



Rainbow Horizons: Don't leave me this way –

fostering intergenerational compassionate
communities to support LGBTI+ people's end of life





Acknowledgements

This project was carried out on Boandik, Kurna, Ngadjuri, Ramindjeri and Ngarrindjeri Country.

We acknowledge LGBTI+ people who came before and have contributed to better deaths for our community through their advocacy and activism.

Thanks to the many community participants who engaged in the Rainbow Horizons project and especially the members of the Rainbow Hub Advisory Group, Project Working Group, Trial Model Group and provider Consultation Circle. See the project website for a list of key contributors.

Community, providers and other stakeholder organisations:

Aboriginal Health Council SA; ACON; Aged & Community Care Providers Association SA-NT; Amber Aged Care; Anglicare SA Residential Aged Care Sites; Australian Funeral Directors Association SA/NT Division; Camatta Lempens Lawyers; Carers SA; Catalyst Foundation; Centennial Park; City of Tea Tree Gully; Dementia Australia SA; Di Monty Training Solutions; ECH LGBTI+ Connect Team; Eldercare; Feast Festival; Fleurieu Pride; Graceful Dying; GriefLink; LGBTIQ+ Health Australia; LGBTIQ+ Mid North SA; Limestone Coast Connect; Multicultural Communities Council of SA; Northern Adelaide Palliative Service, SA Health; Palliative Care SA; Pangula Mannamurna; Pride of the South; Preparing the way; Relationships Australia SA; Replay Creative; SAMESH; SA Office of the Public Advocate; SHINE SA; Silverchain/RDNS; Southern Vales Compassionate Communities; St Anna's Residential Care Facility and Home Care Packages; University of Adelaide; UniSA; Voluntary Assisted Dying South Australia.

This project was supported by
Office for Ageing Well, SA Health



More information at www.cotasa.org.au/rainbowhub

June 2023



Contents

Introduction	05
Compassionate communities	06
The needs of LGBTI+ people at end of life	06
The process	08
The model design	10
Rainbow Horizons: <i>LGBTI+ intergenerational compassionate community model for inclusive end of life support</i>	12
Evaluation	13
7 stages of living	15
Recommendations	16
References	18



There are worse things than death: if you love your partner and friends, get your affairs in order.

Focus group participant

Introduction

End of life planning can be a challenging time, as it asks us to acknowledge our mortality and to make rational and systematic plans for that time and those circumstances, most of which are usually unknown.

We are asked to consider the documentation of our wishes to support doctors and hospitals, for the management of relationships, our estates, and material belongings. In recent years, programs have been developed to encourage people of all ages to engage with this reality. This includes resources and various legal supports designed to enable choice, and to protect the rights of those approaching the end of their life.

The estimated 77,000+¹ members of South Australia's Lesbian, Gay, Bisexual, Transgender and Intersex plus (LGBTI+) community aged 50+ are under-served by existing programs designed to encourage planning for end of life and to provide appropriate care and support for death and dying. As one indicator, 'LGBT' as a search term yielded no results on numerous service websites accessed in 2022 and 2023, confirming the invisibility felt by LGBTI+ community members in many arenas. This project, *Rainbow Horizons: Don't leave me this way*, identified some of the barriers and enablers to a more inclusive approach to end of life and developed a model for accommodating LGBTI+ peoples' needs in such programs and improving community support.

The song *Don't leave me this way*² has long been a popular anthem for some members of the LGBTI+ community. The title resonates with a key theme of this project: don't leave those around you not understanding your wishes at end of life. Our project underlined

the importance of building and empowering community as the best strategy for a well-managed end of life, that includes upholding the dying individual's wishes. It's a reminder that we can bring our activist and community development skills and traditions of '...imagination, transformation and creation' to queer death³.

From September 2021 to June 2023, the COTA SA Rainbow Hub ran the project *Rainbow Horizons*, with support from Office for Ageing Well, SA Health, to explore end of life planning and management for the LGBTI+ community with a specific focus on:

- **Facilitating conversations in LGBTI+ communities across generations**
- **Building an intergenerational compassionate community model that can be adapted, and**
- **Engaging with service providers.**

COTA SA approached this project from the position of creating an inclusive society that moves beyond ageism and enables the participation of older South Australians as co-producers of change, including end of life planning and management aligning with South Australia's Plan for Ageing Well 2020-2025⁴. This project was inspired by the COVID-19 pandemic, when COTA SA's Rainbow Hub Advisory Group observed emerging concerns and needs of our community.

