

Trans Health and Ageing

An evidence-based guide to inclusive services

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Table of Contents

Int	troduction	3
Background in LGBT ageing and aged care		
Legislative and policy reforms		
Μ	edical contexts	4
Ke	y Issues in Trans Health and Ageing	5
Α.	Trans histories	5
В.	Prejudicial treatment	6
C.	Fear of discrimination in services	8
D.	Misinformation and no information	8
Ε.	Trans people living with dementia	9
Tra	ans Inclusive Care	10
Ec	lucation	10
1.	Understand history	10
2.	Be aware of document issues	11
3.	Be considerate of physical issues	11
4.	Be attentive to legal rights	12
5.	Be respectful and professional	12
6.	Don't assume, listen	13
Organisational Action		14
7.	Be welcoming	14
8.	Ensure administrative flexibility	15
9.	Undo gender segregation	15
10	. Respect privacy needs	16
11.	. Advocate	16
Fu	rther Information	18

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Introduction

This resource was developed as part of a research project undertaken by Val's Café at the Australian Research Centre in Sex, Health and Society, La Trobe University, in partnership with FTM Shed, Transgender Victoria and The Gender Centre (NSW). The aim of the project was to document trans people's experiences of ageing and their health and aged care needs, and to develop a resource that privileged the voices of trans people. The evidence for this guide comes from interviews conducted in 2014 and 2015 with 15 trans people aged between 49 and 79 (3 men, 11 women and 1 gender diverse person), two of whom were living with dementia. We also interviewed seven service providers, who contacted us, about their experiences caring for older trans people. Three service providers shared with us the stories of four trans people living with dementia. This guide is part of a tool kit developed from the research, which have been designed to be read together, including a 4 page summary (10) and a resource of participants' narratives with discussion questions (9). *Please read page i of the summary first* (10).

This guide begins by outlining background issues, legislative, policy and medical contexts, and then presents: key issues in trans health and ageing, the experiences and needs of trans people living with dementia, an evidence based guide to trans inclusive care, information on the importance of advocacy, and further information, including suggestions for using this resource as an educational tool.

"The first time that I started to feel good about myself, that there are other humans like me, was at a trans event. Both my wife and I went to those events and had a wonderful time. Fortunately she saw how wonderful many of my brothers and sisters were. [...] I'm a better person because of this change that's come roaring like an out of control vacuum cleaner through my life." - Beatrice¹

Background in LGBT ageing and aged care

History, recent legislative reforms and health research relating to older LGBT people more broadly provide important context for this resource. A series of guide sheets are recommended to provide readers with this background (5) and key points are outlined in this section. Older LGBT Australians have lived through a time in the nation's history when they suffered stigma, discrimination, criminalisation, family rejection and social isolation (7). Older LGBT people have lived most of their lives aware that disclosing their sexual orientation, transgender identity or trans status could result in arrest and imprisonment, psychiatric incarceration or enforced attempted 'cure treatments' (3). Disclosure could result in the loss of family, friends and employment. For older LGBT people their sense of who they are and their place, or lack thereof, in the culture at large, was shaped during this time of institutionalised homophobia and transphobia that predates, not only the reforms of the past twenty years, but also the social liberation movements of the second half of the twenty-first century (3). Older LGBT people carry this history with them not as a cultural relic or curiosity, but as formative and a deeply embedded part of who they are today (3). The experience of growing up in homophobic and transphobic societies has contributed to higher rates of depression and anxiety among older LGBT people (3). It also resulted in the onus of responsibility being placed on LGBT people to conform to sexuality and gender norms in order to avoid upsetting the status quo. This sense of responsibility has persisted across the life span and some LGBT people still believe their sexual orientation or trans status should be hidden to avoid confronting others. The effects of this history also continues to shape the way we interact with LGBT people, regardless of their age.

^{1.} The names of all research participants have been changed (to similarly gendered names they agreed with) to protect their privacy.

Legislative and policy reforms

Recently there have been significant reforms recognising the rights of older LGBTI Australians. These reforms include the development of a *National LGBTI Ageing and Aged Care Strategy* in 2012 (7). The Strategy describes the Australian 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. The Strategy also highlights the need to "empower older LGBTI people as self-advocates and experts to be consulted about their own ageing and aged care needs and circumstances". This resource aims to promote the development of trans inclusive services via consulting directly with trans people. The 2013 reforms to the Sex Discrimination Act provide protection from discrimination on the grounds of 'gender identity' – a term specifically used to describe trans people's gender (4), including in the provision of aged care services. Further reforms in 2012 included an amendment to the *Aged Care Act* (1997) recognising older LGBTI people as a 'Special Needs Group' (7). These reforms are reflected in the *National Standards for LGBTI Inclusive Services* (see 13).

Medical contexts

While there are some similarities between being trans and being lesbian, gay or bisexual, such as historical experiences of discrimination, a key difference is that whilst 'homosexuality' is no longer considered a mental disorder, being trans still is. 'Gender dysphoria' is the current psychiatric diagnosis used to describe trans people. Trans people need to comply with rigorous psychiatric screening and other tests in order to access medical services to transition (change their appearance from one gender to another). These processes were described by participants as 'gatekeeping.' The continued inclusion of trans categories as mental disorders is hotly contested within medical and trans communities. Some people believe that medical services would be withheld from trans people if the psychiatric diagnosis was expunged. Others feel that being trans is part of the diversity and variety of humankind, and that the diagnosis pathologises difference. Many trans people experience the stigma of being labelled as mentally ill. It is important to note that, even as the diagnostic labels for trans people persist, these do not describe mental incapacity. On the contrary, trans people who pursue medical services to transition must prove that they are mentally competent (able to make informed decisions). Participants described being aware that being trans was considered a mental illness by family, friends and health service providers, and that this contributed to a reluctance to disclose this information.

Participants described historical practices where trans women were medicated with testosterone to 'make them real men' and trans men were prescribed oestrogen to 'make them real women'. This was a common practice in Australia until the 1990s. Like many places around the world, Australia has a number of 'gender clinics', which are medical services for trans people and include endocrinologists, psychiatrists, surgeons, speech pathologists and other specialists who have experience with trans patients. These clinics are only located in major cities, and often have long wait lists. Whilst some participants reported a sense of relief at being recognised and felt grateful for gender clinic services, almost all participants described negative experiences using these services: some resented being forced to prove themselves to sceptical medical professionals, whilst others found the services themselves to be unprofessional, poorly organised or parochial.

