HELP FOR THE END OF LIFE

EXPLORING PALLIATIVE CARE AND END OF LIFE RESOURCES FOR OLDER PEOPLE IN THE RAINBOW COMMUNITY

REPORT SUBMITTED TO THE WINSTON CHURCHILL TRUST

JULY 2025

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FOREWORD

Thank you to the Winston Churchill Memorial Trust for awarding me this fellowship to explore palliative and end of life issues for Rainbow (LGBTQIA+) older adults with colleagues overseas. It has been a once-in-a-lifetime experience. Thank you also to the people highlighted in this report who kindly invited me to visit and shared their knowledge so generously with me.

This report offers information about, and links to, resources useful for organisations and individuals involved with LGBTQIA+ older adults. I have interacted with experts in the USA, Canada and the UK who have provided me with new ideas vital for practitioners in Aotearoa New Zealand. I am pleased I can share the fruits of their hard work.

My purpose was to investigate palliative and end of life care in particular. However, many issues intersect, so I decided to cast the net wider and report on related topics as well.

You'll note in the report that the acronyms for LGBTQIA+ individuals change according to the norms of the people I talked to. I've kept their terminology rather than standardizing it.

When I went overseas in 2024 and early 2025, the landscape was much different than it is today, just a few months later. We are seeing the unsettling rollback of LGBTQIA+ rights, especially for the trans community. I hope this report in a small way helps keep visible some of the resources available to those in need as they approach the end of life.

Ngā mihi

Lisa Williams*
Senior Research Fellow, University of Auckland
July 2025

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*As of 30 September 2025, I am retiring from the University. Please direct inquiries to fourlisas@gmail.com

DR KIM ACQUAVIVA
SHE/HER

DR CATHY CAMPBELL
SHE/HER

UNIVERSITY OF VIRGINIA

KIM & CATHY ARE EXPERTS IN LGBTQIA+ ISSUES RELATED TO PALLIATIVE CARE.

THE SCHOOL OF NURSING, UNIVERSITY OF VIRGINIA

I visited Kim and Cathy at the University of Virginia, in March 2024 when spring was making its robust appearance. Both are experts in LGBTQIA+ issues related to palliative care. They shared their expertise and hospitality during my stay in Charlottesville.

I was lucky enough to hear them speak on topics of importance to LGBTQIA+ people and healthcare professionals in relationship to inclusive care. I gave a talk to nursing students on what it's like to be LGBTQIA+ in New Zealand both today and historically. I showed them the trailer to the Topp Twins documentary that came out several years ago, directed by filmmaker Leanne Pooley. I think I earned the Topp Twins some new fans that day.

Kim Acquaviva – Kim's Instagram site sums up her mission. She's 'striving to make hospice and palliative care LGBTQIA+ inclusive'. In 2023 she published a revised edition of her book on the subject titled, *The Handbook of LGBTQIA+-Inclusive Hospice and Palliative Care.* It's packed with information, guidelines, examples and, poignantly, experiences from her own life.

Woven through the book are stories about the journey she and her wife, Kathy, undertook when Kathy was diagnosed with, and later died from, ovarian cancer. They decided to share their journey on social media, and Kim has included some of the posts in the text.

A distinctive aspect of the *Handbook* is its emphasis on inclusive care for all people, rather than promoting some kind of special care for LGBTQIA+ people. This is significant because it underscores the importance of understanding the complexities individuals bring with them to palliative care instead of adhering to the assumption that everyone should be treated the same.

There's too much good material packed within the pages to include here, but I would like to mention the contents of the first chapter titled ‘Self-Awareness and Communication’. It highlights the need for healthcare professionals to start with themselves as the initial step in providing inclusive care. Self-awareness is key, which Kim describes using the acronym CAMPERS: **C**lear purpose, **A**ttitudes and beliefs, **M**itigation plan, **P**atient, **E**motions, **R**eactions, and **S**trategy.

Kim includes a table (p. 231) that provides questions clinicians can ask families to ascertain their knowledge about the signs and symptoms of imminent death. These are broken down by bodily system, eg, neurological, respiratory, etc. For example, a question to ask about someone dying from a neurological condition could be: ‘What have you heard about how a person’s alertness, awareness, or thinking might change as death becomes imminent?’

WATCH ‘DOCUMENTING DEATH, A SHORT DOCUMENTARY, TO LEARN MORE ABOUT KIM AND KATHY’S CANCER JOURNEY.

