation that it is always two ways.*
- *More of a one sided relationship as my partner required more care and it changed our lifestyle together*
- *No social interaction due to physical access hurdles but also lack of support services that respect the need of working carers for support in the evening which is their only time to socialise. (hourly rates at double time 'outside hours')*
- *No communication, partner shuts down*
- *My partner has had 2 strokes, so mentally, he is impaired and can be rude and insulting. He is also HIV pos, Diabetic, has high blood pressure, AF, so there is a lot of medication to watch over. I am also not well and I feel it gets beyond me sometimes.*
- *Beforre I was retired, in love, happy with the person I had found to be my life partner. After a diagnosis o[f] dementia things had to change and through no fault of ours and with no cure we were headed inn one direction - o0f course things changed*
- *Yes, very much. Over time our relationship had begun to break down with constant arguments, and as we wer/are sensitive people we were both very angry at times with the other partner. We saw a Councellor. However, following my partners diagnosis of terminal cancer of the oesophagus he began to rely, more and more, on me and I was happy to care for him. We did grow closer during this period and I felt his death, terribly, when it eventually occurred.*

Experiences of discrimination

43% of participants reported they (or the LGBTI person they were caring for) had experienced discrimination in relation to their sexual orientation, gender identity or sex. Descriptions of discrimination included:

- *I feel we were treated differently in the aged care facility and hospitals - not necesarily in a discriminatory way but not the same as others*
- *Told that our needs can be taken care of by LGBTI services if we want LGBTI support. told "we don't have gay packages' or 'staff OHS [occupational health and safety] means that some workers may not be able to visit due to psychological hazards for them dealing with gay people as its against their religion'*
- *Some really dreadful things when an in home visitor took the person I cared for out of or home while I was in hospital. My friend was taken to her solicitor and our powerr of attourney was canceled because I was deemed an unsuitable person. the home visitor also attempted to have my friends will changed .... An Avoo [apprehended violence order] was taken out against me as I was seen as trying to run a lesbian bordello in our home....It cost us several thousands of dollars to undo the [mess] and it damaged my relationship with my friend and with in home help …*
- *Needed to reregister vehicle, & insurance company wanted to know "have you had your sex change operation yet?"*
- *Usual homophobia*
- *II will not describe it. It is far too distressing to think about it right now.*
- *When taking [my partner] to hospital of a new doctor, we are given that familiar look "oh what is going on here" and "smirks". When you fill out forms for hospitals, they STILL DONT HAVE a section in relation ship for "gay partnered" we still have to fill in "defacto"*
- *People seem to look at us and try to hold back from smiling/smirking. I don't know what it is.*
- *My partner was in a public rehab facility for many months. [The] staff were good and accommodating when possible. But because of shared wards we experienced discrimination from other patients which did not allow us to openly communicate. We were directed in by staff in some instances to walk the gardens or go to 'closed wards' in order to spend some quality time together. Felt like they wanted us out of the way so as not to offend other patients.*
- *A bit but that was [probably] because they had never seen two old farts so dedicated to each other*

Two participants also suggested that the ethnic diversity of communities and staff was a barrier to reaching out to older LGBTI carers because there was a perception that this would be viewed as culturally offensive.

Delaying service access

28% of participants reported delaying access to service they or the person they were caring for need due to the fear of discrimination relating to sexual orientation, gender identity or sex. The reasons for this included:

- *Because I've been told "we treat everyone the same" or told "what you do in the [bedroom] doesn't impact on care'. I put it off as long as possible because its more hassel to deal with accessing services than to do it my self or just go without*
- *Somewhat. After our first contacts my friend became concerned we were seen as an "odd couple" because of my diffrences and didnt want to draw attention to that because she thought it made me an outcast.*
- *You never know who is going to react negatively*

- *Did not like Centrelink[1] or the stigma*
- *No one would help us as we [are] not breeders with three kids in a pram*
- *I would be very comfortable accessing services, but I don't know what's available in my area and when it is known we are gay, straight people may get worried about Hiv*
- *I suppose as a carer (specifically LGBTI carer), I keep doing what I do without accessing providers to assist with the care I give and to provide me with support on the 'dark' days. I feel intimidated hence why I do not access services. My day is full and to try and find information on 'My Aged Care[2]', is frustrating and to be honest has either taken me full circle or led to a dead end.*

Accessing support services

38% of participants reported they were accessing carer support services – although some of the services described appeared to relate to services for their partner, rather than carer support more directly. A number of participants made comments about the lack of support services for older LGBTI carers:

- *No not aware there are any suitable I would want one where I could talk about homophobia and the difficulty it makes for me in my caring role*
- *I used the carer support network available locally until it was made clear i did not really fit in and they would prefer I found other "appropriate" support. Catholic church services were the people who had the local remit to provide these services and I felt very much their religious bias was a decider on who was and who was not appropriate.*
- *Carer's support group trans support group was going, but ate itself with lateral hostility*
- *No. What support services are there for people like me caring for people like my partner? None.*

Another participant reported attending a local carers support group and the response to the disclosure of her sexual orientation:

> *I did attend a carers' support group on its first week, along with two other carers. They were both intrigued that I was in a lesbian relationship, and neither of them chose to return. Was this due to their response to my sexuality? No way of on knowing. But the group convenor hoped to get another lesbian woman in the wings along for the next week - she clearly had no issue with me. I wasn't upset about what may have been the response of the other members. Their problem really, and I have lots of other avenues of support in my personal life. Thank you.*

The interaction between LGBTI carers and others in carer groups was raised across the survey and interviews. While participants seemed prepared to educate other about their LGBTI identities – the onus of responsibility for educating others ought not to rest with LGBTI carers.

Service access was also raised in relation to living in rural, regional and remote areas. One participant described living in remote areas where there were less services available:

> *If my partners's isues deteriorate then everything could change. I my heart conditions should suddenly deteriorate and I can't drive we might need to consider abandoning our rural existence and moving into the city. This would be difficult for us to accept but our gay friend*

[1] Centrelink is a Government program delivering a range of government payments and services for retirees, the unemployed, families, carers, parents, people with disabilities etc.

[2] The *My Aged Care* website has been established by the Australian Government to help people navigate the aged care system

network is city based and this we would expect be helpful. Our local community is our primary community and we both work to maintain our local community linkages and have [gained] a great deal of respect and support from others because we contribute in whatever ways we can.