The project led to the development of a compassionate community model and also identified systemic changes that are still needed to address the specific needs of LGBTI+ individuals and communities.



Compassionate communities

A cornerstone for this project was the idea of compassionate communities in which care is given, and sought, in a spirit of mutuality and responsiveness⁵. The project concentrated on the development of community support for people in all phases of end of life, by responding to the needs of the dying person and their network and working alongside service providers. Such communities can also be involved in promoting community partnerships, awareness-raising, community activation, advocacy and policy.

Compassionate communities can consist of people with a pre-existing connection, social or otherwise; they can be deliberately organised to provide a particular type of support; or they can develop spontaneously in response to an immediate situation.

The needs of LGBTI+ people at end of life

While LGBTI+ people share similar issues with the wider community, society's history of discrimination and prejudice has led to some individuals and communities experiencing greater inequities such as social isolation and poverty. Family and societal rejection have led some older LGBTI+ people to draw less on intergenerational support than heterosexual people. LGBTI+ people are seven times more likely to be living alone⁶, be childless and to have cultural wishes that may not be respected by biological family or next of kin or that are the source of conflict between members of their network. Many will have been deeply connected with, and/or reliant on, peers who themselves are also needing end of life support and care. It is also noted that issues raised above disproportionately impact LGBTI+ people experiencing discrimination for other reasons as well, for example those living with disability or individuals from diverse backgrounds.

”

I don't have the people I thought I'd have in my old age — there are none left and I need to adapt to this.

Focus group participant (HIV survivor)





The process

It is understood that compassionate communities develop organically, based on the primary principle of growing social connection, therefore COTA SA deliberately chose a process of iterative co-design.

Throughout the project, the design allowed for the progressive development of thinking and the involvement of a wide range of members of the LGBTI+ community and service providers associated with end of life matters.

The project was managed by the COTA SA Rainbow Hub Officer.


During *Stage One – Consultation and Assessment*, the project sought to identify the interest and need for intergenerational compassionate communities. A Project Working Group of a diverse range of LGBTI+ members, was established to provide insight and feedback, and promotion included a new website with information to raise awareness and support participant recruitment. The Rainbow Hub Officer chaired the public forum: [Don't leave me this way – honouring our lives in community](#)⁷ to promote community conversations. Issues such as the historical exclusion of LGBTI+ community members from some spiritual traditions were among many experiences raised.

Focus groups, held in six different locations enabled a broad range of people to describe their experiences and concerns. Three groups were run in South Australian metropolitan areas – Adelaide, Christies Downs (south) and Salisbury (north) – and three regional

groups in Burra, Mount Gambier and Victor Harbor. They brought together 29 LGBTI+ participants with a variety of lived experience, including Aboriginal people, unpaid Carers, HIV survivors, conversion practices survivors, transgender people; as well as people from culturally and linguistically diverse communities, people living with disabilities, post-traumatic stress, dementia, cancer, and other challenges. Some people were not out about their sexuality or gender or had been closeted for many years.

A Consultation Circle was established with service providers and other stakeholders with expertise and interest in end of life planning, such as aged care providers, advocacy bodies, doulas, educational organisations, funeral directors, government agencies and health professionals. Some of the members had attended one of two focus groups in metropolitan Adelaide which provided an opportunity for them to respond to community focus group findings, share their perspectives and reflect on more inclusive practices.

During *Stage Two – Codesign Trial Model*, a workshop facilitated by the Rainbow Hub Officer, combined experiences and insights of community members and service providers. The workshop yielded ideas for activities, resources, and collaboration. Following the workshop a compassionate communities model, tested by City of Tea Tree Gully in 2021, was shared with the



This [compassionate community] work takes time. People are attracted and keep coming if they can contribute with their strengths.

Southern Vales Compassionate Communities member

project and served as a draft starting point for the development of the Rainbow Horizons LGBTI+ intergenerational compassionate community model for inclusive end of life support, captured on page 12.

In *Stage Three – Implement Trial Model and Evaluation*, a Trial Model Group comprising intergenerational LGBTI+ community members met with the Rainbow Hub Officer monthly from September to December 2022. The Group hosted guest speakers, refined the model, and discussed future possibilities for outreach and events. This Group continued to meet beyond the trial and started initiating outreach events. Within the project timeframe there was some testing of the viability of the model and it also generated a network of providers who along with the community can draw on the outcomes into the future.

