The content of this toolkit is intended to provide a summary and overview of the subject matter. It is not intended to be fully comprehensive. Nor does it constitute legal advice. All care is taken to provide current information however currency cannot be guaranteed. You should seek legal or other professional advice before acting or relying on the content.
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This toolkit is the fourth in the series and, as has been the case with the others, is being released during National Palliative Care Week.

After a successful partnership on the third toolkit, Palliative Care ACT has again engaged with the School of Nursing, Midwifery and Public Health at the University of Canberra to develop this publication.

We are very grateful to University of Wollongong PhD candidate and Nursing Academic at the University of Canberra, Alicia Hind RN MGer, for her hard work. During the drafting, Alicia consulted with Meridian and LGBTIQ+ health Australia and we are very appreciative of their important contributions.

Canberra is an educated and supportive community, with the Australian Marriage Law Postal Survey to allow same-sex couples to legally marry showing the extent of this support with a 74% yes vote, which was the highest in the country. While a positive outcome, the process of the vote and impact on people in the LGBTQIA+ communities was immense, and we acknowledge the trauma it caused.

The ACT has an Office of LGBTIQ+ Affairs, with a Capital of Equality Strategy, that over the next four years will focus on:

- fostering understanding and awareness of LGBTIQ+ people and issues so that barriers to equality can be removed
- delivering more inclusive and accessible services
- continuing reforms to ensure equal rights are reflected in law, data and policies.

This proactive support from the government is welcome, however, there are numerous other issues that still require our attention before people in the LGBTQIA+ communities can feel completely safe, secure, and fully supported.

One of the critically important areas where our support can be visible and make a difference is language. This resource touches on the ways we can adapt our language to be more inclusive. It gives readers some guidance on easy questions to ask everyone, not only people in LGBTQIA+ communities, so we can all be more inclusive no matter who we are speaking with.

The toolkit also identifies terminology used which readers may not have heard before. The intention of all Palliative Care ACT’s toolkits is to promote conversation and build awareness. The aim is that when anyone is faced with a life-limiting illness they should be supported to prioritise their needs – without judgement or misunderstanding.

If you would like more information there are references to services, websites, and resources that you might find useful.

It is so important to engage with the individual – don’t make assumptions, ask questions, and be prepared to adapt as you learn.

Dr. Louise Mayo, AM
President
WORKING WITH THIS TOOLKIT

This toolkit is designed for carers working with people from LGBTQIA+ communities who have a life limiting illness.

This toolkit is not intended to give the reader all the answers or insights they might be after. It is intended to shed light on some of the issues these communities face when receiving care. It should be a starting point for carers, giving them some insight into the perspective of those they are caring for, and be used as a referral source.

The primary goal of the toolkit is to encourage all carers to engage with the person they are caring for about all aspects of their care. Language is particularly important for establishing a respectful relationship.

While this toolkit is primarily aimed at employed carers/professionals, it should also be a useful resource for everyone.

WHAT YOU WILL GET FROM THIS TOOLKIT

This toolkit provides users with information to:

- understand the important historical context for these communities
- improve communication through understanding of the impacts of language
- be an advocate for the person receiving end-of-life care
- link with a range of resources to better support the person receiving care and their chosen family.
PART 1:
LGBTQIA+
COMMUNITIES

The acronym LGBTQIA+ stands for Lesbian, Gay, Bisexual, Transgender, Queer, Intersex and Asexual. The ‘+’ representing that people may not identify with any of these terms but identify as having diverse sex, sexuality, or gender.

There are varying versions of the acronym used in different documents, in different organisations and in government agencies. We use this version in this document to try and capture all communities and generations within these.

Note: Please be aware the term ‘Queer’ can be offensive to some older people who are triggered by the legacy of when ‘queer’ was used as a term of abuse and derision. The reclamation of this word started in the 1980’s however this reclamation is not across all communities so this word must be used with care.

Many older LGBTQIA+ persons, despite legislative reforms, are still living with, and are affected by, the historical legacy of institutional and societal discrimination and abuse.

There are also current lawful and political oppressions faced by many within LGBTQIA+ communities. Formal decriminalisation of homosexuality varied between the states and territories in Australia with Tasmania being the last to pass this legislation in 1997. Other rights for same sex couples slowly followed, with adoption legislation allowing same sex couples to adopt being implemented across Australia between 2004 (ACT) and 2016 (SA). Same sex marriage became legal nationwide in 2018, with the vote results being announced on the 9th of December 2017.