In order to change their legal sex, trans people are required to prove they have had their reproductive organs removed. Trans men described this process as being 'forcibly sterilised' – being unable to have their birth certificates and other documentation changed from female to male unless they underwent a full hysterectomy. This requirement, which still exists across Australia and around the world, was seen as subjecting trans people to unnecessary risks. It was also viewed as evidence that rigid gender binaries dominate legal and bureaucratic systems, leaving little room to recognise, value or celebrate being trans.

Key Issues in Trans Health and Ageing

- A. Trans histories
- B. Prejudicial treatment
- C. Fear of discrimination in services
- D. Misinformation and no information
- E. Trans people living with dementia

A. Trans histories

"There was this 1950s attitude, you just didn't talk about these sorts of things at all. [...] there was this attitude that you just couldn't bring these things up for discussion at all. Not even with your parents." – Jeanine

Older trans people have lived through vast social changes. Growing up, being different was not valued or respected. Instead ways they were different were kept secret and experienced as embarrassing and shameful. While some older trans people will have transitioned as teenagers, others will pursue a change later in life, particularly as they come to see the world today as more accepting of gender diversity. Some participants described histories of psychiatric incarceration and enforced 'conversion therapies', and all discussed experiences of prejudice and discrimination, often at the hands of medical and health service providers.

"I tried very hard to fit in with society. My parents knew about my transsexualism from a very early age. My father tried to have me cured of it with psychiatric and electro-convulsive therapy. One psychiatrist taught me to lie. He taught me to lie to my father, to other psychiatrists and how to protect myself. And that was sort of the beginning of creating an alter ego with myself trapped inside. I got married three times, had four children, I tried very hard to be normal." – Sandy

Some trans people, like Sandy, feel as though they have spent most of their life living a lie and 'trying to be normal'. As a result, trans people may be very aware of other people's reactions and try hard not to 'rock the boat'.

"One of my huge problems was constant vigilance. Everything from when I woke up till when I went to sleep, everything I did, everything I said, everything I wore, I had to carefully, carefully watch so that I didn't appear to be unusual." – Caren

On the flip side, some participants described being fed up acquiescing to other people's expectations at their own expense. Some participants had a partner who supported them, and they greatly valued being recognised in this way. Several participants described the challenges of transitioning in a long-term relationship, including the legal requirement in Australia to divorce if they were married. For many, the decision to transition was weighed up against the impacts on their partner and family. Most participants lived alone and did not have the support of a partner or their family.

"You know, you don't really fit in. I've lived very much in straight society all my life, [..] As I've grown older what I've found is that you feel very much washed up and alone because I lost my partner, who died. [...] A lot of my trans friends as I got older they died. A lot of my single friends got married, had children, mortgages and now are grandparents with grandchildren and so their lives are very taken up and fulfilled with family issues. Not having a close knit family of my own, you sort of wonder where you fit." – Laura

Participants described experiencing rejection by their families, and having particularly fraught relationships with adult children who do not accept them. They also described being very self-reliant and valuing their independence as a result of these experiences. Trans people may not have the support of their families and may have lost other community ties as well. Therefore, as they age, they may not have the financial, emotional or caring support needed to remain independent longer. When undertaking assessment or developing life stories, it is important that service providers are mindful of historical experiences of discrimination. Questions about experiences growing up, family and early relationships may precipitate anxiety or be re-traumatising.

"Aged care seems to be a problem and this problem was identified in [a trans group I attended] – people brought it up about the fear of going into nursing homes, and how they were going to be treated. I have the same fear and there was one woman in the group who was in her mid-70s and another one who was in her early 70s and they had an incredible fear about – will my family look after me? Because they had sons, and because they had transitioned very late in life, they had this incredible fear – would their sons look after them? They weren't sure." – Laura

The experience of harassment for being 'different' or for being trans was described by all participants. Abuse was perpetrated early on by other children at school, by family members, such as siblings, parents and children, members of the general public and other users of shared services. The abuse described to us was verbal, physical, and included sexual assault.

Experiences of abuse, as well as rejection by family, friends and the broader community resulted in many participants experiencing anxiety and depression and some attempting suicide. Poor mental health or low self-esteem stemmed from societal responses to trans people, not from being trans. A history of negative experiences diminished participants' sense of entitlement. Service providers who understand the historical tensions that occur with some families of origin and the legal rights of trans people are well placed to recognise the emotional difficulty of such conflicts and advocate for the rights of trans people – particularly those who are living with dementia or other illnesses or disabilities.

B. Prejudicial treatment

Trans people who attended gender clinics (medical services specifically for trans people), especially earlier in their life, described enduring a battery of psychiatric and physically violating tests in order to prove their gender and access medical services to transition. Talking about his experience of gender clinic services in Australia in the 1980s, Alfred said:

"You had to have blood tests every three months. You weren't allowed to have Hep[atitis] or herpes or anything – no STDs, [you] had to be pure. So when they signed off on us – and you got a certificate to say that you were transsexual, being the term used in the day, and the whole committee agreed and you were assessed and you had to go through formal interviews. You had to do all your psych work. You had to do the ink blocks. You had to do all of that sort of stuff at your own expense and at the end you were panel interviewed, and if you slip up, you're out. I mean, that was – your life ended really. And I'm sure there's a lot of trans guys out there my age that failed, not because they're not trans guys, because they couldn't handle the pressure of what was being asked of them, or they didn't have, the gift of the gab or whatever. They weren't as street smart as I was. They didn't know as much about the scene as I did, but, I'm pretty sure there's trans guys out there that look like women that are living as butch lesbians, if not suicide. I lost a lot of friends that I knew in the day." – Alfred

Whilst some participants reported a sense of relief at being recognised and felt grateful for gender clinic services, almost all participants described negative experiences using gender clinic services.