The *7 Stages of Living* (see diagram page 15) was adapted⁸ as a resource to provide a framework for considering what a person's end of life process might look like and what an individual, service or community group may need to consider. The Stages can be divided up in numerous ways and have already provided a useful prompt for discussion, particularly about what support is required and when and how it may be provided. Individual community members participating in a compassionate community can be encouraged to 'buddy up' with another for mutual support at different stages of their journeys.

Whilst the experience of Stages 1-7 is not unique to LGBTI+ people, there are key issues that can be considered at each stage. These relate to ongoing discrimination and distrust of general service providers⁹ and the low level of understanding within such services about the specific needs of LGBTI+ people. The claim that it takes on average 16 people to care well for anyone who is dying¹⁰ highlighted the need for trusted and coordinated support. The role of end of life doulas who work between medical and volunteer support was raised as an option to help address this. This alternative deserves greater exploration in future work as it is acknowledged that these services are not currently accredited and are largely self-regulated, like funeral directors, leading to varied service levels and costs.

The model design

Although linear in appearance, the model has been designed to allow for diversity and variation across contexts and identifies six major arenas of action.

1. Collaboration between LGBTI+ community members and service providers

An organisation or group could start off in a small way and increase progressively as new (self-identifying) community members provide further contacts through their networks and the number of participants in activities and the skills they bring increases. Service providers would be invited to participate as guest speakers and resource people, potentially assisting in volunteer training for example, and to share with their networks.

2. A variety of entry points to initial engagement

An organisation or group would need to decide how it will set up situations and activities, offered within the compassionate community, with the potential to trigger conversation and engagement with the need to act promptly about end of life planning. Health and other providers could provide referrals to the compassionate community.

3. A range of sources of knowledge about inclusive end of life options clearly intended for LGBTI+ people

Compassionate community members could develop activities and train and support volunteers to help carry out activities that work towards building participant trust and a sustainable compassionate, collaborative ethos. As examples to stimulate thinking, the model separates primary activities from secondary ones in order to communicate the differences of scale that groups might undertake.

Resources and research about serving the needs of the LGBTI+ community and providers, developed by some of the organisations which are engaged in service provision and advocacy for the LGBTI+ community, are available at www.cotasa.org.au/rainbow-horizons.

4. The importance of resources, service providers and volunteers

Everything in the model requires resources, including volunteers. As Horsfall¹¹ and others found in *Researching Compassionate Communities in Australia* "...critical to success was generation and allocation of formal resources." For this model to be effective, there needs to be access to the resources that maximise self-sufficiency.

We recommend that there be a host organisation which can provide meeting space, a web presence, potentially a newsletter, social media and the capacity to auspice grants from governments and private foundations. A paid coordinator is much more likely to ensure the longevity of a compassionate community as the LGBTI+ community is already very reliant on volunteer support and dealing with extra layers of issues, especially as peers become increasingly frail.

At the same time, the role of trained volunteers cannot be underestimated. Volunteers who are either members of the LGBTI+ community or trusted allies will form the backbone of any attempt to implement this model. At the early stages of this project, a model that would aim to encourage and enable individuals to take responsibility for their end of life planning and management was considered. However, deep engagement with the notion of compassionate communities, as well as the stories from

LGBTI+ people who don't have partners or kin - who takes care of them and what happens to them?

Focus group participant

participants and a recognition of the complexity of end of life support, foregrounded the collaborative nature of the process and that 'going it alone' is not as productive.

5. Understanding the specific needs of LGBTI+ communities

Some providers with years of involvement in end of life care had never thought about the needs of LGBTI+ people. This project helped to facilitate improvements in their services (see Evaluation on page 13). The following are worth taking account of:

- LGBTI+ peer connections are often of greater significance to the rainbow community, especially those without biological family support, who tend to rely more on each other. They are less likely to access intergenerational family support which is the source of much advocacy when dealing with health and aged care services.
- Living regionally impacts significantly on the provision of services, and the following were identified by participants: the importance of face-to-face provision; a lack of alternatives for service provision, problems created when the only option locally is a faith-based organisation that lacks experience in serving LGBTI+ community members' specific needs and/ or is antagonistic to LGBTI+ people.
- Regional access to affordable, suitable transport if someone doesn't, or can't, drive is an issue. People may need to travel to Adelaide to see an LGBTI+ friendly service provider, but if there is only one bus per week and then only a three hour turnaround it leaves little room for delays.