Cathy Campbell – Cathy’s longtime work as a hospice nurse has influenced an important area of research for her: equitable access to palliative care for vulnerable and underserved-people. An aspect of this is her focus on transgender elders at the end of life, including their spiritual needs.

I attended a talk Cathy gave at Hospice of the Piedmont titled *Hospice and Palliative Care for Transgender Older Adults*. I learned valuable lessons about how hospice staff can provide safe, compassionate end of life care to transgender and non-conforming older adults. Using discussion questions, she asked the audience to think about what it would be like to work with transgender older adults.

Her presentation’s overarching question was: *How does a compassionate community provide safe, compassionate end of life care to transgender or gender non-conforming older adults?*

She used a fictitious LGBTQIA+ person needing hospice care to interrogate the subject:

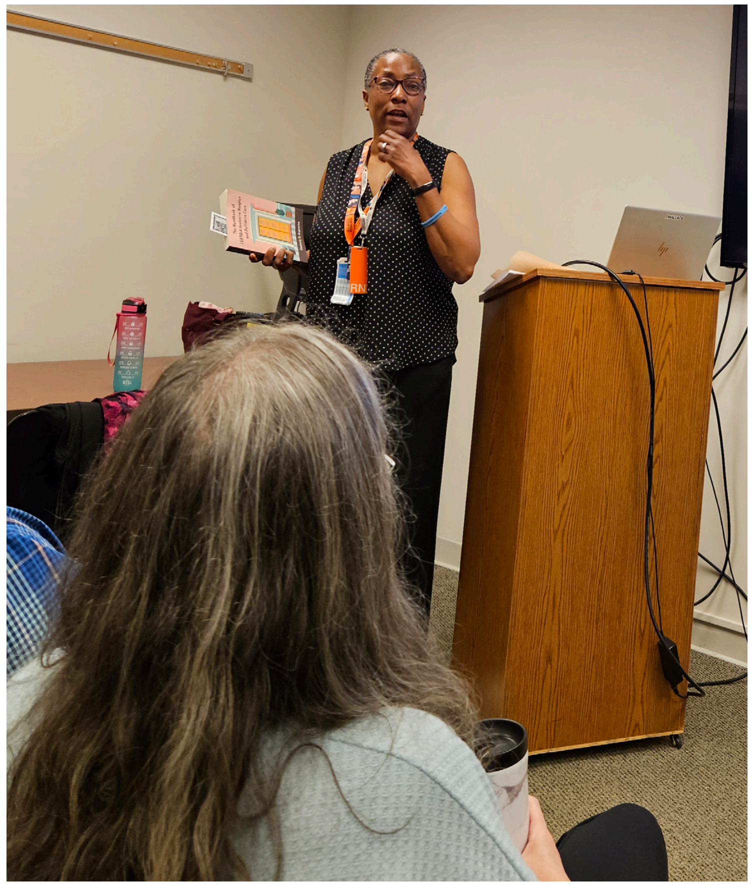
> *Imagine you are working with Maria. Maria was assigned male at birth, is a woman and expresses her gender identity through clothes, makeup, and hairstyle. Maria is about to be admitted to the Acute Care Hospice Unit.*

‘

She posed some discussion questions about Maria that offered no easy solutions. For example: *What information, if any, should you provide about Maria’s sex assigned at birth, gender identity, or gender expression?*