Refusal of care

"The head psychiatrist there does not like trans people. I don't know if it's just trans people or gay people in general. [...] She just walked in and said, 'Oh,' looked at the file, 'One of those,' and walked out." – Sandy

Like Sandy, most participants reported being refused care because they are trans. Alfred describes his experience of this:

"[In the late 1990s, I had to go into hospital] and the staff went on strike. They didn't want to deal with me, because I was trans. I was in emergency. I woke up naked, as you do, and in a room and they had me in a four bed ward. All the beds had been taken out, everything, and I was in the corner and basically no one came near me. And I had to have intensive IVs and everything. I had them everywhere. And they come in and really just shoved them as quick as they could and leave and they were saying things like, 'Oh, I'm the only nurse that will come near you.' And if I hadn't have had a good mate I wouldn't have had a bed change or food or pyjamas. And I was there for over 10 weeks." – Alfred

As Alfred describes, this incident occurred relatively recently. While historical experiences of discrimination and poor treatment taught trans people they were not welcome in services, participants also reported these incidents continue to occur. Many participants described being rejected or refused services on disclosing, or it becoming known, that they are trans.

"I then opted for this lady GP, and I thought she'd be good but I found when I mentioned this sort of thing she was very abrupt, she just couldn't understand my needs. She was totally against the idea of me being on a female hormone regime. So I sort of dumped her." – Jeanine

Participants reported a sense of responsibility to manage disclosure of trans status to escape discrimination and also to avoid making others uncomfortable.

Acting as an educator

"Most of us have had some experience where we've had to talk about trans where trans wasn't relevant for the current discussion and felt that we were providing training at our cost to someone else to get up to speed." – Alison

Trans people are often faced with service providers who know nothing about trans issues or trans people, and as a result, participants described feeling obliged to educate service providers from whom they were seeking help. Many trans people in the study, like Alison, expressed frustration and anguish that this seems to be common practice. As a result, participants described feeling they have nothing to gain from seeking professional services. It is not appropriate for trans people to be put in the position of educating service providers from whom they are seeking help.

"[They] deliberately misuse pronouns. [Or...] when they figured they'd made a mistake, people get so flustered about it. Because the first thing you have to do when you meet another person is tick pink box or the blue box. [...] I mean, quite frankly it's not relevant." – Meredith

As Alison and Meredith suggest, having their trans status brought up repeatedly and when it is not relevant was described as tiresome and frustrating, as well as distressing and hurtful. Information about people's gender, or health needs, should only be collected or discussed where there is a legitimate need for that information (4).

C. Fear of discrimination in services

"First of all, the staff here don't know [I'm trans]. I don't see there's any need to tell. [...] A short time ago I would never have disclosed it ... to anyone, you know. It's only when I got on very well with a couple of nurses here that I started telling them. To say they were in a state of shock was an understatement." – Leah

Like Leah, participants discussed being reluctant to disclose their trans status or history because they fear discrimination, rejection or inferior treatment. Discrimination takes many forms. As well as the overt rejection and refusal of care described above, subtler experiences of discrimination were also reported. Participants described being very conscious and aware of being stared at or treated differently from other people.

"I still feel judged when I go to a different medical provider and I try to avoid that if I can. And sometimes it's not in my best interests to do that and I struggle with myself, and I don't know why. I'm very confident, I'm very out, but in the medical setting I sometimes still struggle to do what I should do." – Alison

Reactions from service providers and others, such as 'being stared at', have a negative impact on trans people who have spent a lifetime being judged, dismissed, rejected, or humiliated because of their appearance or trans status. Participants described feeling especially sensitive to rudeness or other less than professional forms of conduct. As Judith describes:

"I've heard that from various people that a doctor even treating [nontrans] heterosexual people can be very abrupt and non-communicative. And if that's just the way they are, that's who they are, but they've got to improve on that. But if they then do that to a trans person, and the trans person has just got all of these personal issues to deal with as well, of course it's not going to be well received. And the trans person will feel very aggrieved, like he or she hasn't been fully understood. So it's not just the fact that a medical practitioner can be rude or uncommunicative or abrupt with a trans person, they're like that with everybody. But the trans person, of course, wouldn't necessarily see it that way, they would see it on a personal level." – Judith

Previous experiences of discrimination and prejudicial treatment contributes to a fear of health services and aged care. What is important is what someone's immediate needs are, not that they are trans or make known that they have a trans history.

"They like to call us 'trans', but my transition ended 20 years ago when I was completed and a complete female. And I've just been a woman, plain woman since then. And these days they like to put us back in the box of being a 'trans woman' [...Someone] said to me the other day, she said, 'You don't want to be known as trans?' I said, 'No, I'm a woman. My transition ended 20 years ago.' She said, 'We could understand you don't want to acknowledge what you did for the rest of your life.' I said, 'That's got nothing to do with it'." – Sandy

As Sandy highlights, many people with trans histories are simply men or women and do not identify as 'trans'.

D. Misinformation and no information

"And nobody is sure if the hysterectomy does you good or does you bad, whether having a hysterectomy makes the T[estosterone] work better or makes your bones brittle – nobody knows." – Alfred

A lack of research into trans ageing and trans health more generally means trans people do not know what will happen and what risks they face as they age. Additionally, participants reported that doctors and other service providers tended to know even less about trans health and ageing than they did.

"I realised that some of the stuff that [medical] people say about our health is not true. There's a mythology around [...like] there is no medical reason why we should have to have a hysterectomy. [...] I'm anti hysterectomies, anti-Government forcing people into hysterectomies and them making out that it's all about health when it's lies, that's lies. And it's people saying, 'Oh, you'll have to pay for it yourself,' when you don't. I think for me that is really important because that was one of the biggest things that stressed me out because I thought I had to find five grand because of all their lies. Well, I didn't have to pay. It was free." – Gary

A lack of reliable information about what trans people's health needs are can lead to 'myths'. As Gary describes, the myths he encountered were not solely relating to his health but also the costs of accessing treatment. Many participants described struggling with the financial and other costs of medical services. Difficulties using Australia's Medicare system, where accessibility is based on one's gender as it is recorded with Medicare, were also reported. Across Australia, trans people are required to have their reproductive organs removed in order to change the gender on their birth certificate. This is what Gary means by the 'government forcing people into hysterectomies'. Additionally, if trans men are not listed with Medicare as 'male', they cannot access testosterone via the pharmaceutical benefits scheme (PBS). Laura describes other misinformation related to trans women:

"We were always told that because we had the type of vaginas that we did, we couldn't get HIV or any of that kind of stuff. It's all wrong information. And that was from my GP. [...] I mean it wasn't just my GP, there's others out there as well. Because there was a lot of women that thought the same way as I do." – Laura²

When seeking information about trans health and ageing, make sure it is evidence-based. If you can, check the sources of any trans health information you read.