- Services are often dependent on the individual level of knowledge and attitudes and goodwill of professionals. A story was shared where a regional community member acted as an advocate to a local doctor who was unfamiliar with transgender issues and medication on behalf of two local transgender people who subsequently left the town.
- LGBTI+ people often delay seeking services or avoid services due to prior discrimination, or fear of it, therefore services aiming to be inclusive need to be explicit about their openness and desire to be accessible to all.
- More tailored resources¹² and ongoing training to meet specific needs for transgender and intersex people are required. These are the least understood of all LGBTI+-specific needs.
- Understanding different cultural practices and how they influence and guide responses to death and dying, including the importance of dying on Country for First Nations people and a range of challenges for members of multicultural and multifaith communities.¹³
- Increasing interest in recently introduced voluntary assisted dying legislation and process.

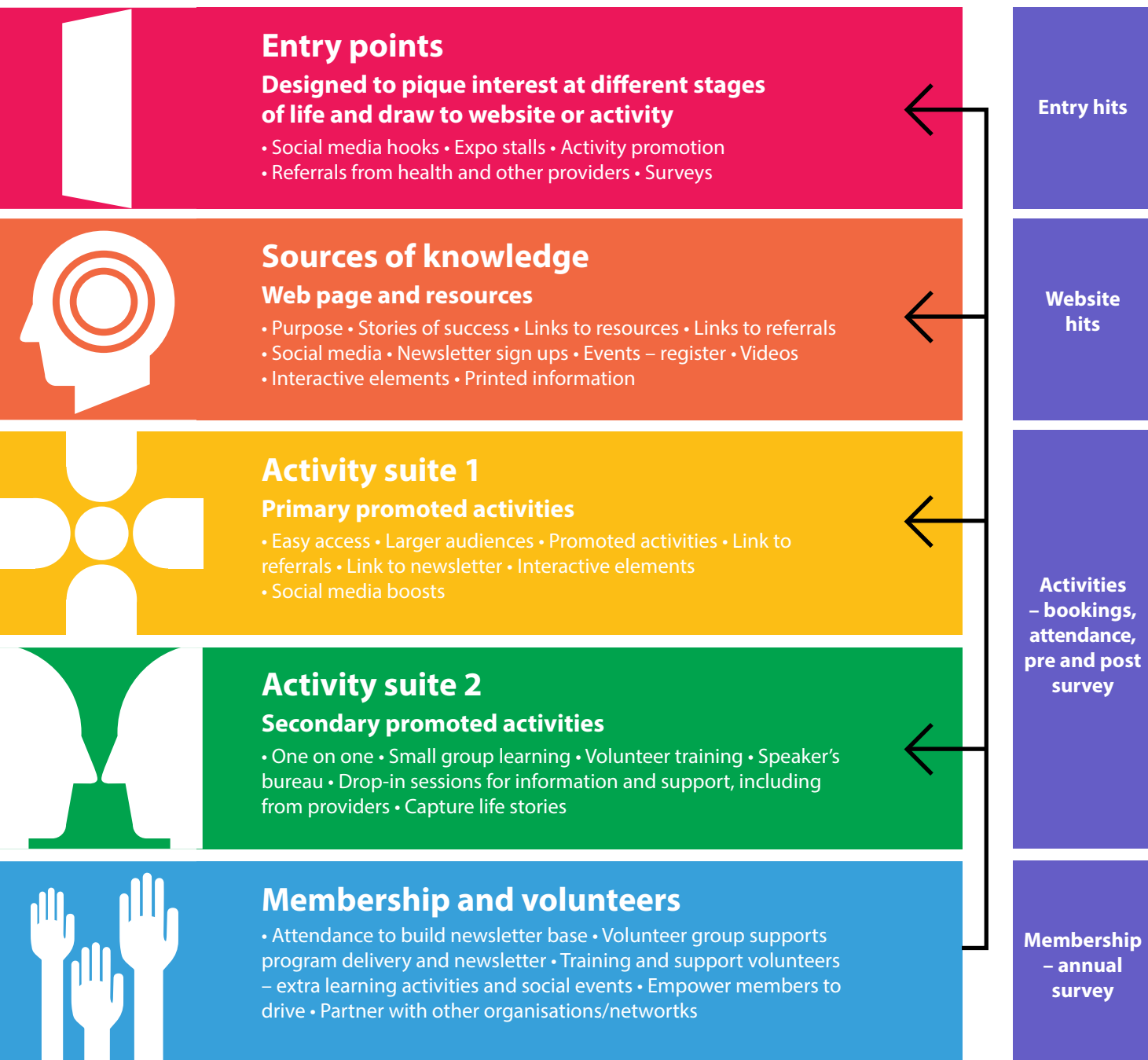
6. Ongoing evaluation and adaptation of the model as circumstances change