Another suggested existing support services were focused on the needs of metro LGBTI people and not as accessible or relevant to others:

> *Qlife[3]'s referall list are both metro centric and focused on older people who are able to get around between 9-5. I have contact them twice and they have been unable to assist and also didn't even provide a friendly ear they just kept trying to refer me to services in Brisbane at the AIDS council which is a great organisation [but] 2 and a half hours drive each way for me to access.*

What services need to do

Participants were asked what they thought service providers needed to do to be inclusive of LGBTI carers and the carers of older LGBTI people. Several comments were made about the use of labels, for example: *Don't discriminate and treat all people as people and not as labels*. Concerns about labelling were also raised in relation to the provision of 'special needs group status' discussed earlier. This was highlighted in one survey where the participant noted:

> *I dont want to be 'tolerated' by service providers and i dont want to be identified as 'special'. As a former DON [Director of Nursing] of several nursing homes and HACC [Home and Community Care] services provider I know the limitations of care staff and, whatever the good intentions of service providers, the message doesnt often get to the people actually delivering the service. I am happy to get services for my mother (though my mother is not keen!) but I dont trust non-LGBTI care providers to provide services for me. I dont want to feel an alien in my own home.*

While there was a lack of consensus about the words used there was widespread agreement on the need for LGBTI inclusive services. Most participants express fears of discrimination in services and identified a broad range of suggestions for the development of LGBTI inclusive services:

- *By including GTI(gay/trans/intersex) wording into their communications*
- *Try to show they understand what intersex is and what intersex people need*
- *Go out of their way to advertise that they are LGBTI friendly by advertising in local papers and organizing special inclusive events*
- *State that they are LGBTI friendly [and] include service to the LGBTI community in their policy and goals. Not tolerate homophobic or transphobic conduct by staff*
- *By actively recruiting LGBTI workers rather than treating us like unique [oddities] to some how be compressed into current service model*
- *Communicate LGBTI awareness and openness, use a program like the Rainbow Tick[4], have LGBTI folks on their committees and as service providers*
- *Make sure there are accurate options for gender id[entity] on forms, give staff sensitivity training about diverse sexuality and gender identities, have posters reflecting the [LGBTI] community.*
- *Have a gay option for relationships on forms …*

[3] QLife is an LGBTI telephone support service

[4] The Rainbow Tick is and LGBTI inclusive accreditation program developed by GLHV (glhv.org.au)

- *By never assuming that the carer or person being cared for are heterosexual. By being trained well in LGBTIQ[5] issues so they aren't shocked or uncomfortable when talking to a LGBTIQ a person*
- *… I guess pictures of LGBTI people receiving services, along with others, could help, but in the end it's the interaction we have with service providers that dictates how accepted people feel. Calling each partner / party by name, addressing the carer as well as the patient, asking both patient and carer if they have any questions, all help*
- *In this day and age I suppose social media is the way, or a section on the providers web sites that specifically acknowledges LGBTI people, maybe giving a name of a person to contact*
- *Positive, affirming, inclusive statements in your literature; advertising in LGBTI publications; training staff in positive attitudes*
- *If you are caring for a partner at end stage of life, and the hospital knows that this is your partner. All correspondence and communication should be with the partner of this person. No meetings to take place without the partner being involved.*
- *… I am not religious so mentioning God would be a real "downer" for me. Don't display a negative reaction when they see LGBTI People. It is difficult for straight people to do this if they haven't had experience and I accept that it can be an eye opener for some. Non LGBTI people would need instruction in what they can expect to see when visiting an LGBTI couple.*

A number of participants highlighted the importance of organisations being LGBTI inclusive that this also needed to encompass staff. One participant who worked in aged care reported making a complaint about transphobic colleagues. The participant noted that "*I found the couple of residents who know didn't care less about my history ..... but some of the staff treated me badly*."

[5] LGBTIQ: the letter Q is sometimes used to represent people who identify as 'queer' though some older people dislike this term because they feel it means 'odd'

Section 4: Stories

This section presents 5 stories from interviewees, in the participants own words. At the end of each story we have included some questions that could be used to guide discussion and education. In your discussion please consider the key issues and strategies outlined in Section 2.

Story 1: Mark – State of being fallen and a carer

My mother has three sons. There are two of us that live in the city and a third that lives in the country. She is 91, in reasonable health, but lives in a fairly large house in the suburbs on her own, and, of course, as she ages her needs are increasing.

As much for social support as practical – a long time ago we organised to get a bit of home care from the council which she gets once a fortnight. They're sort of stress points, I think, for her. She's got fantastically supportive neighbours, a long term friend for 70 plus years who lives in the next suburb and a very supportive parish community. She's Catholic. They really do look after her quite well, you know, church will take her to mass and inviting her to stuff and that.

Needs default to me

Because I don't work in a regular job there is a bit of a tendency for me to be the one that deals with the more urgent issues or the crises or whatever, like losing glasses or, you know. There's no reason why it is my role more than them but somehow I get a sense it's going to be me that'll be organising the team. So stuff like that tends to default to me. So in a way perhaps I'm the most involved, although my brother sees her once a week and that's a big part of her support network. I've raised with my two brothers that I think we need a bit of a schedule. The stress points seem to be around the medical appointments, which are increasing naturally. I'm keen for a bit of a roster so I'm not always the one on the default, yeah

Level of support

I can be seeing her three times a week or, you know, once a fortnight, it depends on her needs and my availability and also I have three adult children that I'm in the process of launching their careers or helping them do that, so I often get, if you like, caught between the two. Last weekend being a great example where the only time I could get them all away for a long weekend to the country was the same time as my mother had a friend's 90th birthday also in another part of the country, so I was crunched between sort of my family of origin and my own family. And managed to regale my brother to do the second half of the shift and, you know, it was a big day but I managed it all.

Thinking about my future I am not entirely happy but, I do – the bit of the Catholic … belief of that, you know, it's our role to care for others. I do believe in caring for, you know, parents and the same way that I expect my kids will, you know, care for me. I signed on for that really, yeah, that's part of my core belief system, which I hope to be able to see through, yeah.

Being single

I'm also single so I think that makes a difference. Although my former wife and my mother enjoy a good relationship and we do sort of see her occasionally together but she has contact with my former wife probably once a fortnight, things are amicable, very amicable there, which is great. But, I think perhaps the singleness makes me seen as more available.

Coming out as a gay man

I came out, what, 15 years ago and I went from being perhaps the most favoured son to the black sheep in one nanosecond. I think coming out has made [it difficult for my mother because I am] not fulfilling the Catholic dream of a married life and all that stuff. I think has been the most serious break really between us

And unfortunately that's coincided with the need for more contact, you know, – with the caring role. So there's an ambivalence there that I think we both struggle with in the sense that on the one hand she disapproves of who I am and what I do and probably thinks I'll be burning in hell, and on the other hand she needs my support more and more.

Definitely coming out has made the whole process a lot more complex for sure.

If I hadn't come out it would have been easier. For a start I would have, you know – I suppose I would have had fewer competing demands as well.

My mother's needs

Obviously I'm fearing that the trend is going to be worse. I've always balanced a caring role with my, you know, queer lifestyle. And when I had three kids that were under 18 it was even more demanding. So compared to that it's not – nowhere near as stressful as being a, you know, what we call a gamo gay and married or formerly married man. The degree of difficulty there is like 9.9 routinely, so this is less challenging than that. But it's probably more emotionally challenging in the sense that there's this constant sense of disapproval that I get that, you know, whatever I do or however much I assist it's not going to make up for my basic state of being a fallen, you know – my basic sinful state.

The influence of religion

My mother's really I would say a fundamentalist Catholic in that she believes that there are certain things about your behaviour that she fears will lead me to internal damnation or – in the long term, and also shame to her in the meantime. I've been out for 15 years. She tells me that there are two other women who've got gay children at the church but they never talk about it.

And with the change of Pope there's been a slight thawing of issues from mum – because she's the old type of Catholic who does whatever the Pope says, you know. And the Pope has been a little more tolerant and so there's been a little bit of a thawing. So she actually said to the local Parish priest that I was gay. Now, I think that's a huge step forward.