E. Trans people living with dementia

Dementia, like all diseases, does not have universal effects. That means everyone experiences dementia differently, depending on their individual context and experiences. The same is true for trans people. There is very little research into the experiences and needs of trans people living with dementia. Despite this, and as with many aspects of trans health, service providers often deduce or assume what the needs of trans people will be, based on the experiences of nontrans people (2). As each person experiences gender (and dementia) differently, it is very difficult to anticipate how dementia will affect trans people. Just like other people, most participants described experiencing their gender as stable throughout their entire life, though a lack of clinical research means it is not possible to know how dementia will impact trans people's experiences of themselves and their bodies. The best way to care for and support a trans person with dementia is to pay attention to their current situation and present needs, without assuming what those might be. See our guide to inclusive services for lesbian, gay, bisexual and trans people living with dementia (1).

The right for trans people to live as their affirmed gender is a legally protected right (4). Some participants feared that dementia would make them vulnerable to abuse, particularly from service providers or family members with whom they have historical or ongoing conflicts. This can result in a delay or refusal to access services. Service providers could significantly address the fears of trans people living with dementia by demonstrating their commitment to providing trans inclusive services, and advocating for the needs of trans people.

^{2.} Trans women can get HIV regardless of the kinds of surgeries they have undergone. There are no surgeries that prevent the transmission of HIV.

Trans Inclusive Care

A trans inclusive service does not need people to disclose or identify themselves as trans. A trans inclusive service is set up in particular ways that make it a comfortable service for trans people to use, where they feel safe to share all of their needs. There are some educational, practical and organisational ways to make your service trans inclusive.

Education

What do I need to know?

- 1. Understand history
- 2. Be aware of document issues
- 3. Be considerate of physical issues
- 4. Be attentive to legal rights

What do I need to do?

- 5. Be respectful and professional
- 6. Don't assume, listen

Organisational Action

- 7. Be welcoming
- 8. Ensure administrative flexibility
- 9. Undo gender segregation
- 10. Respect privacy needs
- 11. Advocate

Education

"The majority of trans people seeking medical support, advice, consulting with the medical providers, is one of having to almost be a 'guinea pig', almost to be a novelty because people aren't informed, aren't aware, aren't able to meet their trans needs. And often we end up providing training to providers because of their own ignorance and often their lack of interest in terms of finding out for themselves." – Alison

Education about trans issues and trans people's needs is incredibly important, and needs to be provided to all staff in all roles. Older trans people tend to have been 'forerunners' in medicine, as well as socially. Many participants discussed experiencing being the first trans person someone else has ever met, including health professionals from whom they were seeking help. Put in this position, as Alison suggests, trans people have to act as educators to service providers who know nothing about trans health. Being a trans inclusive service means staff in all roles understand what being trans inclusive means, are aware that trans people may be using their service, and know that it is professionally inappropriate to need or expect trans people to explain themselves.

What do I need to know?

1. Understand history

"[Service providers] would need to understand the – I was going to say traumas, but not actually traumas, but they need to understand the moods that the trans person is going to go through because they have to deal with issues themselves because – family issues, for instance, workplace issues and all of these things. So they've gone through a difficult period as well, so the [service provider] should really understand all of that and not add to it, but try to allay the trans person's fears, and just reassure. It all comes down to a bedside manner I guess." – Judith

Trans people's historical experiences of discrimination, including from service providers, impact how they relate to services, as well as a fear of accessing and using services. As Judith points out, trans people may be sensitive to what might otherwise be considered 'poor communication' or rudeness. Judith suggests service providers are better equipped to provide a good service to trans people if they understand

some of the hardships a trans person might have endured, and not add to their difficulties. *Trans inclusive* services have a real opportunity to assist trans people in caring ways that they may rarely have experienced throughout their lives.

2. Be aware of document issues

"I've got paperwork issues. I haven't had the hysterectomy, so I don't have a male birth certificate. And I have not changed my gender on my superannuation account. Because I don't want – when I'm dead and gone, I can't fight the war. I can't leave a mess for my son, I want the money released to him. He's going to need it. I rang the superannuation and I said, 'Well, how does it work?' and they were very nice to me, [we had a] very open conversation as to why I needed to know. And they said, 'Well, when we're paying out on the money, the death certificate must match the person on the account'. He said, 'We can easily change your gender for you, that's no worries, but when your death certificate comes out, it'll be female, and then the account will be male, and it might hold it up, there's a possibility. And it's up to the discretion of the person assessing your paperwork at the time.' Once again an individual, how friendly is that individual to us? So I didn't change my gender on my super account." – William

Trans people may not have all of their identity documents and records in their current name and/ or gender. It is a very complex and arduous task, and for many older trans people it was not possible to change their documents when they transitioned. Only recently have the laws changed to make it easier for trans people to obtain an Australian passport in their current gender (4). Each Australian state and territory has different laws for amending the gender recorded on birth certificates, and in most this means proving they have undergone surgeries that remove their reproductive organs. Australian law also currently requires divorce if a trans person is married. As William conveys, often the bureaucratic and administrative systems in place make it impossible for trans people to update their records. It is important to recognise this is not the fault of trans people. Trying to navigate these systems was described as distressing and frustrating. As a result of the difficulties in updating their records, participants described how it is common for trans people to go to a new service, set up a new record and not link their historical records with their current name.