A group would need to reframe and reorganise its activities in light of participants' feedback and responses as well as in response to changes to the external context. Evidence of people's experience and storytelling should also form part of evaluating the success of this work¹⁴.

Rainbow Horizons

LGBTI+ intergenerational compassionate community model* for inclusive end of life support

Evaluate and record at each stage, including evidence of storytelling



To achieve all this: Ideal resources to maximise self-sufficiency, including host organisation with meeting space, web, newsletter, socials, capacity to auspice grants.

**with thanks to the Compassionate Communities model tested by City of Tea Tree Gully in 2021*



Evaluation

Evaluation of the project provided insight into the benefits of a collaborative compassionate model. There is a sense in which the project itself became an example of what the model could achieve in that it involved collaboration between service providers and LGBTI+ community members, resource identification, input from LGBTI+ people about their needs and ongoing adaptation and growth of thinking. Awareness raising and advocacy were also undertaken.

A pre and post project survey (47 and 39 people respectively) was conducted that included several factors to evaluate the success of the project such as connection to community and intergenerational links. People responding to the surveys reflected the diversity of the LGBTI+ community, including a fairly evenly spread age range of 18 – 80+. However, these were low sample sizes, so most outcomes reported are not statistically significant.

Two of the highest increases in average agreement from pre-participation to post-participation for community members were in relation to the opportunities for engagement with providers. They noted: (a) the need to *know the services available to help in end of life planning* and (b) *feeling confident about the steps needed to put plans in place*. (c) *Feeling listened to* and (d) *confident of not needing to educate providers about gender and sexuality* were the other two aspects that increased markedly during the project. Seeing providers and others take an interest in learning about this content appears to have increased community members' confidence that they would be listened to and that they did not need to educate providers about their needs. This latter point contrasts with the frustration expressed in all community focus groups about having to be activists educating providers at the same time as being recipients of services.



Feedback received from participants confirms that people felt the project was informative and increased their knowledge:

Has caused me to think seriously. I realise I have to get organised so that things happen as I want them to. I realise the importance of documenting my plan.

I realise I need to think about it earlier than I planned.

It has definitely highlighted to me the importance of end of life care planning education and activism needed within our community. That intergenerational connection provides positive results and ends stigmas and biases we may carry in regard to ageism.

Most of the providers said that their responsiveness to LGBTI+ needs had changed as a result of their involvement, leading to improved knowledge and understanding of the resources and support available. Changed action was reflected in the evaluation data.

Extra information has been added to noticeboards and information stands. Admission paperwork has been updated to include additional options for providing personal information around gender and identity. For me personally being more aware of individual needs and promoting a safe environment where residents feel comfortable to be themselves.