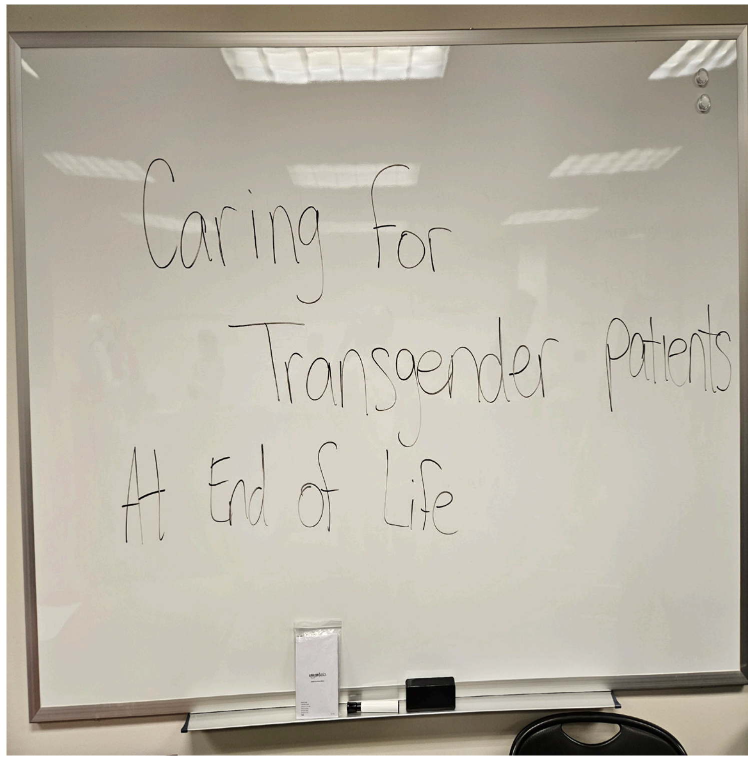
This question made me think of research I’ve been involved in with transgender people. In an interview, one person discussed the hurt caused by unthinking healthcare professionals who assumed they had a right to discuss her genitalia when it had no bearing on the treatment she was receiving. The point being that such discussions would not occur with those who are cisgender (people who identify with the gender they were assigned at birth).

Another resource Cathy pointed me to, is a booklet titled *Little Star* produced by Lauren Catlett, who has now finished their PhD in the School of Nursing. I met with Lauren and they told me more about it. It concerns the life of Carmelita Estrellita, a transgender person Lauren met while they were volunteering at an adult day centre. Later, they connected again when Carmelita enrolled in hospice with a terminal illness. Through a shared love of storytelling and art, they wrote *Little Star* which through words and pictures tells Carmelita’s story, which includes a lot of pain. Even so, as Lauren mentions in the foreword, Carmelita opened their eyes to ‘dimensions of suffering I had never understood and to the capacity of the spirit to find beauty in it nevertheless.’



CATHY GIVING A TALK ON TRANSGENDER ISSUES FOR HOSPICE OF THE PIEDMONT STAFF.

“CARMELITA OPENED THEIR EYES TO ‘DIMENSIONS OF SUFFERING I HAD NEVER UNDERSTOOD AND TO THE CAPACITY OF THE SPIRIT TO FIND BEAUTY IN IT NEVERTHELESS.’”



I recommend this book for those who would like to deepen their understanding and empathy for transgender and gender non-conforming people.

Kim is is the Betty Norman Norris Endowed Professor in the School of Nursing. Cathy is an associate professor in the School.

CHARLIE BLOTNER
HE/HIM
DR VERN HARNER
THEY/THEM
MICHAEL LIGHT
HE/HIM
DR AUSTIN OSWALD
HE/HIM
SEATTLE, WASHINGTON

Update – July 2025: Since I visited Seattle in 2024, the political climate in the United States has deteriorated dramatically. LGBTQIA+ rights are under significant threat, with transgender people especially experiencing the effects of a hostile political climate. [Human Rights Watch](#) reported on the Trump administration's dismantling of protections for transgender people, going so far as to withdraw funding if they engage in research or services for trans individuals.

Charlie was my host for the week. He is a licensed social worker with Evergreen Health. He and Vern, who is an assistant professor in the School of Social Work & Criminal Justice at the University of Washington, Tacoma, took me to dinner one night. We discussed transgender people's issues in relationship to healthcare. I learned about the discrimination they often face that is expressed in many ways, including in insensitive questions about genitalia. To put it in perspective, they pointed out how unlikely it was that cisgender people would be subjected to the same questions.

VERN HARNER, CHARLIE BLOTNER AND ME.

Vern shared some of their research, pointing me to their paper [Transgender Patient Preferences When Discussing Gender in Health Care Settings,](#) The paper reports on the same issues we discussed during dinner including the all-to-common occurrences of harmful experiences for trans people when receiving healthcare.

Conversely, gender-affirming, competent healthcare improves their health and well-being. Vern and co-authors concluded that providing competent healthcare for trans individuals is a multi-faceted endeavour that 'requires flexibility and responsiveness to patient preferences.' Healthcare practitioner humility and engagement – rather than impersonal interactions – are key. Furthermore, it must be backed up by 'institutional policies that support competent and gender-affirming spaces.'