"I didn't start a new file which a lot of [trans people] these days are doing, they're not recognising their old file at all. So there's no reference back to them. I had a lot of allergies and a history of medical problems, and so I actually changed the name and gender on my file. And someone in their great wisdom changed the gender back a few times until I went down to the administration office and got right up them again, and gave them certified copies of the certification from my psychiatrist to change my name" – Sandy

A trans inclusive service recognises that trans people may not have all of their records in their current name and gender and does not demand that they do. A trans inclusive service will be able to deal with this issue in a way that respects a trans person's current name and gender.

3. Be considerate of physical issues

There has been little research into what ageing means for trans people. Trans people discussed worrying about a variety of physical and health issues, including the long term effects of using hormones, the risks or benefits of diminishing hormone use or ceasing to take hormones, the maintenance of hormone use if they become unable to manage their own medication and the risks of osteoporosis and kidney disease. They also described concern about managing their own sexual health (for trans women who have undergone genital reconstruction surgeries, this can mean the regular use of a pessary).

"A difficulty too is a person may be transgender – well, a male to female, for instance, may not be completely female in appearance. Top maybe, but the bottom no. And this would be of a significant concern for a lot of people." – Judith

One of the main concerns trans people shared with us was a fear of prejudice and poor treatment because they have trans bodies. Not all trans people have undergone particular surgeries. Trans people's bodies, like all other people, can be very different from each other. Some trans people will not have had genital reconstructive surgeries, some will not have used hormones or not used hormones regularly, and hormone use effects people in different ways. Some trans women will have undergone electrolysis to stop facial hair growth, and some will not. A trans inclusive service is non-judgemental about the different types of bodies trans people have and is committed to keeping up to date on emerging research about trans health and ageing.

4. Be attentive to legal rights

It is illegal to discriminate against someone because of their 'gender identity' – a term used explicitly for trans people (4). This means that there are legal ramifications if trans people receive inferior or prejudicial treatment. There are also ways that trans people can protect their own legal rights, such as advanced care plans, powers of attorney and wills (see 6, 12). **Due to the complexities of managing identity documents and records for trans people, they can be especially vulnerable to potential legal and bureaucratic difficulties, especially in death or loss of capacity.** Many participants reported having spent their lifetime educating service providers and family members about being trans, as well as their health care needs and wishes. Diminishing capacity can mean losing the ability to advocate for themselves. Participants described fearing this would make them vulnerable to the prejudices of family members and service providers.

Documenting future health care wishes in an advance care plan as early as possible is a useful strategy for everyone, and trans people in particular, to ensure their rights are upheld if they become unable to continue to communicate their needs and wishes. This point was emphasised by Alison:

"I think personal care plans that address the particular needs of an individual, both from a physical health point of view but also a presentation point of view. I've heard stories of family members denying the trans-ness of their parent, wanting to try and ensure that they are dressed and presented in the way that they were prior to a transition. So we need personal care plans which are in the interests of the patient or the client that are clearly developed following their needs and their expression of those needs and which address presentation, dress, make-up, rings or not, clothing and which as best as possible reference hormone treatment, other drug treatment and particular needs around their sexual health because it might be different to what's normally done for a person presenting the way they are." – Alison

Trans inclusive services encourage and assist trans people to legally document their future care wishes in detail and as early as possible.

What do I need to do?

5. Be respectful and professional

"I don't think she sees me any different to other female patients that she has. Basically I'm treated like another female patient, most people just treat me that way. They don't treat me as something different. I'm very lucky in that way. They don't treat me as something special, or as something odd." – Philippa

The most important thing service providers can do to provide a trans inclusive service is respect a trans person's gender. This means using the correct name and gender pronoun ('he' or 'she') in reference to that person, including when talking about their past. If you're not sure which pronoun to use, start with the gender-neutral pronoun 'they' (it is never okay to refer to someone as 'it' or 'he-she'). While most trans people identify as men or women, some prefer other terms (such as 'gender diverse') and these also need

to respected as legitimate. If you do not know someone's gender or preferred pronoun, ask politely. If you are having trouble adjusting to someone changing their name or pronoun, practice talking about them with others in the right way. This will help you become comfortable and any awkwardness can be quickly overcome.

While many trans people look like other men and women, some people look more androgynous or trans. It is very important that you respect a trans person's current gender pronoun and name, even if you struggle to understand how that person fits into your own values and beliefs about gender. Everyone experiences gender in their own way and it is a very personal aspect of identity. What is important for trans people is that you take them at their word regarding their gender, and do not press them to explain their gender experience to satisfy your curiosity. This was emphasised by Philippa:

"She was very fascinated and would ask me really stupid questions, which in the end I found very, very insulting. Stupid bloody questions she was asking like I was some sort of freak. And I think that's the sort of thing that happens with a lot of trannies, they get people that are curious for whatever reason. Maybe to satisfy their own gender position or something." – Philippa³

Trans inclusive services respect the gender of trans people, without needing them to explain their experiences of being trans, or discussing their trans status when it is not relevant.

"Just because I didn't have a penis and I had a uterus, they didn't actually treat me like I was a female patient. It was just like whatever. You know, we're going to do this surgery and this is what's going to happen. I even went back in and [the surgeon] was like, 'Oh, mate, I'm so sorry but we found ovarian cancer. I know how much you hate gynaecologists but you have to go and see another gynaecologist now and I'm really sorry.' It was good to have someone who's talking to you about your health just like you're a regular person, like your body isn't really that [different]. He just talked to me. He was just a really nice person." – Gary

Trans people's care needs might differ from other men or women, but the most important aspect of a professional relationship is for trans people to have their gender respected. As Gary explains, his positive experience was due to be being treated with courtesy, kindness and professionalism, and respect for his male gender was not compromised because he needed care with parts of his body that are traditionally understood as female. Trans inclusive services use the correct gender, name and pronoun for trans people, consistently and in all contexts, regardless of the kinds of bodies or care needs trans people have.

6. Don't assume, listen

It is important not to assume what someone's needs are. Trans people's needs may be different from other men or women. For example, some trans women grow facial hair, and shave their face. If they lose the capacity to shave themselves, they may need assistance in doing so. For other trans people, they might like to grow their facial hair. Gendered accessories and body parts, such as facial hair, jewellery or clothes, tend to have greater significance to trans people, as they have spent much of their lives having their gender misread or misunderstood.