There's a sort of a ghetto mentality where you've all got to be the same. Colin Tabene talks about what happens after two World Wars and the depression people sort of got the suburbs and they want to live in the suburbs and they want everything to be controlled and they want to be the same. And the sort of Irish Catholic community was, you know, very keen on we've all got to do the same things and, you know, go to church and go to Catholic schools and we'll all be saved. And so when you deviate from that, which of course everybody does, because no one can live up to those ideals, there's a shame, a community stigma. So my mother is – really has trouble dealing with the shame of having a gay son, and I get the wash up of that.

Some of my friends sort of get by having minimal contact with their parent, you know. That's a coping mechanism for a lot of people. My mate who lost his mother recently, that was his way of coping. She was openly homophobic and he protected himself by seeing her maybe every two or three years. So, yeah, people cope differently, you know, I think.

Reward and disapproval

It's emotionally complex to be distanced by the person who you're trying to look after I think. And that's one of the reasons why I've been talking about getting a carers group because – because I see here is an extra degree of difficulty where – particularly the sort of baby boomers like me who are dealing with ageing parents. There's some fabulous exceptions but many of them will have a, you know, an older mindset which is inherently disapproving, so there's going to be that – and there's a lot of – that's going to make this caring task more complex.

Because it's sort of the normal, you know, inconvenience and getting yourself organised around somebody else's routine and whatever, and then there's the sense that the normal – you know, if I do that to my kids I get a sense of reward usually, you know, I feel good about myself as a parent and I think, you know, all in all we're going well and, you know. So it's usually the caring role is a satisfying one. In the case of my mother it's highly – you know, sometimes there's thanks but the note of disapproval never entirely goes, so it's always more complex interaction.

I think she treats my brothers differently. It appears that way but I'm trying not to be too over sensitive about it. I think she has a tendency whoever – whoever she's with she praises the other two. That's part of her sort of way of controlling the situation I think, yeah.

Her own personal style which has been fairly industrial strength all her life, you know. A little bit Irish matriarch. Expecting us to sort of run around and make things happen, you know, which we sometimes do and sometimes I say, "Well, you have to wait, you know. Well, I can't do it then".

Also I do think there's a certain increased rigidity as her, you know, mental functions are declining slightly. You know, it's hard for her to hold more than one thing in her mind. And, you know, it's that sort of single mindedness which you can understand because she's got nothing else going on, but that also drives me nuts.

I think it makes me feel a little concerned both about the present and the future because it's not going to get any better, you know.

Coming out –responses of family

I still have problems with my extended family and my country cousins who partly raised me. They don't accept me being gay. They take every opportunity to politely ignore it. So there's a sort of deafening lack of acceptance in – yeah, from my mother and from my aunt and cousin and others, and even my older brother, who I'm sort of fairly close to, has a very conservative Swiss wife and, you know, it's all the stuff they don't say all the time that drives me nuts.

But I do find – like, for example, the woman who picks my mother up and takes her to church, so there's a volunteer role, she will not look me in the eye, you know. She's sort of a good woman of the church, and it's like – so when I coincide with her, which is only maybe once every 12 weeks or so, when I'm there at the same time as she arrives to pick mum up for church, it's that sense of disapproval and fear that you're getting. In fact, you know, it means that I can't just say – ring her up and go, "Aileen" – or, you know, "Here's my number, ring me if you can't make it to the church – you know, to take mum to church one day and I'll organise something else", there's just not that rapport because I get the same sense of disapproval, you know.

it's not universal and my mother's best friend of over 70 years who's an honouree auntie, you know, I was with her on the weekend and she's totally comfortable and no problem at all with me being gay and hasn't changed one iota. And, you know, my country aunt was the same before she died, completely – there's some rare individuals who continue – who focus on who you are, not – you know, like – they care for you either way, they don't care with what you do really. And slowly that's been the exception rather than the rule in my family

Supporting LGBTI carers

One of my friends his mother is just going into a nursing home and I'm thinking he doesn't have a clue about the system. He's never had to take his kids through the health system and he's never had any health issues himself.

And, you know, queer folk need to know stuff around like carers allowance and, you know, residential respite and all those carer support systems that are out there that we're entirely eligible for but which, you know, we don't know about, so.

And so it's all the things that he doesn't that he doesn't know, you know. Like, about the health system, about the caring system, about the aged care system. There are so many things that life as a single gay man has not equipped him for this role.

You know, it's funny you can pick up a pamphlet on safe sex or a pack of condoms but [there is], nothing on the responsibilities of being a gay carer or the supports available.

I think carers organisations and …other players …need to get their act together and actually have more of a proactive approach rather than sort of – because I know these things come up with individuals but nobody's pulling it together into a information and services for LGBTI carers. I think [we need] support groups plus some carefully tailored information.

It would be my vision to have something that good happening for queer [people] where we would learn from each other and the people who knew the system would teach the ones who didn't.
I do think it needs to be specific services for LGBTI carers because of that ambivalence that many, but not all, carers – gay carers will experience. Probably what would help me would be getting more into the carer support system.

I wouldn't go to a generic carers group, no, I wouldn't find that useful. It would be good to meet other gay men who are in the caring role, yeah.

Let’s make a start. Get some funding from Commonwealth or State Government and just do it. It's not that hard. It's not rocket science. We actually – it's like we've got all the piece of the jigsaw puzzle. We just need to put it together.

Questions for discussion:

1. What reasons does Mark describe for others relying heavily on him as the “default carer?"
2. What impacts does Mark’s mother’s disapproval of his sexuality have on him?
3. Why do you think Mark wants to access an LGBTI specific carer support group?

Story 2: Jo's story: That's what you do for a partner

I'm carer for three people, and I'm a particularly supportive friend for another. I actually retired 18 months ago, so I've been able to pay more attention to them since then.

My partner has cancer, Non Hodgkin's Lymphoma, and it's not curable. So my role with her is ongoing. Last year she had six months of chemotherapy. That has finished now for the time being - there will be more. So building up her immune system through diet and exercise and stress reduction is absolutely critical. She's still at work for the time being, but she'll leave soon.

I've always been the one who prefers cooking. And so I do all of the work around food now. It used to be a third/two thirds division before - two thirds my way. Now I do it all. It's tiring. I guess I'm a little bit long handed about it as well, I insist on doing things properly. I don't think you can take shortcuts with food if you're looking after someone's immune system.

So I spend a lot of time planning, shopping, cooking, juicing etc. the whole foods way, starting from scratch with everything. So it takes a lot of time, lots of trips to the shops etc. But I enjoy it. I love food and I love all the stuff about food. But I'm really glad that I have a little break from it as well.

I actually feel like a "housewife". Because Lyn is still working, and I want to keep her stress levels to a minimum, I just take care of almost everything around the house. I've got no idea how much of my time it all takes. It's actually a good exercise for me to carry out, 'cause it might actually be a lot less than I feel like it is. It certainly feels like a major preoccupation.

I retired 18 months ago. And by that stage I was completely burnt out from work. The whole process of Lyn's diagnosis and the shocking reality of it sort of finished me off, really. I did bring my retirement forward a little bit, but that wasn't about caring, it was just about being exhausted.

I also felt like I needed leave work so I could recover from my burn out, in order to be ready in case Lyn needed chemo. We didn't have any idea when that would be. But as it happened, she needed it six months after I retired, so at least I had that time.