In 2013, amendments were made to the sex discrimination act making it unlawful to discriminate against lesbian, gay, bisexual, transgender, and intersex people. Religious schools and hospitals are exempted from gender identity and orientation protections, but aged-care providers are not.

The LGBTQIA+ communities are not one homogeneous group of people. They are people of varying backgrounds and life experiences who are grouped within this umbrella term as they are considered a minority due to their sex, sexuality, or gender identity.

Despite these differences there are important similarities that have, and continue to, affect the communities, which makes resources like this one and continuing education and understanding important.
Transgender and non-binary people are still one of the most affected groups with legislation in many states and territories hindering their gender identity being formally recognised on identity documents. This very brief overview gives us some understanding of why many in LGBTQIA+ communities are fearful when accessing formal government supports and healthcare.

End of life journeys are times of heightened reflection and emotion for any person. Research into the perceptions LGBTQIA+ people have around end-of-life care suggest that this is magnified due to fears of discrimination. Particularly, they fear discrimination due to their gender identity, sexuality, bodily diversity as well as their different family and relationship structures.

Note: HIV (Human Immunodeficiency Virus) is discussed in this document as the AIDS epidemic disproportionately affected LGBTQIA+ communities. It is important to note though that many people who are HIV positive are not part of the LGBTQIA+ communities.
PART 2: PALLIATIVE CARE

Palliative care provides care and support for people who have a life limiting illness and for their families and loved ones. Palliative care is not only about end-of-life care; it also provides the person with quality of life by relieving, managing and even preventing symptoms associated with progressive illness, as well as practical and emotional supports.

Palliative care can be provided in many different settings including people’s homes, residential facilities, hospitals, and hospices. Where the person accesses the care will depend on their formal (medical and allied health team) and informal (family, friends, loved ones) supports.

People of all ages and walks of life receive palliative care; often it is a misunderstood form of care and there are many misconceptions.

Some common misconceptions include:

- palliative care will hasten death
- palliative care is only for old or elderly people
- palliative care is only for end of life in the last few weeks and days
- palliative care is only delivered in hospices.

However, these misconceptions are untrue and commonly cause people to delay seeking palliative care support and can affect the level of referral from medical professionals.

Legal steps

It is important for all people to discuss what their wishes would be if they were no longer able to communicate effectively (due to declining health, function, or nearing end of life). This discussion becomes somewhat more important when someone has a life limiting illness as things can progress quite quickly.

There are legal steps in place to ensure that a person can choose who their decision maker is if they become incapacitated. For LGBTQIA+ people this may be a difficult conversation to have as their biological family may be estranged or not involved in their life. They may also be concerned that someone may try and step in, instead of their chosen person or people, when their condition deteriorates. It is important that we advocate for LGBTQIA+ people to have their decisions formally recognised through power of attorney and advanced care directive documentation. You can find out more about this in Parts 4 and 5 of this document.
PART 3:
THE IMPORTANCE OF INCLUSIVE LANGUAGE

Our society is largely cisgendered and heteronormative – see the glossary below for full definitions of these terms. This means that systems, structures, social expectations, and media mainly focus on people who are in opposite sex relationships and identify with the sex they were assigned at birth. Due to this, much of the language that comes naturally to us, and exists on official forms and paperwork, sits within this frame.

One of the easiest steps to take to make services and interactions more inclusive and safer for LGBTQIA+ people is to think about the language that you use every day and, in a professional setting, what language is used on any required paperwork.

When interacting with a new person in your care, assume they are LGBTQIA+. This is the opposite to what happens in most interactions and avoids the person having to self-identify. Many LGBTQIA+ people report waiting for the right moment or right question to be asked before they would disclose their gender and, even then, they would only do so if they felt comfortable with the person asking. These ‘right moments’ or ‘right questions’ often don’t happen as the language used is cisgendered and heteronormative.

Assuming someone is LGBTQIA+ doesn’t mean you have to specially ask if someone is, it just means that you ensure that your language is inclusive, some examples for initial conversations are:

• What name would you like me to call you? (This may be their legal name or not.)
• What pronouns do you use? (e.g., He/Him, She/Her, They/Them, Ze/Zir)
• Who are your important people or family? (This may be biological family, chosen family or a mix of both. People may have one or multiple partners that fit into these criteria.)
• Who is available to help you at home when you are not well?

Note: Many people who identify as Trans may not wish to discuss the gender assigned at birth or their dead name.

These questions do not exclude heterosexual or cisgender people, however, they are inclusive for all including LGBTQIA+ people. These questions also don’t guarantee that someone will disclose and that is ok, some people will never disclose, however, inclusive practice is still just as important for them.