> “I LEARNED ABOUT THE DISCRIMINATION [TRANSGENDER PEOPLE] OFTEN FACE... INCLUDING INSENSITIVE QUESTIONS ABOUT GENITALIA.”

A few years ago Charlie featured in a ‘Thinking Differently’ series sponsored by the Mayo Clinic in the US, which is worth watching to gain more insight into transgender issues. Titled, *Establishing Trust in Healthcare: How the Transgender Community Is Building a New Ecosystem for Health*, his presentation and the Q and A session afterward highlight issues such as how healthcare providers can build trust with trans patients.

Earlier in the week, I participated in a cultural roundtable with Charlie and his colleagues at Evergreen Health, Hospice. I talked to them about assisted dying in New Zealand and they talked to me about Washington’s assisted-suicide laws. I came away having learned more than I taught. The group shared with me the Washington Portable Orders for Life-Sustaining Treatment form (POLST). This form guides the responses of emergency medical personnel who respond to an emergency in which the person receiving treatment has requested in writing that futile emergency medical treatment not be carried out. This might include their wishes for resuscitation, medical interventions and artificial feedings.

MICHAEL A. LIGHT
SOCIAL WORKER, HOMELESS PALLIATIVE CARE TEAM
HARBORVIEW MEDICAL CENTER

DR AUSTIN OSWALD
ASSISTANT PROFESSOR OF THERAPEUTIC RECREATION
SCHOOL OF HEALTH AND HUMAN PERFORMANCE
DALHOUSIE UNIVERSITY (FORMERLY OF THE UNIVERSITY OF WASHINGTON)

I met with Michael and Austin to discuss issues related to older Rainbow adults that impact on their health and healthcare. They are both devoted to issues of equity and to looking systemically at the factors that contribute to good or poor health – issues such as housing/homelessness, poverty, social connection and ethnicity. They are advocates for community-led research and practice that brings about lasting social change.

Unfortunately, the recording of our very stimulating conversation didn’t come out well, and I wasn’t able to process nearly as much as I would have liked from our time together. A point they made that resonated deeply with me was that systems designed to help older Rainbow people can be very dysfunctional. This may cause moral distress for the healthcare professionals working within the system and who genuinely want to bring about good in the world.

They cited an example of one GP who adapted her business model so she was able to treat low income people for a low cost or for free. “You can’t put a price on these moral dilemmas and the peace of mind that comes with knowing that you’re making some sort of contribution,” said Michael.

A STILL IMAGE FROM THE VIDEO NEVER MARRIED

DR INGRID HANDLOVSKY

SHE/HER

DR ROBERT BERINGER

HE/HIM

DR ALLIE SLEMON

SHE/THEY

DR NATHAN LACHOWSKY

HE/HIM

UNIVERSITY OF VICTORIA,
VICTORIA, BC, CANADA

At the University of Victoria, I visited with Nate, Ingrid and Robert. Allie was set to join us but was unwell. All are health researchers conducting work with a focus on 2S/LGBTQIA+ (2 Spirit/Lesbian, Gay, Bisexual, Trans, Queer, Intersex, Asexual and others) individuals. We discussed some of their research projects and the resources they've produced that focus on

They also pointed me to the CBRC (Community-Based Research Centre) which contains useful news, information and resources centring on the health and wellbeing of people of diverse sexualities and genders. I recommend having a look.

2S/LGBTQIA+ Liaison Nurse (LN) project
Allie and Ingrid are conducting a project with Registered Nurse Emily Wyatt to explore the effectiveness of a new, global-first 2S/LGBTQIA+ Liaison Nurse (LN) position located within the local Island Health Authority. Emily, as the originator of the role and current 2S/LGBTQIA+ LN practitioner, has been supporting 2S/LGBTQIA+ patients who visit the ED, inpatient mental health settings, and medical units. The need for this role stems from the alienation that 2S/LGBTQIA+ people can face when interacting with health services.

The team's preliminary results, based on 28 unique clients and 91 client encounters, have found several ways in which Emily supports 2S/LGBTQIA+ people. Her typical day begins with reviewing client files and new client referrals. Other activities include:

Being present with clients	Care planning
Discharge planning	Advocacy
Medication review	Medical procedures
Support for family & friends	

FROM THE: REACH AND IMPACTS OF A 2SLGBTQIA+ LIAISON NURSE: REPORT OF PRELIMINARY FINDINGS

They've found that the most common reason 2S/LGBTQIA+ people in their study are accessing care is for mental health concerns. Gender affirming care, surgical intervention, acute injury or illness, and chronic conditions are also on the list. Twenty-nine percent of the clients are Indigenous and 78% are trans or non-binary.