My relationship with my partner hasn't changed so much, except that it's become more intense. 'Cause you know, that's what you do for a partner, isn't it. You care for her. The general flavour certainly hasn't changed, it's just a matter of that intensity. During her chemo, because she was too unwell to do much, we would just do gentle, slow stuff together, or else just sit around together. It was just so beautiful in that sense. And it's a very reciprocal process, you know. She helps me in other non-physical ways. Sometimes Lyn will take me out for a meal, and we're going on a holiday to Europe later this year for a month and she has paid for that. So that's how she contributes, which is absolutely priceless.

My mother

We also live with my mother who's 90. And she is becoming increasingly frail. For the most part she cooks for herself, but there are times when she needs a lot of help with that. She actually had a really horrible fall last year, and for a long time she was completely dependent for a lot of things. Not personal care, but certainly everything to do with housework and contact with the outside world, because she lost her speech for a while too - and so I filled that void. She's coming to now. But the fact remains she's 90, and she is actually ageing quite quickly.

She's extremely exhausted a lot of the time - there's not a whole lot that she can do physically. She really struggles with losing her independence and keeping her place together. So I'm in there a lot more than I ever have been before. But you'd expect that, because of her age.

In terms of actual activity with Mum, there's some planned stuff each week, like weekly shopping, medical appointments, but it's mostly situational and spontaneous. I go into her area and she's doing something and needs a bit of help. She's learning how to walk more confidently again after her fall, and I try and motivate her to do her exercises. So it's mostly responsive rather than programmed sort of stuff that I do with her.

Mum and our relationship

Mum certainly supports our relationship. I mean I don't think she wants to know anything about the sex bit. But certainly she - to the extent that she can, she is supportive. I'll never know whether it's about lesbianism or whether it's about my partner per se - but she is guarded around Lyn. They haven't embraced each other fully.

As I say, I don't know whether that's about lesbianism or about the personalities involved. It might just be that she doesn't like sharing me or something, you know? It might be as simple as that. But my mum has friends who are lesbian - she has had over the decades. So the intellectual idea isn't one that she baulks at. When we invited her to live with us, she jumped at the opportunity.

But our living situation is that we have the main house, and Mum lives in the unit that was built on, just on the other side of the door in the back room. It's all under the same roof. Mum has her own private living quarters, kitchen, lounge, bathroom, et cetera.

Friends that are ill

As well as that, I have two close friends who over the years have developed more and more severe mental health illnesses. I've been close to them for about 35 and 40 years respectively.

With one of them, it's sort of a social thing where I take her out once a week, because she's so incredibly isolated. And with the other friend, I'm part of a team of friends and paid people who go in on a rostered basis every week, and help her with shopping, washing and housework, and stuff.

Support for me

I don't think that I have a balance yet around my support for others, and focus on things for myself. You know, I need to actually be a little bit more proactive for myself, for making sure that I have a balance of other activities that are focused on myself as well as other people. I'm quite capable of doing that, it's just a matter of me pulling my finger out and doing it, basically.

In terms of support for me my partner certainly supports me, and I have a handful of wonderful friends who actively support me, and my mother is for the most part supportive as well. And I do feel quite acknowledged by the people I support, absolutely. In terms of other people, I don't think they get it. I don't think that they realise that the vast bulk of my time goes into caring. But they don't see the sort of daily action.

Comfortable being out

I'm actually really lucky. My work was in the human services. And in the human services there are many lesbian women and gay men. There were many of us. And I was completely comfortable about being quite out, once I got used to the idea of my new identity. So I'm actually just used to that.

What I've always noticed, even before I was comfortable - I noticed other lesbian women being completely comfortable about their identity. And consequently the people around them just took it at face value.

And that's what I emulated. And that's what I do now. And so when I go to cancer care groups and anywhere else, I just say, "Well, my partner Lyn", and no one bats an eyelid. If they do it internally, they don't react to me personally.

I'm friendly and I think that people find me quite approachable and warm. Whereas if I was kind of shy and withdrawn, it might be a bit different. I'm just really straightforward about it. So I don't look for their responses. Don't ever notice anything untoward.

Responses of service providers

I suspect that there was a little bit of hesitation with Lyn's surgeon. I went into the initial interview with Lyn, and I had a question of him, and he was obviously a bit narked that I was even there, let alone that I had the gall to ask something. And he didn't really answer my question. I was given short shrift. He did the operation for the biopsy, but that was a brief interlude, and it didn't bother me. But everywhere else I have been included in the conversation very deliberately. And I have always been asked if I have any questions, as well as Lyn being asked.

But I have to stress that I think I'm very lucky, because I'm in such a strong lesbian identified community - and that certainly has given me a lot of confidence around that stuff. It was literally water off a duck's back for me, you know. So I'm just very lucky that that's how it is for me. It might've been difficult for someone else, you know.

Our strong lesbian identified community has helped out a lot. Just for an example, when Liz was having her chemo, we had incredible support from our friends. And not only lesbian friends. Also the heterosexual community, and some gay men as well. But certainly our lesbian community were unbelievably wonderful.

Through food drop offs and frequent messages, you know, texting or ringing up. They were quite sensitive about whether we were up for personal contact, or whether it was just better to leave a message. Really very, very thoughtful, very generous. It's just a lovely, warm, supportive - a happy community together, you know. It's wonderful. And has been the case since - really since I worked out that I was lesbian, back in the early 80s.

Carer support services

Carer services just treated me the same as they treated anybody. Which is exceptional. They are really terrific with everybody. And I was no exception. So it wasn't that they did anything special. They didn't have to, you know. 'Cause everyone gets treated really beautifully.

I mean they don't have anything pictorially, like for example images of two women together or anything like that. But then there aren't lot of images around, to be honest. They just demonstrate acceptance by doing it.

I was part of a small carer support group run by the Cancer Care Centre. There was one meeting, and none of the others wanted to continue for various reasons. I was a bit disappointed about that, because I felt that the group had real potential. The Cancer Care Centre also runs all sorts of other groups and activities. People with cancer are welcome to join them, and their carers are also welcome to join.

So I have actually joined in a few of those groups. The meditation group is great, and also a Wellness Information course. It's really helpful information, but it's also about being in the milieu of the whole cancer care environment, that kind of acknowledges what you're going through.

Questions for discussion

1. How has being part of a 'strong lesbian identified community' enabled Jo as a carer?
2. What do you think the carer support group did to send a message of welcome to Jo?

Story 3: Sharon - another side hidden

So I am diagnosed with Asperger's, I am good at figures and fact and organising, I used to run my own business. I also do a bit of part time work when I feel I can. It's in a place where I feel relatively safe, and it's structured. But there is still Aspergery things that I have to deal with. I'm on a DSP [disability support pension] and so is my son.

My mother

My mother lives on her own in a retirement village. Her mind is very good, her body's faltering a bit. I do all her shopping, take her to appointments, fix her iPad when it's not working because she gets frustrated she can't get email. Dad died in 2006, so I was caring for him and mum then. And then she moved to a retirement village, so I did all that. I mean I've been looking after mum since - for years.

What else? I have no siblings who give any real help for mum. Two of them have my son to stay for a couple of nights four times a year.