If someone discloses something about their sex, gender or sexuality or HIV status it is important that you ensure who they would like to be privy to that information. People may disclose information in an interaction that they don’t wish to be on their medical records or client notes.

If the person does wish for something to be in their notes and available for everyone, so that they don’t have to keep explaining it, it is important to work with your team on making sure this information is easy to access whenever an interaction may occur.
GLOSSARY OF LGBTQIA+ LANGUAGE

In the interest of promoting inclusive language, it is important that resources are available to explain language used in and around LGBTQIA+ communities.

**Aromantic/Aro:** Someone who does not experience romantic attraction. They may or may not identify as asexual as well as aromatic. They may or may not be in a relationship/s.

**Asexual/Ace:** Someone who has little or no sexual attraction to other people. Asexual people may still experience romantic attraction and have a libido and sex drive. Asexual people may be sexually active or not.

**Bisexual/Bi:** An individual who is attracted sexually and/or romantically to multiple genders. This term does not infer that gender is binary and the ‘bi’ actual represents two in terms of same and others rather than male and female.

**Cisgender:** Cisgender describes a person whose gender identity and sex assigned at birth are the same. The word cisgender is the antonym of transgender. The prefix cis- is not an acronym or abbreviation of another word; it is derived from Latin meaning on this side of. Cisgendered is the promotion of cisgender being the preferred or normal way of identifying your gender.

**Chosen family:** A chosen family consists of people we find to fulfill the roles of support, teaching, comfort, and kinship. This can look like almost anything and in most cases is defined to be purposefully broad and encompassing. Chosen families are meant to pull people together, not shut them out through rigid definitions. This term is used by many LGBTQIA+ communities who may or may not be in contact with their biological family as well.

**Dead name:** The former name of a person with which they no longer identify. Using this name may cause distress to this person and heighten their dysphoria around their gender or identity.

**Dysphoria:** The distress someone feels when they are misgendered or when they feel that their gender and body don’t feel connected and feel incongruent.

**Gay:** Someone who identifies as a man and is sexually and/or romantically attracted to men. Some non-binary people will also use this term if they are attracted to men. This term is also broadly used to describe same sex attraction on a whole.

**Heteronormative:** Heteronormativity is the concept that heterosexuality is the preferred or normal mode of sexual orientation. It assumes that gender is binary and that sexual and marital relations are most fitting between people of the opposite sex.

**Intersex:** This is an umbrella term used to describe people whose innate sex characteristics differ from what is considered male or female by medical and conventional understanding. This can include differences in anatomy, chromosomes, and hormones. As people are generally assigned a sex at birth from their visible anatomical features many people may not know or will discover later in life that they are intersex.

**Lesbian:** Someone who identifies as a woman and is sexually and/or romantically attracted to women. Some non-binary people will also use this term if they are attracted to women.

**Misgendering:** Using language that does not match a person’s gender identity.

**Polyamory:** People who have multiple romantic relationships at one time. Polyamorous people have multiple ways of explaining the dynamics of their different relationships and may or may not cohabitate with one or more of their partners.

**Pronouns:** A pronoun is a word that refers to either the people talking (‘I’ or ‘you’) or someone or something that is being talked about (like “she”, ‘it’, ‘them’, and “this”). Gender pronouns (he/she/they/ze etc.) specifically refer to the person you are referring to.
Pronouns are part of someone’s gender expression, and people can have multiple sets of pronouns for themselves (such as using he/him/his and they/them/their). Pronouns are not "preferred" but instead are required for respectful communication. Not only transgender or nonbinary communities use pronouns, as it is something we all use and have since we were children.

**Queer:** This word was historically used as a slur against LGBTQIA+ people, however, it has been reclaimed by many in recent history. For many elder LGBTQIA+ people this word is still not accepted. People will use this word to encompass many experiences of gender and sexuality.

**Transgender/Trans:** Someone who doesn’t identify with the sex they were assigned at birth. They may or may not choose to modify the way they present to the world either in dress or physical changes. Trans is an umbrella term that also encompasses people who don’t identify with gender in a binary way at all. Terms commonly used by these people to explain their gender include genderqueer, agender, genderfluid, non-binary.

This is by no means an extensive list of terms and language is continually evolving. Please always check in with the person involved regarding the language they identify with/prefer.
If you identify as LGBTQIA+ it can be hard to know where to go to access safer services and to know where to go for help. If you are unwell and have had poor interactions with healthcare in the past this can be even harder.

Often if services are safer spaces and understand the needs of LGBTQIA+ communities they will openly explain this on their website or advertising material. The service may advertise that they have LGBTQIA+ clinicians or that they have participated in training or some form of accreditation.