"The number of times you're in a situation where something's not quite gonna work for you – and they just sort of walk off, [like recently] I had to have a procedure [...] So you get all your gear off, and you get the apron job, you know. And you're trying to say, 'Look, hang on, how – ' 'cause she said, 'Oh put it on open at the front, not open at the back.' Well, this really isn't gonna work for me. But she's, 'Oh, it's all right, love' and she just walks off. And you think, 'No, you've got to listen to your patients.' But this should

3. 'Tranny' was a word used by some participants to describe themselves and their friends. For other trans people, this is an offensive term.

be general care. It's hardly about being trans. [...] If someone's not doing what you want, immediately stop and look at them, and ask, 'How can I make this work for you?' But I suppose it's time pressures. Or they think they've seen it all and they don't know what you're worried about." – William

Trans people's needs are often misunderstood because service providers assume they are not trans.

"I just told my doctor I had known for 15 years, we started discussing my hysterectomy, and I said, 'Well, it's about time I told you some facts of life.' And she hadn't guessed it in 15 years treating me. She just didn't realise I was trans. They wait until the people say something. It was only when it got to the stage where she started talking about gynaecological factors that I thought, 'Right, it's probably about time I told you something, I don't have [a] quite normal system.' And she was wondering why I hadn't had pap smears and the like. She thought I was getting them somewhere else where I was more comfortable." – Sandy

Sandy's comments show why being a trans inclusive service is important whether or not you know a trans person is accessing the service. It also conveys why knowing or 'finding out' someone is trans is not the most important aspect of a caring relationship. Assumptions about gender make it difficult for trans people to share all of their needs. Assumptions are usually based on gender stereotypes, which are common understandings of what it means to be a man or a woman. The belief that men have deep voices and women have higher voices is an example of gender stereotyping. For trans people, they may not fit these gender stereotypes. For example, some trans people's voices are deeper or higher than other people of their gender and they may struggle to be recognised as the appropriate gender when on the phone.

Many older trans people will not be visibly or recognisably trans. Yet they may have trans needs, especially with personal care, because their bodies are different from other men and women. William suggests a 'stop and look' protocol for service providers:

"I tried to formulate an answer to what would you want someone to do, and the answer is to stop and look. When someone's not doing something quite like everyone else would – they've hesitated in their chair, they're looking hot and flustered, and there's no obvious reason for it – stop and ask, 'How could this work for you, what do you need me to do?' And if that were put into normal practice, it'd cover a lot more than trans. But it would cover trans too. [...Service providers could say] 'What do you need me to do for this to work?' 'Oh, I need a towel over my genitals while washing.' Or, 'I need my special undies from the drawer that have the tight elastic, I'm going off to this appointment – I need to get those out, that's what I need.' And if they just went, 'Oh, okay,' and got the ones you needed." – William

Trans inclusive services do not assume the needs of a person because of how they appear or sound, or because it is known they are trans. Instead, they take an active role in addressing the immediate needs of the present situation.

Organisational Action

Providing education to staff in every role about what being trans inclusive means and how to be respectful to trans people is an important step, but the usefulness of such education is very limited without some practical changes in your organisation. Organisational leadership is required to achieve the systematic reforms necessary for trans inclusive services.

7. Be welcoming

"My legal name is different to my preferred name. I'll do something about it in fullness of time and all that. But, when I go to a [health service], they always say, 'OK, now when you talk to me, what is your preferred name? What is your preferred pronoun for you? What's your preference?' And then they respect that preference. They respect the way you have chosen to live with your way of being and I think a lot of problems can be solved just by suggesting that this respect is important." – Meredith

Trans inclusive care is more than being 'LGBTI friendly'. Participants described not necessarily feeling safe or comfortable in places that advertise as "LGBTI-friendly". This acronym tends to be based around gay and lesbian people and experiences. There are ways to communicate that your service is open to and respectful of trans people; that it is trans inclusive. For example, using the transgender flag symbol (pictured on the last page of this resource) can help you identify your service as trans inclusive. A message that trans people are welcome, which is backed up by appropriate care and respect, is an important part of trans inclusive care.

8. Ensure administrative flexibility

"I find now that going into male toilets and things like that, I just can't hack. I've just had to do one of the bowel cancer things and on the form that I had to fill in to send back it said, it didn't say 'sex', it said 'gender'. So I crossed the whole lot out and I put 'Not specified'." – Jeanine

Bureaucratic management of residents or clients tends to be organised by gender. While it is standard to classify people by gender, as Jeanine conveys, this can be complicated and distressing for trans people. Some trans people will struggle to answer these questions, which seem 'basic' to nontrans people. Using open-ended questions (e.g., 'How do you describe your gender?') rather than binary questions (e.g., 'Are you male or female?') provides the opportunity for trans people to describe their own experience of gender. It also signals to trans people that your service has an understanding of gender that includes trans people. Trans inclusive services have flexible documentation requirements that allow for the complexities of trans people's experiences of gender.

9. Undo gender segregation

"I can visualise all sorts of complications, like if I'm in a nursing home or a supported care environment where there's still rigid separation of the males and females, where do they put me? It's not only the physical side of it but let's say they put me in a male section, how are the other residents going to take the fact that I'm going to look at times like a girl? If people are coming in to see them, what are they going to say if they are asked 'Why is that creature living in your part of the world?' And again, how are the staff going to treat you?" – Jody

'Gender segregation' means when areas, events, programs or activities are divided into males only and females only. Dividing people by gender can exclude trans people. An important way of showing your service is trans inclusive is have spaces (including bathrooms) that are gender-neutral, that is, for use by everyone regardless of gender. For example, if you have a 'women's activity group' consider renaming it by activity (e.g. 'craft group') and making it welcome to people of all genders. If you think there is need for a gender-specific area or event, consider asking the advice of a trans-inclusive organisation (or Val's Café) and make it explicit that trans people are welcome (e.g. 'men's group, trans men welcome'). This lets trans people know that such a group respects trans people as members. Trans people have a history of being excluded from gender-segregated areas and events all together, and making trans people feel welcome to participate is an important part of providing an inclusive service. Trans people are legally entitled to use gender-segregated services according to their affirmed gender (e.g. trans women must be able to use a women's bathroom). Not all trans people identify as men or women (some identify as gender diverse and other terms that are not male or female), and gender segregation is often difficult for these people, and can serve as a hurtful reminder that 'they don't fit in.' *Trans inclusive services do not arrange facilities, programs, areas, events or activities by gender.*