I ring me mum every day, especially at the moment 'cause she's sick. It has in the last probably 12 to 18 months. Because she is a lot more dependent. And she doesn't hear as well, and you know, that can be frustrating. The other problem is that when she gets to the point where she requires personal care, I'm not sure how that's gonna go. I do all her shopping and everything that she - well, I mean she's just stopped driving.

My son

I have a son with an intellectual disability and an autism spectrum disorder. He also has dyscrasia and dysphonia. I case manage with a little help - my son's function. I self-manage his individual support plan. I organise all his care and his therapies and his day program, and I'm currently applying to make sure he can live independently.

If my son does live independently it will mean that I will be economically challenged. I'll have to look for social housing because there's no way I can afford to live on my own. And I am extremely anxious about that. Extremely anxious about ending up on the street. That's been a worry of mine for some time.

He is living with me at the moment and that's a lot of work, and it will still be ongoing work. And then of course there's the changes with the National Disability Insurance Scheme - it's a whole different ball game. It's much more specific, it's much more different. So my days are spent making sure my son's schedule is all right, that he's as happy as I can make him, and manage his behaviours. His father has no input - has never done anything as far my son's development goes. Which is probably good because - it means I don't have to have him around.

Two lives

I separated from my husband because he was bloody hopeless. I always knew I was probably gay, but didn't really understand it until later on in life. I met someone, a female. My partner now lives overseas. And so she lives there and I live here.

There was a big problem between my partner and my daughter, and it ended up so that I didn't speak to my daughter for a number of years. And then she was unwell, which she is just now starting to come out of. And we see each other about once a month.

And my mother doesn't recognise my sexual preference. She just - as all older people do, just ignores it and hopes it'll go away. I had a conversation with mum about being a lesbian. I probably didn't do it very well. You know, I'm a very accepting person. And I suppose I expected everybody else to be.

I took my partner over to meet mum one day and said, "Oh, we're moving in together". And that was my Aspergery acceptance of everybody else, you know. Well, why wouldn't they accept what I'm doing? My partner was happy to be friendly with her, but mum never was with her.

I have to be different people at different times all the time. And I mean I've always had that problem because of the Asperger's, but now it's for a different reason. Mum's not interested to hear about my trip to see my partner. I have to remember not to talk about my partner in front of my daughter and my mother. I can't talk about things that happened involving my partner with them. So I'm very guarded in what I'm saying all the time. It's tiring.

It's having to live a different life when I'm here compared with when I'm there. And mean I've had to wear many hats all my life because of the Asperger's.

I've got two lives, it's dreadful. When my partner comes here, she doesn't want my son to stay here. So when she comes over, I have to find somewhere else for him to stay. She has a history of abuse and she's been raped, and she - look, to give her her due, she is quite perceptive and intuitive. And she thinks every time she has seen my ex, she just thinks there's something really weird and wrong and funny about him. And my son looks exactly like my ex. And I mean frankly sometimes I feel like telling them all to fuck off, but anyway.

And so I feel like I've got two lives. And one of them's where I'd like to be and one of them's where I have to be.

I want to be where I am, but I - you know, when I see my partner just recently, for my last visit, I had my nephew staying with my son and taking him away for a week. So I actually psychologically switched off, and I had a very good time, 'cause I knew he was in good hands.

Mental wellbeing

I had post natal depression after my son was born. I've had a history of mental illness. But because I think of my Asperger's I'm able to use the CBT [cognitive behavioural therapy] a lot more successfully than normal people, if you want to put it that way. I wouldn't say everybody with Asperger's can do the same thing 'cause we're all different.

I use CBT in my own life - to manage things, and not get too involved, and to let go, and do all those things. It's changing your thinking. And putting into practice things like it doesn't really matter. And there's always two sides to an argument, and everyone's allowed to have their own views. And just seeing the best in people and not assuming the worst.

But I'm very practical, I'm results driven, I am very black and white. So if I make a decision, then that's what you do. You don't fluff around with it, you make the decision and you do it.

I also go to a yoga class. Wednesday I go to a gym class for carers of people over 65. Friday I go to a class which is for carers of people under 65. Weekends, [my son] goes to his father's for Saturday and Sunday night.

Being a lesbian and a carer

I guess when I go to carer support groups I don't necessarily advertise that I am a lesbian. I mean, nobody goes out of their way to talk about their sexuality. But as it stands, I can be selective about who I tell that I have a female partner, and who I don't.

They have a mother's weekend away, they're all heterosexual women and they drink. I mean I don't drink. They're all over the top, and I just don't function well in large social groups. They all dress

nicely and, a lot - will dress femininely, and I don't. And I don't have the money to. And I don't really have the money to go out a lot anyway.

I don't advertise the fact that I am a lesbian, and as a carer it doesn't generally interfere with what I have to do. I don't advertise it, I have explained that.

It's something that happens. I haven't pointed out that this is the name of my partner and this is the term that's used for our relationship.

So it's like another side hidden, you know. Because I only tell people who I think will be understanding.

If I hadn't had my son, I certainly wouldn't be who I am today. I mean some other experience may've led me down the path to being who I am, but I'm relatively pleased with who I am at the moment. The way I see life. And without my son that wouldn't have happened.

Questions for discussion

1. How does Sharon describe the impact of her mother's response to her sexuality on her wellbeing?
2. What do you think Sharon means when she says she feels she has two lives?
3. What differences does Sharon describe regarding herself and the other women in the carer support group – and how does this impact on her willingness to be participate in group events?

Story 4: Martin - Just don’t judge me

I've been with my partner, Rayyan, for 35 years and about five years ago he may have had his sort of stroke and he went back to work after that. It wasn't as severe. It was only a transient ischemic stroke. It wasn't severe. But anyhow, he had a one roughly two years later and I've been told that he will need someone to watch him and be around, so I gave up my job and took on the role of carer.

It was advised that somebody be around Rayyan to watch him. Examples watching that he might forget to turn off the gas after he's cooked. Or the gas – he'll turn the gas on and I've discovered gas on but not alight. I have to be around with him when he's buying anything so that he gets the right cash and he forgets and he walks away from the cashier without collecting his change.

He has improved a bit. He can shower himself but he has not got the mobility in his hand, so I have to dress him with the buttons on the shirts and the cuff links.

Then I have to [do] the gardening and he still tries to cook but he gets a bit agitated if I interrupt him while he's cooking. So then if I don't help him he gets agitated because I'm not there helping him.

Don’t talk about it – cultural differences
We don't have any family. Well, I don't have any family. They're in Adelaide or they've passed away. My family has dropped me like a hot stone because my father didn't leave anything for them in the Will, they – just evaporated real quick.

Rayyan’s family is all overseas. That's a Muslim background so when you go to Malaysia you don't, you know, hold up signs saying I'm gay, love it or leave it sort of thing. You keep quiet and – because it's a different country, it's a different culture, but his sister doesn't seem to have any issues at all and she's very appreciative of me looking after Rayyan. It's one of those situations where everything is okay as long as you just don’t talk about it.

Relationship changes big time
It has changed our relationship. Sometimes I feel like I'm more of a servant than a partner. So it gets a bit hard and then he sometimes – he's very sharp and harsh with his words and it causes friction between us. And then sometimes I just get tired of having – I feel like I do everything. And then it gets into an argument where Rayyan tells me what he did for me all these years so, I should basically shut up and just do a bit for him in return. So, yeah, it has changed our relationship big time, yes.