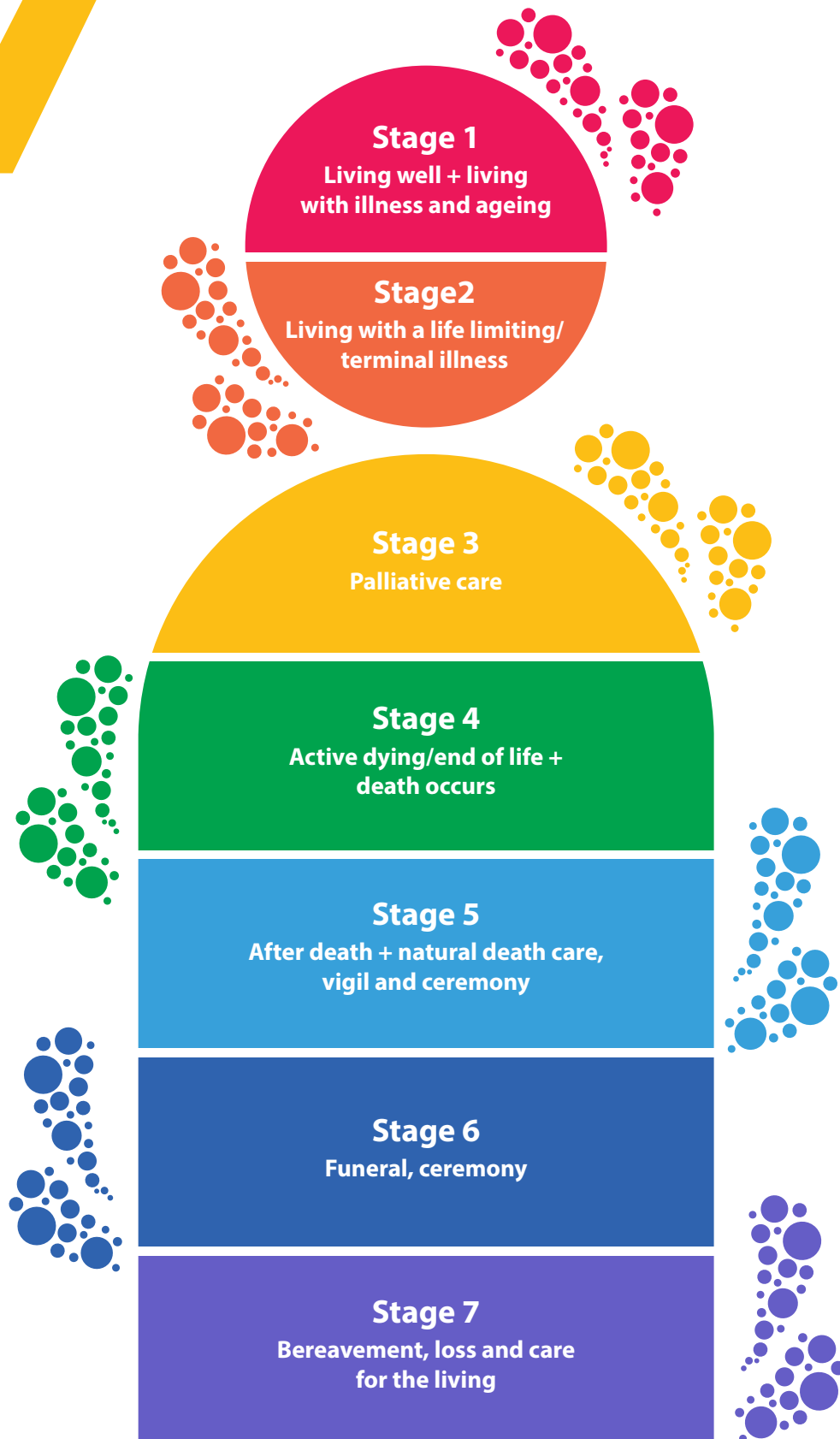
We are moving towards Rainbow Tick accreditation in the 2023/24 financial year and this project has helped to reinforce the importance of this trajectory. I have also learnt more about the challenges at the end of life for the LGBTIQA+ community and am much more aware of what supports they may need.

Communications and planning a dedicated campaign around the needs of the LGBTIQ community.

Overall, the experience for LGBTI+ community members involved in the development of this model:

- Demonstrated a great appetite for targeted information and spaces for safer conversations.
- Increased social connections, including intergenerational.
- Built links with a network of providers, many of whom indicated a willingness to continue to work with the Rainbow Hub and learn more about and adopt more inclusive practices.
- Created a group of committed volunteers who wish to build on their initial work with resourced support.

7 STAGES OF LIVING





Recommendations

The COTA SA Rainbow Horizons project consulted and engaged with hundreds of older LGBTI+ South Australians and key stakeholders.

Through this journey lessons were learnt, activities trialled and the following six recommendations are made for government, organisations and individuals so that they can move forward in enabling safe and inclusive end of life care for members of the LGBTI+ community. The recommendations sit in the context of five guiding principles.

Guiding principles for organisations to address LGBTI+-specific needs:

Lived experience – include formal avenues of active engagement to gather LGBTI+ perspectives on advisory bodies, in data collection, surveys, feedback and other mechanisms.

Identity – include options for LGBTI+ community members, staff and volunteers to identify their gender and sexual orientation in organisational processes.

Co-design – incorporate LGBTI+ people as clients, staff and volunteers in diversity and inclusion plans.

Partner – strengthen links and partner with LGBTI+ organisations in order to provide appropriate referrals to customers and people in their care.