Testimonials from clients add nuance to the value of 2S/LGBTQIA+ liaison nurses:

> *"Having a healthcare worker that was also trans and understood the issues I was facing helped me feel validated and more comfortable in hospice."*
>
> *"After speaking with this nurse I felt like I could come back to this hospital for help when and if I needed to. I felt safe and like this was a place for me to take respite instead of another possible hazard."*

The source for this information is listed in the resources section at the end of the report.

The team hopes to expand the Liaison Nurse programme across British Columbia as well as scale up the role within Island Health.

Intersectionality in research & the creative arts

Nate is an epidemiologist by training, with a background in biology and sexuality studies. He draws upon these areas to take an interdisciplinary approach to his research, which has included conducting research in Aotearoa New Zealand. His PhD project concerned improving the sexual health and wellbeing of young gay, bisexual and takatāpui men.

A particular interest of mine has been turning research undertaken by the research group I belong to (Te Ārai Palliative and End of Life Care) into creative pieces like graphic novels, short videos, digital stories, and audio plays. Therefore, I found it exciting to hear Nate talk about his Verbatim Theatre project. I didn't know anything about Verbatim Theatre, which involves using the words of real people exclusively to form the dialogue of a play. (Here's an explainer link if you want to know more about how it works.)

Nate's project started as an oral history comprised of 118 interviews with HIV survivors and their caregivers from British Columbia titled, In My Day'. The interviews cover the early years of the HIV/AIDS epidemic. If you'd like to explore the collection, the interviews are available online through UVic Libraries. They include video and audio files and transcripts. The Canadian playwright Rick Waines used the interviews to craft his script and Zee Zee Theatre in Vancouver presented it. For historical context, check out the online review that appeared in The Vancouver Arts Review.

Since I visited with them, Nate has moved from the University of Victoria to be Professor of Health Sciences and Dean of the Faculty of Human and Health Sciences at the University of Northern British Columbia.

Dignity for Older 2SLGBTQIA+ individuals

Robert has undertaken a number of research projects that inform my goal to bring back useful information on topics related to LGBTQIA+ palliative care and end of life issues. For example, he has completed research on advance care planning involving LGBTQ older adults who live in rural or non-metropolitan settings. (Advance care planning helps people document their wishes regarding future medical care,

A STILL IMAGE FROM THE VIDEO A SPECIAL OCCASION

especially if they become incapacitated.) This has relevance for our country given the number of people who live in similar settings.

People who participated in the project provided feedback on an advance care planning tool titled *My Wishes, My Care* developed for a general, non-LGBTQ audience. The tool, a booklet, helps people think about and discuss their wishes. Their feedback reinforced the need for organisations involved in creating health-related tools to consider the particular needs and preferences of LGBTQ communities. For example, the people in Robert's study who evaluated the booklet suggested it could use more inclusive language and photographs and be more inclusive of 'families of choice' rather than focusing primarily on the 'biological family'.

A worthwhile study that could be conducted here in Aotearoa New Zealand would centre on taking a tool like *My Wishes, My Care* and adapting it for our LGBTQIA+ communities.

Videos tackling hard issues

A second project of Robert's I want to draw attention to is the trio of videos he and his team created that present vignettes in assisted living facilities about discrimination and bigotry that LGBTQIA+ people can face. The images from them are included throughout this section of the report. They would be good tools to use for discussions among staff in assisted living and other aged care facilities on how to practice inclusive, non-discriminatory care. The videos are listed in the Resources section at the end of this report.

Ingrid and Allie are assistant professors in the School of Nursing. Robert is an assistant professor in the School of Health and Social Policy. Nathan is Dean, Faculty of Human and Health Sciences, University of Northern British Columbia.

DR JOLIE KEEMINK UNIVERSITY OF KENT

SHE/HER

JOLIE KEEMINK

> “IT WAS A MASSIVE EDUATIONAL EXPERIENCE FOR STAFF – LEARNING FROM LGBTQ+ PEOPLE AND THEIR LIVED EXPERIENCE.”