People of your own type
We moved down to Sydney three and a half years ago, so his second stroke was just before then.

Our life is different. I mean, it's harder now to make friends. We can't get out and do things as much because I've always got to watch Rayyan, if we go out. So socialising is a bit harder for us, so we're more or less at home. We have friends that come over for dinner and that's when, like, Rayyan will cook one dish and I'll cook the rest and – but, yes, it has impacted on our – being able to get out and make new friends.

We've got three sets of friends that I've used and Patrick and Stan are quite helpful, you know, they take Rayyan for a few hours and that gives me some break, so they're good. And I'm trying to resurrect a friendship with a fourth group. It's not going too well. We had a big argument well over a year ago. I've known them for 35 years.

Now, I was saying to Rayyan, we really need to make some new friends that perhaps aren't connected to our old friends so we could start on a new road, a new off shoot and see what happens.

Before Rayyan was sick we would go out to nightclubs. You know, this is also when we were younger, we'd go out to nightclubs and we'd stay out drinking and – then we would also have people over for dinner and or we'd have friends through work. Now that we've moved interstate we don't have friends through work, we only contact them on Facebook now.

So we have a few friends down here that we had that moved from Adelaide to Sydney or we met friends through other friends. We have some friends Pat and Stan and they have some people they'd like to introduce us to, so that is one avenue that I'll try to push, because Patrick has quite a few friends and so he wanted to try and help us so we can meet new people that way.

So it's nice to have a gay circle of friends when you are gay because it's easy to relate to them. It's a different type of life, different type of jokes and you feel comfortable amongst people of your own type, if you can put it that way.

Breathing spaces - LGBTI carers support groups

I would prefer an LGBTI specific carer support group because you know that you would be going amongst gay people – because gay people have a different sense of humour, you know, they joke about different things, to straight people, and you feel comfortable.

I'd think twice about it because turning up [to a carers support group that wasn't LGBTI]. I'm not too sure. I'd have to go I think, wouldn't I? I'd just have to go and see what it was like and see if it was me. Sometimes my partner doesn't want to mix with this sort of thing but if it was completely gay I think he'd be more comfortable to. You just don't know if those people would be happy to have a gay person there.

Well, because Rayyan's HIV positive he doesn't want to be in the situation where he'll feel depressed. And I can relate to that because when I was told I was epileptic I was a little bit suicidal myself, this is going back to when I was 16, and I was shown the door to an epileptic self-help group and now I look back on it I can laugh about it. I'm in two view, two views to that self-help group and I wanted to commit suicide I tell you. It was depressing and I never went back. So I can understand what Rayyan says, he doesn't want to get involved in anything like that's going to bring him emotionally and mentally down.

So it's better to be in a happy environment, you know, and that's what I was thinking, well seeing a gay movie, being in a park with other gay people or a restaurant.

Going out or doing things socially might be more uplifting because from my own experience it wasn't pleasant to some sort of counselling group and you see everyone else there that's a hell of a lot worse than you. It sometimes can have the reverse effect, you don't want to go anymore, you know.

So – but I'm still here, it cured me of my suicide, didn't it?

It would be nice to have people coming over who are gay, probably have similar problems that we do. Like I suffer from epilepsy. I have high blood pressure, diabetes. You know, my partner, he's HIV positive as well as the stroke, diabetes and atrial fibrillation. So we wouldn't mind being amongst people who have the same issues plus being gay is a bonus because we can all relax a bit, we don't feel we have to be on guard.

I was thinking maybe, to help carers maybe where carers could go out for a lunch with other carers and they can bring the people they're caring for but they'd be in a caring environment, maybe like in a restaurant or maybe in a park for a picnic or maybe to a gay cinema.

I don't think you'd have many gay people that would be really happy sitting down to a roast beef lunch in the local RSL. It isn't the same. It doesn't make gay people feel comfortable because they would think – I imagine they'd have a lot of straight eyes looking at them, "Oh, look at that lot over there", you see, and that's one of the worst things that gays people suffer from. I don't know whether myself or Rayyan would have so much of a problem because we more or less would just say, "Oh well, you know, if you've got a problem with it it's your problem not mine".

But there are gay people who wouldn't like that situation. They'd much prefer to be in a situation where they're completely surrounded by gay people and they could just, you know, let go and carry on as gay people do.

Because you could talk to other carers. You could have probably a little whinge. Then you could probably hear what other people do to get around certain problems, situations, instead of letting it lead into a fight like happens between Rayyan and I. There might be a way where one of us just walks away to quieten everything down and then 10 minutes later everything is fine again. I'm trying to learn to just walk away a bit, go to another room or into the garden, and then when Rayyan calmed down and I've calmed down I'll come back in and everything is fine again, you know.

Because we're in each other's pockets now more than ever before because neither of us go out to work now. So there are times when it gets a bit too much and Rayyan gets shitty and pick at me and I get shitty and pick at him. There's no outlet for either one of us and I've worked out if I just walk away, go outside or come into the computer room here, Rayyan stays and watches TV, that sort of gives us some breathing space.

But I was thinking if there was a group organised where the carers could go out, bring their partners with them, for the sake of offloading the stress and having a glass of wine and having some food and just talking about your problems and then you'll come back refreshed.

Discrimination in services

I think I have experienced discrimination in services. I talked this over with my partner and my partner sort of disagrees but I remember we were in – while living in Adelaide Rayyan had to go in to hospital to get his cataract removed. And Rayyan was taken into a room to question him for medical reasons before they went ahead with the procedure on the day. And they didn't want to let me go with him. And I said, "Excuse me, I'm his carer". I said, "I certainly am coming with him". And I also have an enduring power of attorney so I said, "I'm legally bound that I can be with him. I have a power of attorney, medical power of attorney", and I said, "You don't dare stop me".

I was treated as if I am the problem, you know, that oh, not a bloody carer I have to deal with. It seemed to be that attitude.

LGBTI inclusive services

We always tell people we're gay. I hope that's not going to be a problem for service providers. I'm very open and upfront. And I know other gay people they're very closed. They don't want to let other people know and I think those sort of gay people have a problem because they still want to live in the closet. But you know, one gay can suss out another gay real easily.

I'm doing most of the work, the cleaning. We still share the work but we do it ourselves. If it gets to the point where it's too much, Rayyan can't do it or I can't do it at all, then I would need services. So

we're a bit fortunate that I haven't had to deal with them just yet, whereas I guess you've had other clients that are using services because they can't do it all themselves.

You know, we're not at that point yet. And I wouldn't feel confident or comfortable accessing services if you needed to. I'll tell you why. I look at the information for our local Council where I am and the pictures that they have, you know, they are of older Australians, they are straight couples or they are ethnic couples, and I'm thinking well, what is it they could provide for a gay couple? And the answer in the back of my mind is 'nothing', apart from coming in to clean the house.

We are not getting any messages from our local council, no, there's no messages, no statements, nothing that they're gay inclusive. Because I sometimes think helping in the community is just seen as a drain on their economy, on their finances anyway so why would they want to also add an extra drain by looking after gay people? So I can understand why they're not bothering to include any reference to gay people; why they're just doing the basic minimum they have to do.