Some services may be more subtle with their inclusion and have a rainbow present on their signature panel of emails or visible in waiting rooms. Some clinicians may wear a rainbow or ally lapel pin or lanyard to signify that they are safer people.

If you are accessing services for palliative care, it can be hard to ask questions if you are feeling unsafe. It may be best that you ask a loved one or chosen family member who is feeling well to ask these questions for you. Whilst the hope is that care provided will be gender/sexuality affirming and trauma informed this isn’t always the case. If you or your loved ones can make your needs known this may prevent a shock or poor interaction in any future care.

Needs to consider may be:

- Who would you be more comfortable with if physical care is needed?
- Do you wish for a loved one to be present whilst care is being performed so that you feel safer?
- How do you wish to be addressed?
- Who are your important people/chosen family and who should be contacted?
- What gender affirming care are you receiving that you wish to continue until and after death?
- Who don't you want to be informed of your health concerns should they enquire?
- What legal documents do you need to ensure your chosen decision maker is respected?

Note: We use the term safer services as we acknowledge that no space can be completely safe for everybody.
Below is a list of services and websites that may assist you:

**A Gender Agenda**
A Gender Agenda (AGA) aims to support the goals and needs of the intersex, transgender and gender diverse communities of Canberra and the surrounding region. Through education, advocacy, peer support and professional networks it connects people and builds on the wisdom of collective experiences.

Website: [www.genderrights.org.au](http://www.genderrights.org.au)
Phone: (02) 6162 1924

**IHRA (Intersex Human Rights Australia)**
A national body by and for people with intersex variations.

Website: [www.ihra.org.au](http://www.ihra.org.au)
Phone: +61 (0)418 356 131

**Meridian (formally known as AIDS Action Council)**
An ACT based peer-led and community-controlled organisation supporting the LGBTQIA+ community.

Website: [www.meridianact.org.au](http://www.meridianact.org.au)
Phone: (02) 6257 2855

**ACON**
A community organisation, established in 1985, coming together to respond to the HIV/AIDS epidemic in NSW. As it has grown, it works with a diverse range of people to ensure their voice and health needs are represented. Its website hosts a comprehensive resource on palliative care.


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**NOTES:**

Note: This is not an exhaustive list of services however it is a starting point. Referral to other support agencies is always dependent on individual needs.
PART 5:
ROLE OF THE PAID CARER OR HEALTH PROFESSIONAL

As a health care worker, you have an important role in advocating for everyone in your care and attending to their needs. However, this must be individualised, as this is crucial for people from diverse backgrounds. There are significant things that can be done to show your willingness to learn and be supportive.

For LGBTQIA+ people their initial interactions with you may encourage them to seek care when it is necessary and timely, or when urgent and desperate, depending on whether they felt safe within those early interactions. Many people outside of LGBTQIA+ communities are often worried they will say the wrong thing or offend someone and hence their interactions are short and surface level, which doesn’t meet the needs of the consumer. As discussed in part three of this toolkit, language is a very important step in ensuring care is inclusive for LGBTQIA+ people. It is also important that the environment in which care is provided feels safe and accepting.

You can advocate for this in your workspace by:

- looking at the advertising material about your workspace and seeing if it uses inclusive language
- checking intake forms and paperwork for inclusive language
- suggesting that your workplace signal they are inclusive with signage
- suggesting, and participating in, training around the needs of LGBTQIA+ people in healthcare
- not asking your LGBTQIA+ colleagues to do the work for you. They may have personal experience; however, they are part of a minority group and shouldn’t be asked to do the work for others. They may, however, wish to assist and offer an opinion on situations
- being aware of LGBTQIA+ people’s chosen decision makers and advocating for these people with guidance to legal processes and documents
- being aware of the gender affirming care needs of trans people
- being an open ally and being willing to get it wrong and to keep trying
Below is a list of services and websites that may assist you:

**A Gender Agenda:**
Offers fee for service training as in-service professional development workshops at the request of services and organisations. Discounted rates available for community-based organisations. Please contact training@genderrights.org.au or (02) 6162 1924 for more information.

**Meridian (formally known as AIDS Action Council):**
Meridian is able to offer LGBTIQ+[AI] Awareness and Inclusivity training to organisations, and businesses across the ACT and surrounding region. To enquire about these education and training packages, or to schedule a training session, please call 02 6257 2855 or email training@meridianact.org.au

**RAINBOW HEALTH AUSTRALIA:**
Rainbow Health Australia is a program that supports lesbian, gay, bisexual, trans and gender diverse, intersex, and queer health and wellbeing through research and knowledge translation, training, resources, policy advice and service accreditation through the Rainbow Tick.