10. Respect privacy needs

"I thought that was really gender sensitive that they'd organised it so I could have my own room. It helped to have my own toilet and shower and stuff like that so we could just shut the door." – Gary

Trans people's requests for privacy need to be taken seriously, and understood differently from other people who might prefer private arrangements. A diminishing level of independence is hard to deal with for most people. For trans people whose bodies differ from other men or women, a lack of privacy can be very invasive and distressing. As Gary suggests, it is preferable that trans people are offered their own private room and bathroom if they are staying in residential services. This can also apply to other kinds of care, which was highlighted by a service provider:

"In a public hospital emergency department, a transman needed urgent gynaecological surgery. Initially he was interviewed in a private room and the procedure was discussed in detail. Use of a separate room was not possible for subsequent conversations, but the staff kept the patient informed and referred to 'your abdominal surgery' or 'your surgery' thereafter, rather than using sex-specific terms." – Service provider

Privacy also refers to keeping confidential information about someone's trans status and their health needs, just like any other part of someone's medical records. Everyone has the right to discretion, and 'not becoming a gossip item' (Alison). Trans inclusive services make provisions to respect trans people's special need for privacy, both with information and space.

II. Advocate

An advocate is someone who acts on someone else's behalf. Trans people often particularly need and will especially benefit from an advocate. **Having an advocate to help manage some of the difficulties and complexities outlined in this resource can be crucial to trans people's care.** Speaking about his carer, Lawrence, Gary said:

"It's really good, you've got this voice, so you're not really alone. If you go to the hospital by yourself it's hard to find nurses, especially when you're sick, whereas having him as an extra voice helps because he knows I'm like, 'Don't let them do this. Don't let them do that.' It makes a huge difference that you have a carer that knows about you and loves you, you feel a lot safer." – Gary

As his carer, Lawrence acts as Gary's advocate, but an advocate may not be someone in a personal relationship with the person they are advocating for. The importance of advocacy was highlighted by Laurel Walter, who is employed at the Gender Centre (NSW) as the 'Over 55 Support Worker', a position that involves advocating for trans people in a variety of contexts. Laurel explains how advocacy impacts the lives of older trans people:

"One of the greatest fears expressed to me by ageing trans people is that they will be dependent and in need of care, and that the care will not be respectful of their identity. They describe being fearful of being marginalised, revisiting their past trauma of 'coming out,' being alone, and being too vulnerable to face these difficulties. Some express that suicide is a preferable option. It is vital to be able to tell them that there have been reforms, and that most service providers are training themselves and their staff about what it means to be trans and to be ageing. It is crucial that I can offer to help them locate such services and liaise on their behalf. Here are some of my experiences advocating for older trans people (for their privacy, names and other identifying details have been changed):

"Jane has been in a Residential Aged Care Facility (RACF) for some months, following a series of falls and hospitalisations. She is also suffering some cognitive loss. She is one of the luckier trans people, in that she has a very supportive daughter. Many trans people have lost contact with all or most of their family. Jane's daughter found a suitable RACF and though Jane is not happy to lose her home and to be dependent, she accepts this stage of her life. I visit her regularly and keep her informed about the many trans activities she has been involved with in the past. Jane has told a number of the staff – those she likes and trusts – that she is transgender. Jane is exasperated by the treatment she receives from some of the staff, though it is not clear why.

"With her consent I liaise with the nursing staff and her doctor (GP) about some of her medical problems as she has some difficulty articulating them herself. With Jane's agreement, I offer to give the staff a presentation and discussion on being trans and ageing. The staff are interested but some think that, really, Jane is a man underneath, and that is why she is 'difficult' at times. We discuss how she experiences her gender, as intrinsic and deeply felt since she was a small child. We talk about 'difficult' behaviour, which is how the care staff describe Jane when she is irritable or grumpy. This behaviour has increased recently. We discuss how Jane's mood is actually related to physical pain, and to her frustration with losing her independence and needing others to do what she used to do for herself. We discuss how they could respond to that behaviour in a compassionate and respectful way.

"Leonie suffers from longstanding depression and significant anxiety. Over many years, she has experienced many episodes of verbal harassment and abuse from strangers in public places, because they see that she looks 'different.' She is very tall and stands out among other people. She is vigilant and wary when out and about. She has no family contact and a small number of friends. Leonie's rent has been increased and she can no longer afford it, being on a Disability Support Pension (DSP). She needs to move. She has been refused rental accommodation in the past and feels that potential landlords don't like the look of her and refuse her, despite her good tenancy record. Her anxiety and depression have increased and she has become emotionally fragile. She feels unable to cope mentally with the bureaucratic requirements of applying for subsidised housing. She is at risk of homelessness.

"I assist her with the application, liaise with other professionals who can support her application, and accompany her to meetings. I locate some community services that can offer her additional psychological support. In accompanying Leonie to some of her meetings, she feels supported and strengthened. She gains some confidence. She reports being asked inappropriate questions by health professionals, such as related to 'her uterus,' though the questioner knew she is a trans woman. She is able to respond to the questions, though it causes her discomfort and annoyance.

"Nerida is in her 80s and has lived as female for more than 20 years. This is the happiest time of her life; she expresses her contentment often. Nerida hasn't changed her official documents; they show her previous male name. She has been experiencing considerable cognitive and hearing decline and other health problems, needing medical consultations and interventions. She is unable to negotiate her various medical appointments on her own, unable to recall or follow instructions. I accompany and assist her on many occasions. Nerida's male name causes confusion to professionals meeting her for the first time. When she is called by them – by her male name – and they see a woman approaching, I tell them 'she has lived as Nerida for 20 years.'This generally provokes interest, and the opportunity for Nerida to make known a brief account of her story."

Service providers are well placed to advocate for the rights and needs of trans people, including within your own service, with other services and organisations, with other service-users and with families.