That's what I would hope the councils would do, so that when people came they would be – if not gay at least gay supportive. They need to be fully equipped to understand what they're going to encounter and don't think that every gay guy is going to want to strip you naked if the service provider is a male. You know, it's not the case at all like that.

Education – just don't judge me

People coming to look after gay people need to understand that they need to be taught about gay people, what their background is, what makes them laugh, that sort of thing.

Yeah, because for example we have some friends next door, they're straight, and the wife Anna, she's very, very comfortable with us. She comes in, has a few drinks with us and she's very relaxed but her husband, he suffers the problem that a lot of older straight men suffer whereby they freeze when they're around gay guys because they think we're undressing them with our eyes.

It is very much a problem, like, a single woman being in a room full of straight men. It's the same thing, a straight guy surrounded by gay guys, they feel very, very uncomfortable and this is what her husband suffers from. I can pick it up very easily. He doesn't even like to sit down and talk with us even if his wife is there. I've seen her trying to get him to come and he just says, "Oh no no no" and he disappears. He doesn't know I saw that.

So I understand he has that. Like, it's like a phobia but maybe these people that, you know, supply services that they could have the same problem and they will need to be told that we're just the same sort of people, we just laugh and not to be worried, you know, about us.

It makes me feel uncomfortable. It makes me feel that it's a situation, I don't know, should I be here? Should I not be here? I'm not going to worry about it because Anna is very open. She's very opening and welcoming and she comes into the house and looks after our dogs when we go away in the caravan and we've given them keys to the house. I mean, we trust them but I know not to try to be too friendly with her husband because he won't appreciate it.

I mean, gay carers need the understanding from service providers that look, this is my life. It may not be what you accept or understand but, look, you know, just don't judge me because I'm not judging you.

Questions for discussion

1. What reasons does Martin give for wanting to access an LGBTI specific carer support group?
2. What issues does Martin describe as contributing to his stress?
3. How would your service communicate to Martin and other LGBTI clients that they won't be judged – and that you are an LGBTI inclusive service?

Story 5: Trevor - On the watch

My role as a carer developed. It's one of these random things, isn't it, you have to accept it as part of life, it just develops.

I was compensating for him. When he got stuck I would shout out the word that he was looking for. And I think that's not exceptional. I think a lot of people, partners, close partnerships, do that. I think close partners do it naturally anyway but – that's the way it was and of course with dementia, you've got to fill in. I was not really controlling him, I was filling in for him.

It's stressful because you're trying to do a number of extra things. I realised that I was running the house. I was organising the holidays. He basically switched off at home and, so I was doing everything.

You don't realise it. I used to go to friends and complain, "He has me organising this holiday and he's not making any decisions whatsoever". I was making all the decisions.

I remember Peter coming home and I knew that there was a few sort of general health issues and he said, "Oh, I've been referred to the memory clinic". And I thought memory clinic, what's going on there? I thought it was a lot of bullshit.

[I went with him to the clinic when he was] diagnosed with Lewy Body dementia. I sat there and suddenly this woman was also there and she introduced herself as a nurse and she said, "You look grey". I said, "Well, I'm just shocked. I just can't believe what has happened". And she said, "You're not the first person to sit there and say that".

Up till the time he went into care he was pretty good at cleaning things. He couldn't cook but we developed a system where I did the cooking and he did the washing up and afterwards, whilst I watched television, and I could keep an eye on him but I didn't really have to do anything.

Relationship changes
I think over the time we got closer. I think that is probably proof of the fact of the way he passed away. He'd been in a coma for quite a number of days, I think it was 10 or 11, and he was fairly – he was sinking. They called me into the nursing home and basically I had to say to him, "Look, you aren't gonna win. I think you better give up", and I gave him a big cuddle and said that and he stopped breathing.

He was waiting for me basically. And that is extremely stressful to talk about it but it's stressful – I mean, the effect on you is incredible.

You then realise how dependent he was on me the whole time he was alive.

Life has changed
Before he was diagnosed I was a partner in a partnership – my partner was a very healthy person and didn't drink, didn't smoke. And suddenly he was told, he had a terminal disease and it will take a long time, so life changes, it has to change. I guess you've got to come to terms with that. It is a massive change to get the brain to take that in.

You always worried about him, I was always keeping an eye on him. I went on this Living with Memory Loss Course, I met other people who were in a similar situation. They had some of their

partners who left home and got lost and things like that and all the time you were wondering about was that a possibility, you had to keep an eye on him.

I was on edge. It's a question of stress because it was a massive stress in that you just can't live with that. You can't sort of say, oh well, just forget it now.

All the time you are worried. And also he made it a little bit worse by refusing to have a carer here when I was away. As soon as I left he went to bed because that was a safe place to be. And he knew what time I would be back and he got up and made out that he'd been up all the time.

We went on a Living with Memory Loss Course with Alzheimer's Australia and that was good because it put me in touch with people who are in a similar situation, and I wasn't alone.

A different sex now

We managed to arrange [to have sex in the nursing home] ultimately. I think he became more dependent upon me and then made it much closer. But there were issues along the way. Obviously his interest in sex weened a little bit, and this was seen by my own GP. He said, "Look, you are somebody who needs something like this and you ought to [go out and meet other men]. We had a monogamous relationship and I didn't really want to but in the end the GP pestered me to, and I said, "Well, I'm not doing it unless Peter knows", and he said, "No, obviously not".

So one night I gathered up the courage to raise the issue with him and I said, "The doctor has told me that I should go elsewhere", and Peter looked at me and said, "I've been trying to tell you that for months".

I found it extremely difficult. I found it difficult because what went on when we stopped [dating scene] 22 years before -was not the same thing. That was a very stressful business bringing yourself, I suppose, up to date. People's attitudes were different.

But even people of my age had a little bit of different attitude to sex. It has changed over the years and sex is now regarded as a sort of staple of life I think, whereas maybe 25 years ago it was regarded as something special.

I think there's a different sex, I think there is a difference there. I think nowadays people sort of yes, you do need sex, and whereas 25 years ago it wasn't like that.

Sex sort of – I think is fairly important. And also, of course, that it was yet another stage in the process of him ultimately passing away.

On the watch – residential aged care

When he was in residential care I would visit. It started off seven days a week but after about six months I cut it down to five days a week. He was in residential care for two and a half years.

It is a lot of visiting and he was dependent to a certain extent on me. Obviously there was a stress there every day that you want to make sure that they're not being maltreated.

I mean, you're on the watch for that everyday anyway. [Because historically there was discrimination]. I think all of us everyday are [on the watch].

With watching for ourselves and then if you get into a partnership with somebody and they are at a disadvantage, you're watching for them.

But I'm just saying it's a normal gay thing.

I had no problem with the permanent staff and absolutely I want to make it clear. But when you have so many temporary staff and they have probably arrived in the country not very long ago, and they come from different religions, you have to wonder about how they're going to cope.

I think maybe some of the temporary staff there was an issue there but I can't be sure. I think the permanent staff would pick it up and deal with it – you can't be sure.