Research Fellow Jolie Keemink and colleagues have created *The CIRCLE care home guide.* Co-designed with older LGBTQ+ people and care home staff, it offers practical suggestions for making care homes more inclusive. CIRCLE stands for Creating Inclusive Residential Care for LGBTQ+ Elders. The guide sprung from the team’s larger CIRCLE project completed between 2022 and 2024. A community-focused initiative, it arose from the need to address the barriers and inequities LGBTQ+ people experience when engaging with social care services in the UK.

An important feature of the CIRCLE project was its focus not on what care facilities were doing wrong but on what they can do to make their care better for LGBTQ+ people. “There was a knowledge gap in what care settings knew about caring for LGBT people,” Jolie said. “They didn’t see the relevance of gender and sexual orientation to care. Don’t you just treat everybody the same?” Yet this idea about ‘sameness’ or ‘equality’ meant “treating LGBTQ+ people in heteronormative ways that disregard their life stories, histories and unique health histories.” What was needed was “a much more explicit demonstration that care places have thought about inclusion.” The message then becomes, “You’re safe here.”

CHECK OUT THE CIRCLE PROJECT

To develop the guide, the team held six online meetings of two hours each separately with care home staff and LGBTQ+ members of the community. They finished with a meeting that joined both groups together. “It was really interesting bringing together the perspectives of the two groups. And really healing because of differences in the past.” These differences included LGBTQ+ older adults concerns about their invisibility, having to go back into the closet when entering care homes due to their heterosexual cultures. “It was a massive educational experience for staff – learning from LGBTQ+ people and their lived experience.”

During the guide’s creation phase, they “bounced around ideas”, answering such questions as, Who is the audience? What are our core messages? What are the decisions LGBTQ+ people are facing? They then tackled nuts and bolts elements like content and format. Jolie stated her role was to act as shepherd, with the process remaining clearly rooted in the principles of co-design and community.

While the care guide is targeted to staff in care homes, the tips within it would be useful for other organisations or even individuals who interact with LGBTQ+ adults. For example, under 'Personal Care', the suggestion is to 'Ask gently what gender someone would prefer their carer to be.' Carers are instructed not to make assumptions about what people wear, what their body looks like and what personal care they prefer.

Relevant to palliative care are the guide's end-of-life care instructions, such as:

- Give people privacy with their chosen family and respect their space in the last moments of life.
- Understand that LGBTQ+ older people have experienced a lot of abuse in their life and that their relationships have not been honoured. Make sure to honour them at the end of life.
- Ask people about their preferences for the end of life and who they want to be involved.
- Consider Power of Attorney and understand that in the LGBTQ+ community this might be a chosen (not always biological) family member.

DR PANAGIOTIS PENTARIS

HE/HIM

GOLDSMITHS, UNIVERSITY OF LONDON

VISITING PANAGIOTIS AT GOLDSMITHS

After talking to Panagiotis, I felt I'd barely scratched the surface of his diverse projects related to death, dying and bereavement. Our conversation centred on LGBT+ people's interactions with healthcare professionals. He is Director of of Research and Research Studies in the Social, Therapeutic and Community Studies Department.

We discussed the importance of inclusivity when considering the Rainbow community and healthcare. Rather than pigeonholing people, he said, it's important to maintain a "delicate balance" between recognizing people as unique with individual preferences and needs versus understanding their desire to be with people who are like them, which fos-

> “MICROAGGRESSIONS CAN BE ANOTHER CONSEQUENCE OF HETERONORMATIVE PALLIATIVE CARE.”

ters safety and belonging. “Give people options but don’t make assumptions.”

He wants practitioners’ interactions to be shaped by their experiences with individuals rather than by the implementation of a pre-fab suite of services. “Specific programmes often put people in a box, and they are still discriminated against.” The goal is to determine how best to create a safe space for whomever is being treated.

He discussed current research in which he’s interviewing LGBT+ adults 70 years-old and older about end-of-life issues. Palliative care tends to be heteronormative, he said, which means practitioners may overlook experiences of historical trauma. For example, Some older gay men experienced PTSD during Covid-19 due to their experiences with HIV in the 1980s.

Other factors contributing to their distress was the difference in global policies enacted during the two pandemics. Government responses to AIDS took five years whereas countries acted far more quickly to Covid.

Microaggressions can be another consequence of heteronormative palliative care. End of life care is part of a service that should be as sensitive as possible, he believes, as it’s about the comfort of patients. Yet when people have to keep coming out, explaining who they are, it can be exhausting.