Representation – use more diverse and inclusive images, language, perspectives and testimonials in promotional avenues such as websites, brochures and case studies.



The recommendations are directed at:

Government

1. **State Government and Local Government** increase the resourcing of regional health services to provide local options, including face-to-face provision, that are LGBTI+ friendly and support people to remain in regional communities at the end of their lives.
2. **State Government** provide ongoing investment in consumer education programs to increase end of life planning, including completion of an Advance Care Directive, an Enduring Power of Attorney and a will.

Financial investment

3. The compassionate communities model is important to proactively build community connection across generations, with the potential to save on the need to invest in reactive measures down the track. A key learning of this project is that embedding a compassionate community to a level of maturity where it can be self-sustaining requires resourcing beyond establishing it. COTA SA's Rainbow Hub has a track record of working successfully with older LGBTI+ people in South Australia to provide information, advocacy, connection and support and is well placed to continue this work with additional funding.

Providers, advocacy, and educational organisations, including professional health bodies

4. Commit to ongoing education of staff and volunteers about the end of life planning, care and dying needs of LGBTI+ community members, including transgender and intersex people.

LGBTI+ community organisations

5. Draw on the practices and principles in the intergenerational compassionate community model to help LGBTI+ people plan for and be supported towards the end of their lives.

LGBTI+ community members

6. Prioritise discussing their end of life wishes and plans with people closest to them and document, updating as needed, their wishes in an Advance Care Directive, an Enduring Power of Attorney and a will, and advise key people where documents are stored.

References

1. Australian Bureau of Statistics 3222.0 Populations Projections, Australia 2021 (base) to 2101
2. [Don't Leave Me This Way - Wikipedia](#)
3. *What being queer taught me about death*
<https://xtramagazine.com/health/queer-taught-me-about-death-167538>
4. *South Australia's Plan for Ageing Well 2020-2025*, June 2020
<https://www.sahealth.sa.gov.au/wps/wcm/connect/Public+Content/SA+Health+Internet/About+us/Department+for+Health+and+Wellbeing/Office+for+Ageing+Well/South+Australias+Plan+for+Ageing+Well+2020-2025/South+Australias+Plan+for+Ageing+Well+2020-2025>
5. *Compassionate communities implementation guide*, nous, July 2018
<An-implementation-guide-for-community.pdf> (palliativecare.org.au)
6. York, F; Walton, R, *Out of the Closet, Out of Options: Older LGBTI people at risk of homelessness*, page 2
https://www.oldertenants.org.au/sites/default/files/out_of_the_closet_out_of_options_-_final_report_october_2020.pdf
7. Watch Rainbow Hub Officer, Jackie Wurm in conversation with Christos Tsiolkas and Alana Valentine
Don't leave me this way – honouring our lives in community
8. 7 Stages of Living diagram adapted with permission from Preparing the Way
<https://preparingtheway.com.au> and Natural Grace <https://naturalgrace.com.au>
9. Thorne Harbour Health, *The cost of adverse mental health outcomes in the LGBTIQ+ Victorian adult population*, 2022, Page 15 https://cdn.thorneharbour.org/media/documents/Full_Report_Deloitte_2022.pdf
10. Demystifying death with care and compassion, 2021
<https://www.australianunity.com.au/wellbeing/money-and-finances/what-happens-when-i-die-season-2-episode-5>
11. Horsfall D, Psychogios H, Rankin-Smith H, Read N, Noonan K. Researching Compassionate Communities in Australia: A short-term longitudinal study. Groundswell Project, 2020, page 5
<https://www.thegroundswellproject.com/compassionate-communities-report>
12. Hospice UK. 'I just want to be me'. Trans and Gender Diverse Communities. Access to and Experiences of Palliative and End-of-life Care. London: Hospice UK; 2023
<IJustWantToBeMe.pdf> (hukstage-new-bucket.s3.eu-west-2.amazonaws.com)
13. (publication forthcoming) Pallotta-Chiarolli, M; Sudarto, B; Chee, Y. X (2023). "Scared to Care" to "My Care, My Choice": Palliative Care From Multicultural and Multifaith LGBTIQ+ Perspectives and Experiences. Melbourne: Palliative Care Victoria
14. Horsfall D, as above, page 6

We welcome the chance to discuss with you how we can work together to improve end of life support for LGBTI+ people. Please contact COTA SA's Rainbow Hub rainbowhub@cotasa.org.au or 08 8232 0422.