Space to get sick
Only after he passed away [was I able to get sick]. [I've been in hospital] and the doctor who was seeing me he said, "You're exactly where I would expect you to be after what you've been through". They say that [getting sick] is a direct result of all that had been happening. [While Peter was alive] the adrenaline keeps running as rapidly as possible whilst he was alive and I was needed, as soon as he went I relaxed.

I mean, that happens with us all, doesn't it? I mean, you know what it's like if you have a busy period when you're working. Once you relax you're liable to get a cold. It all boils down to stress.

Grieving
[To hear your partner is] not going to be here in a few years' time. You just can't get that into your brain. I know it's very easy for the doctors to say, "Sorry, you've got dementia, you've got seven years", or whatever, "Get your affairs into order. Do what you want", but actually coming to terms with that, particularly for the one as you're going to be left behind, is extremely difficult.

In fact, I would say in all honesty it's probably impossible for most people to come to terms with that, but you have to come to terms with it but that is extremely stressful in its own right.

Support after
Well, there's no support after [your partner has gone]. You report to Centrelink because he was getting a pension and he'd gone and bang and your connections with the support groups, the local support groups are cut straightaway.

They go and there is no support. There is support but is very little support for the carers during the whole process. I did have the added problem which was about six months before Peter went into care, would you believe five of my mentors died one after the other. I got to the stage where I didn't answer the phone and people had to leave messages.

LGBTI inclusive counselling
My doctor had some fairly good contacts with [a local LGBTI health service] and they counselled me and they provided a lot of counselling during that time. [But] I had to fight for my counselling. I had to sort of push people to arrange it for me. I had to identify the need for it basically and I had to say to people I wanted it and for gay people you have to have a gay counsellor and I think that's important and if you have a look at that interview you will see the counsellor actually specified why he thought it was better that I had a gay counsellor.

I did try going to a straight guy but he didn't understand. He did not understand what was the stressors, past stressors and extremes were about. He didn't understand what one's relationship was. He couldn't perceive it and I think well there are – particularly with the generation that I'm part of, there's an element in it of you [got] yourself into the situation.

I found myself caring for somebody and my life falling apart again. [In my younger years] I left a very good job and I left my family, with their agreement, with more or less agreement, and I come to Australia and I'd re-established myself.

Let me go back to the beginning. I had grown up during that very persecuted period of the 50s and 60s and the 70s. I carried that baggage all along. I got myself married, I've got kids. Things that become very liberated and therefore I could do what I wanted to do on the side which my wife found out about. We decided to stand by the kids until they left school and, yes, we went through those stresses and strains. So that was a very tumultuous time. I had then emigrated.

I re-established myself a decent career path and became state sales manager and I established close friends.

I established a relationship where it looked as though it was going on forever, which was a very close relationship, it was monogamous, and looked as though it was going on forever. People respected it.

And suddenly I was thrown into this situation.

Recognising carers

I'm beginning to take the view that if you want the carers in good [health] after [the death of the person they are caring for] - and that would be very beneficial to society, you probably need to treat the carer and the patients equally and invest amounts of time and money in both of them.

A friend of mine and his partner has had cancer for two years and passed away and I rang him. This was after Peter went. And I rang him and sympathised with him and passed on my condolences etc. and he said, "You lost Peter two or three years beforehand but you still had to visit him". And I think that in fact to me sums it up.

I think in fact the GPs have to concentrate a lot more on the carer than on the patient. [The carer is] ignored. Totally ignored. He doesn't come into the equation. But if he didn't do what he's doing the doctor's job would be a lot lot worse.

The fact that it's going reasonably smoothly is down to the carer, but they don't support the carer.

There is no support for the carers. In fact, I don't think carers organisations have got a very good job to be quite frank. I've never had much support from them. I went on a couple of their courses which I thought were very good. But I think it's more than that they need.

I think it may be a question of ringing carers and saying – I know it would take a lot of resource, "What are your problems? What should we be talking about? How could we help you?" They've got to make the initiative. [They have got] to pursue it. And sort of saying, "Well, what are the difficulties?" To sit down with people and try to bring it out of them.

I was a senior manager in a large organisation so I had those abilities but I still ended up with problems at the end of it. But, I mean, I see people who can barely manage themselves normally being thrown into this carer's role, no money basically, you know, on a carers pension. Well, it's not much more than the dole. Basically it's cheap labour [and the government is] taking advantage of it and they're not really supplying [carers] with any support.

I think society has turned their back on a lot of people basically.

Nobody says, "Trevor is an expensive person to treat at the moment because he didn't get the support [he needed when he was a carer]. Perhaps we didn't make life easy enough during the critical period he went through". [Because I'm now sick] I'm just a new statistic versus somebody that might have [been well if I'd been supported as a carer]. They [just] don't ask why [am I sick]?

Questions for discussion

1. What do you think Trevor means when he say he was on “the watch” and that was a ‘normal gay thing’?
2. What do you think he means when he says the straight counsellor did not understand?
3. How do you believe Peter’s passing has impacted on Trevor?

Section 5: Resources and further information

Val's Café: valscafe.org.au
Val's Café is situated within the Australian Research Centre in Sex, Health and Society at La Trobe University and seeks to improve the health, wellbeing and visibility of older LGBTI Australians. The Val's Café website includes comprehensive information on LGBTI ageing and aged care. Join the Val's Café mailing list for updates our research, resource development and education.

Carers Australia: www.carersaustralia.com.au or call 1800 242 636
Carers Australia is the national peak body representing Australia's carers, advocating on behalf of Australia's carers to influence policies and services at a national level. It works collaboratively with partners and its member organisations to improve the health, wellbeing, resilience and financial security of carers and to ensure that caring is a shared responsibility of family, community and government.

How to use this resource

This resource can be used for education in conjunction with general information about LGBTI ageing and aged care. The following table outlines a step-by-step interactive education program. It is important that facilitators familiarise themselves with the information in all 6 steps and tailor education to the learning needs of their audience. The duration of education may vary from 2 hours to a full day or series of workshops and can include staff, volunteers or carers. All the resources in the following table are available on the Val's Café website.

Step	Suggested Use
1. Terminology	• Read the *Aged Care Assessment Service LGBTI Inclusive Guide Sheets* (see reference list #14) to familiarise yourself with commonly used terms
2. History and its impacts	• Watch the *Then and Now* films (see valscafe.org.au) • Read narratives in the *My People My Story* resource (see valscafe.org.au) • Read stories in the *No Need to Straighten Up* report (see reference list #7) • Discuss the historical treatment of LGBTI Australians and how this might impact on LGBTI carers • Discuss how historical perceptions of LGBTI people might still influence the attitudes and beliefs of service providers and other carers in carer groups
3. Legislative and other reforms	• Read the *Aged Care Assessment Service LGBTI Inclusive Guide Sheets* to familiarise yourself with legislative and other reforms (reference list #14) • Read the *National LGBTI Ageing and Aged Care Strategy* (see reference list #13)
4. Principles of LGBTI inclusive aged care	• Rate your service using the Val's Café *Self Assessment and Planning (SAP) Tool* (see valscafe.org.au)
5. Key issues and strategies for older LGBTI carers and the carers of older LGBTI people	• Read the key issues and strategies outlined in this resource and discuss how these strategies will be implemented in your service.
6. The lived experiences of older LGBTI carers and the carers of older LGBTI people	• Read the stories in this report and utilise the questions for education and reflection.

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