Further Information

Being trans is different from being intersex. Our **guide to intersex inclusive aged care services** (8) is available at www.valscafe.org.au. See also **Organisation Intersex International Australia** www.oii.org.au

FTM Shed a peer support service for trans men

www.transshedboys.com | > @FTMShed

The Gender Centre (NSW)

www.gendercentre.org.au | * @thegendercentre | f facebook.com/GenderCentre

Transgender Victoria

www.transgendervictoria.com | > @TransGenderVic

Val's Cafe

www.valscafe.org.au | > @ValsCafe_AU | f facebook.com/ValsCafeAus

How to use this resource as an education tool

This resource has been developed to provide service providers with an evidence base on the experiences and needs of trans people as they age and to promote the development of trans inclusive services. It should be used for education in conjunction with more general information about LGBT ageing and aged care. The following table outlines a step-by-step interactive education program that encompasses general LGBT ageing and trans specific information. It is important that facilitators familiarise themselves with the information in all 9 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. All the resources are available free on the websites listed on the following page.

1. Terminology	Read Guide Sheet 10: Glossary (5)
2. History and its impacts	Watch the films 'Sally & Toni' and 'Andrew & Dale' (14)
	Discuss the historical treatment of trans people and how this might impact on their experiences of ageing
	 Discuss how historical perceptions of LGBT people might still influence the attitudes and beliefs of service providers and other people in shared services and programs
3. Legislative reforms	Read Guide Sheet 3: Legislative and Other Reforms (5)
	Read the National LGBTI Ageing and Aged Care Strategy (7)
4. Principles of LGBT and	Read the Self-Assessment and Planning Tool (13)
trans aged care	Rate your service and discuss ways to improve your rating
	Read Opening the Door (15)
	Discuss what it means to be trans inclusive, not just 'LGBTI-friendly'
5. Experiences of ageing	Read "Gender is just part of who I am" – Stories from Trans Australians (9)
trans people	Discuss the stories using the questions provided
6. Key issues in trans ageing Read the key issues section of this resource	
7. Strategies for trans inclusive services	Read the strategies for trans inclusive care in this resource and those in Appendix A of <i>Improving the Lives of Transgender Older Adults</i> (16)
	Discuss how these strategies will be implemented in your service
8. Administrative strategies	Read the Australian Government Guidelines on the Recognition of Sex and Gender (4) and the Polare articles (6, 12)
	Discuss what your service needs to do to ensure records will be trans inclusive, and how you will help trans people set up legal documents that outline their needs and wishes
9. Conflicts and advocacy	Read the Advocacy section of this resource
	Discuss how you can advocate for trans people accessing your service

Australian resources

- 1. Barrett, C; Crameri, P; Lambourne, S & Latham, J (2016) We are still gay... An evidence based guide to inclusive services for lesbian, gay, bisexual and trans people living with dementia. La Trobe University, Melbourne. www.valscafe.org.au
- 2. Barrett, C; Crameri, P; Lambourne, S & Latham, J (2015) We are still gay...': The needs of LGBT Australians with dementia. Australian Journal of Dementia Care 4(5): 26-30 http://journalofdementiacare.com/we-are-still-gay-the-needs-of-lgbt-australians-with-dementia/
- 3. Barrett, C; Whyte, C; Leonard, W & Comfort, J (2014) *There's No Need to Straighten Up: Discrimination, depression, anxiety and older lesbian, gay, bisexual, transgender and intersex Australians.* La Trobe University, Melbourne. www.valscafe.org.au
- 4. Commonwealth of Australia (2013) *Australian Government Guidelines on the Recognition of Sex and Gender*. Attorney General's Department, Barton. <u>www.aq.gov.au</u>
- 5. Crameri, P; Barrett, C & Firth, T (2015) Aged Care Assessment Service (ACAS) Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Inclusive Guide Sheets. La Trobe University, Melbourne. www.valscafe.org.au
- 6. Cunningham, M (2004) 'Even in Death: Retaining Transgender Identity.' *Polare* 59 www.gendercentre.org.au/resources/polare-archive/archived-articles/even-in-death-retaining-transgendered-identity.htm
- 7. Department of Health and Ageing (2012) National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy. Commonwealth of Australia, Canberra. www.valscafe.org.au
- 8. Latham, J & Barrett, C (2015) "As we age": An evidenced-based guide to intersex inclusive aged care services. La Trobe University, Melbourne. www.valscafe.org.au
- 9. Latham, J & Barrett, C (2015) "Gender is just part of who I am": Stories from Trans Australians. La Trobe University, Melbourne. www.valscafe.org.au
- 10. Latham, J & Barrett, C (2015) "We're people first": Trans health and ageing: Summary An evidence-based guide to inclusive services. La Trobe University, Melbourne. www.valscafe.org.au
- 11. Latham, J; Crameri; P; Barrett, C & Lambourne, S (forthcoming) Listen Up! Stories from Older LGBTI Australians.
- 12. Mayne, R (2010) 'Wills, Enduring Guardianship, Powers of Attorney [for trans people]' *Polare* 84 www.gendercentre.org.au/resources/polare-archive/archived-articles/wills-enduring-guardianship-powers-of-attorney.htm
- Vals' Café (2014) Self-Assessment and Planning Tool for LGBTI Inclusive Aged Care. La Trobe University, Melbourne.
 www.valscafe.org.au
- 14. Val's Café & Minus18 (2014) *Then and Now* [films]. www.valscafe.org.au/index.php/education/then-and-now

International resources

- 15. Mottett, L & Tanis, J (2008) *Opening the Door to the Inclusion of Transgender People: The nine keys to making LGBT organizations fully transgender-inclusive*. transequality.org/issues/resources/opening-door-inclusion-transgender-people
- 16. SAGE (2012) Improving the Lives of Transgender Older Adults: Recommendations for policy and practice. www.lgbtagingcenter.org/resources/resource.cfm?r=520



Using the transgender flag can help you identify your service as trans inclusive, but there is a lot more to trans inclusivity than displaying a sticker. It is important to make sure you have undertaken all of the steps and strategies described in this resource, and receive positive feedback from trans people about using your service (7) in order to achieve a trans inclusive service.