Website: [www.rainbowhealthaustralia.org.au](http://www.rainbowhealthaustralia.org.au)
Phone: (03) 9479 8700

**LGBTIQ+ HEALTH AUSTRALIA:**
LGBTIQ+ Health Australia is a member-based organisation, with many members providing LGBTIQ+ training and professional development in their local regions throughout Australia.

Website: [https://www.lgbtiqhealth.org.au](https://www.lgbtiqhealth.org.au)
PART 6:
INTERSECTIONAL IDENTITIES

Being part of LGBTQIA+ communities is only one part of people's identities. People within these communities have many identities and facets to their lives. Sometimes other parts of people's lives and experiences mean they are part of more than one minority group; people may also be a part of more than one LGBTQIA+ community. When this happens the impact of being part of a minority can be intensified.

Older LGBTQIA+ people

Older LGBTQIA+ people have lived through many political and social changes when it comes to the acceptance of their identity. Many of these people lived much of their lives hiding their identity for fear of persecution or assault. Many still don't live openly due to this fear.

Older LGBTQIA+ people accessing palliative care services are likely to be doing so in conjunction with accessing aged care services. These environments can be hard for LGBTQIA+ people to be their true selves and to be able to include the people they wish to include in their end-of-life care.

Older people in general are also seen by society to not be sexual beings. So, despite their sexuality being a big part of their identity they are often not asked or able to speak about this part of their life.

LGBTQIA+ people living with disability

LGBTQIA+ people living with a disability may face challenges daily when it comes to accessing services or information. They may find that they don't have sufficient energy to assert their needs to be affirmed in their LGBTQIA+ identity as well as having to advocate for themselves due to their disability. LGBTQIA+ people living with a disability may also live in residential care and these services may not be affirming of their identity. LGBTQIA+ people living with a disability may also face societal misconceptions that they are not sexual beings, so their sexuality is not considered in their care.

As access to care can be more difficult for these people, they may have access to palliative care services later in their journey than is optimal which impacts on how holistic the care they receive can be.

People of colour and First Nations LGBTQIA+ people

First Nations people in Australia face poorer health outcomes due to systemic discrimination and generations of stolen culture. Their life expectancy is much lower, and they are less likely to access formal palliative care services due to availability in remote and rural communities and acceptance in metropolitan areas.

People of colour may have been born in Australia or migrated from overseas. There are still society assumptions they migrated and hence English is an additional language for them. Many people of colour, whether they were born in Australia or overseas have cultural practices around death and dying which are not widely understood by white Australia.
Both groups face societal misconceptions around their culture’s acceptance of their LGBTQIA+ identity. Whilst some cultures are not accepting of LGBTQIA+ identities it is important not to assume this and to ensure that all their identities are acknowledged in care. To ensure your practice is culturally safe, undertake research to identify support agencies for First Nations peoples and people of colour within your local area and make contact to seek their guidance.

**LGBTQIA+ people living with HIV and people with HIV outside LGBTQIA+ communities**

It is very unusual for someone in Australia to need palliative care due specifically to HIV/AIDS.

Appropriate drug therapy and support from the health sector means that people living with HIV in Australia will expect to live a normal healthy lifespan.

However, stigma, discrimination, judgement, and exclusion of people with HIV, unfortunately still exists in Australia. To maintain wellbeing in palliative care both health professionals and carers should be aware of the care needs of people living with HIV.

It is useful to remember being an older gay man does not equal HIV positive.

Also, not all people living with HIV are part of the LGBTQIA+ community.

It is also important to note that health professionals and carers are NOT at risk of HIV transmission when providing for intimate needs such as assisting with meals, providing personal hygiene, toileting etc. as long as universal precautions are followed (as they should be with everyone in palliative care regardless of their background).

These are just a few examples of the intersecting identities people might have. In all cases it is important to understand that the person might face extra barriers, stress and hesitancy around care and therefore need differing advocacy from day to day.
This last section outlines some important additional resources and the resources that have been used to inform this document.

**Document resources:**


"Gender Pronouns" [https://uwm.edu/lgbtrc/support/gender-pronouns/](https://uwm.edu/lgbtrc/support/gender-pronouns/)


This document was also contributed to by those with professional, academic and lived experiences with, and being from, LGBTQ/A+ communities.

**Additional resources:**


ACKNOWLEDGEMENT

Palliative Care ACT would like to acknowledge all who contributed their time, knowledge, and skills to the development of this toolkit.

FOR MORE INFORMATION

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