Another exciting goal of his research is to tease out data useful for a new VR game applicable for the LGBT+ community and health. A 75% increase in learning results when VR is used to impart knowledge, he said.

GREN DUCHIEN-MATHEWS

HE/HIM

GOLDSMITHS, UNIVERSITY OF LONDON

Gren, a nurse by training, cited his own experience as being a very personal motivator for the PhD topic he’s undertaking with Panagiotis at Goldsmith’s. His partner Paul died of a brain tumour, and now he’s focusing on the end of life and bereavement periods LGBT+ people experience during and after their partner’s final illness.

There’s a “paucity of research around same sex bereavement,” he says, and too often LGBT+ people are “subjected to a one-size-fits-all heteronormative approach.” Through his research he’s planning to give expression to some of these unheard voices.

While Paul was dying, he noted differences in how they were treated. Some hospital staff understood and embraced their relationship while others engaged in “benign bigotry.” He was asked questions like, “are you really his husband?” and “have you got married?”

Gren felt it was “quite frightening” that those kinds of questions were still being asked. “That we’re having to argue, to justify our relationship.” Conversely, Gren said hospice staff treated them like a couple “from the moment of contact. No questions or judgement about their relationship.

WITH GREN IN LONDON

However, after Paul's death he found bereavement services operating out of a "we treat everyone the same" model of care – "if you're bereaved, you're bereaved, you're bereaved". There weren't resources or services that referenced LGBT+ experiences.

Among the issues that Gren believes may surface are older LGBT+ adults' suspicions of research based on past traumatic events. In addition to the HIV/AIDS epidemic and its legacy, he mentioned chemical castration of homosexual men during the 1950s-60s.

Gren is using an auto-ethnographic/exo-autoethnographic approach to his thesis, which means he'll be drawing on his own experiences and those of others who have faced the death of a partner and bereavement.

DR JED JERWOOD

HE/HIM

GEMMA ALLEN

SHE/HER

LISA TROMANS

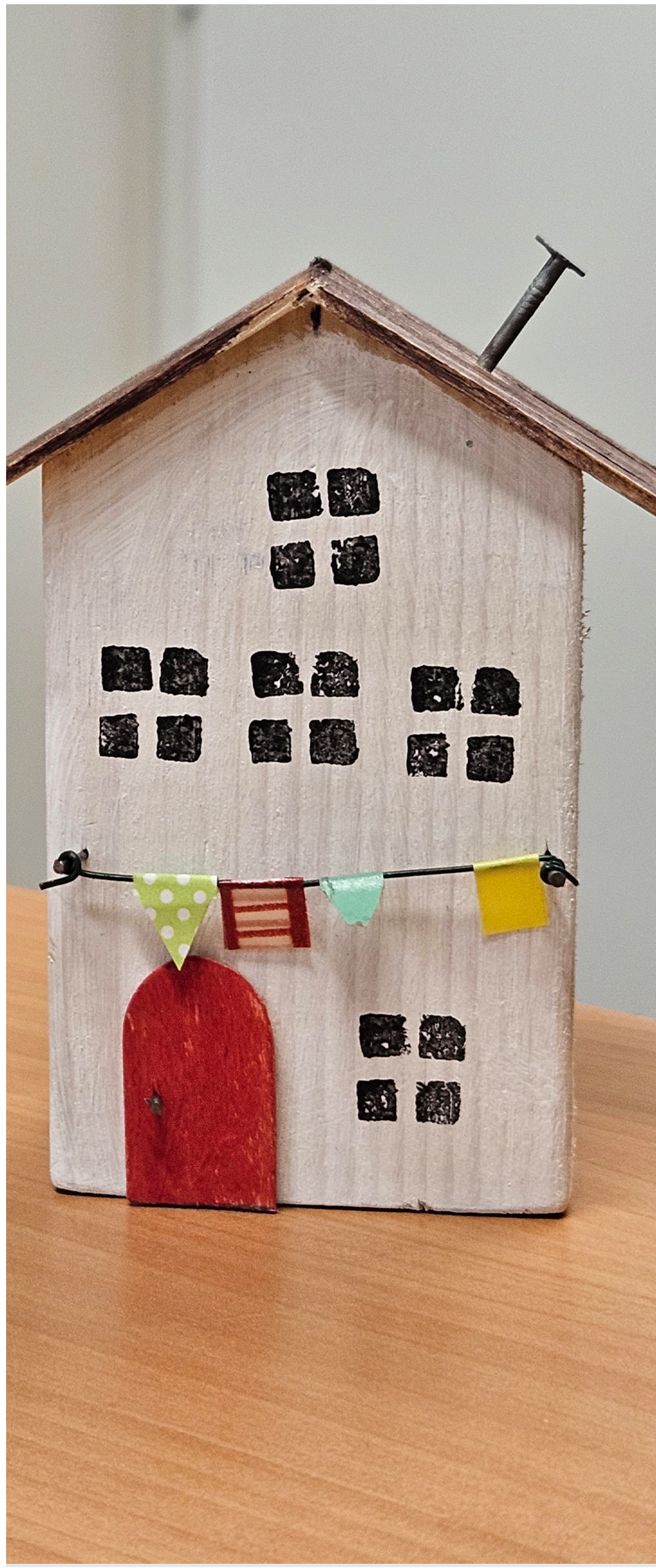
SHE/HER

CLAIRE TOWNS

SHE/HER

THE MARY STEVENS HOSPICE
STOURBRIDGE, UK

Jed was my host at Mary Stevens Hospice, with Lisa and Claire also hosting me.. Gemma was set to join us, but was called away on the day. I first became interested in their work because of their resource, *It's more than rainbows in receptions': Working with LGBTQ+ People in Palliative and End-of-Life Care.* This booklet provides a blueprint for individuals and organisations interested in becoming more inclusive of LGBTQ+ people in the healthcare services they offer. It offers information on such topics as using inclusive language; imagery and representation;



Creative Wellbeing

For hospice employees and volunteers

Create a wooden Scandinavian winter house... or due to demand a beach hut if you must!

Tuesday 22nd October 2024

13:30 - 15:30 (Board Room)

Booking essential, please contact:
Lisa.Tromans@marystevenshospice.co.uk

Funded by The National Lottery | Light refreshments available

The Mary Stevens Hospice

> “I LEARNED FROM MY VISIT THAT THE STAFF INTEGRATES CREATIVITY INTO ALL ASPECTS OF THEIR WORK.”

personal, medical and spiritual care; and advance care planning. It’s well worth downloading a copy.

Their groundbreaking project titled, ‘No Barriers Here’ uses arts-based methods and co-production to explore different approaches to advance care planning. It focuses on those who have been excluded from the conversation due to factors such as identity, culture, ethnicity and sexual orientation.

‘No Barriers Here’ originated as a pilot project during the covid-19 pandemic co-produced with people with learning disabilities, a group that has experienced inequities in palliative and end of life care.

‘No Barriers Here’ Workshops’

A key feature of the ‘No Barriers Here’ series of three workshops is the opportunity they provide for participants to explore their own wishes and preferences. They use arts-based methods which allow attendees to go beyond words to express themselves. The workshops also provide data for the No Barriers Here team to develop educational tools for healthcare staff so they may more confidently interact with people they regard as different from themselves.

Arts-based approaches

I learned from my visit that the staff integrates creativity into all aspects of their work. Whether interacting with patients, families, volunteers or staff, they’re keen on using creative methods to promote wellbeing and dissolve barriers to care. For example, Lisa delivers weekly workshops for day stay patients utilising crafts to encourage fun, socialising, connection and opportunities for those often challenging conversations about palliative care, end of life and bereavement.

In the weeks before I visited, Lisa had patients making miniature beach huts, tiny re-creations of the bigger structures found on UK beaches. Dating from Victorian times, the brightly colored sheds are used for changing into your togs and perhaps preparing a simple meal on a hob with a grill. Lisa supplied the materials and patients got to work. They displayed their finished products in the hos-

pice's Makers Fair. Titled 'A Day at the Beach', they earned a best-in-show certificate. "They were very proud of that," Lisa said.

"Tomorrow is the first day of the rest of your life"

Patients, staff and volunteers shared their words of wisdom on paper leaves they also decorated. These are being displayed on a hospice wall and will be added to indefinitely.

Accessibility and inclusion are central features of Mary Stevens' initiatives. Lisa ensures those who need help with their crafts are paired with staff or volunteers to help their participation.

Jed and Lisa agreed process is as important as product. The arts reinforce this. Those involved at the hospice gain connection as well as the chance to craft something.

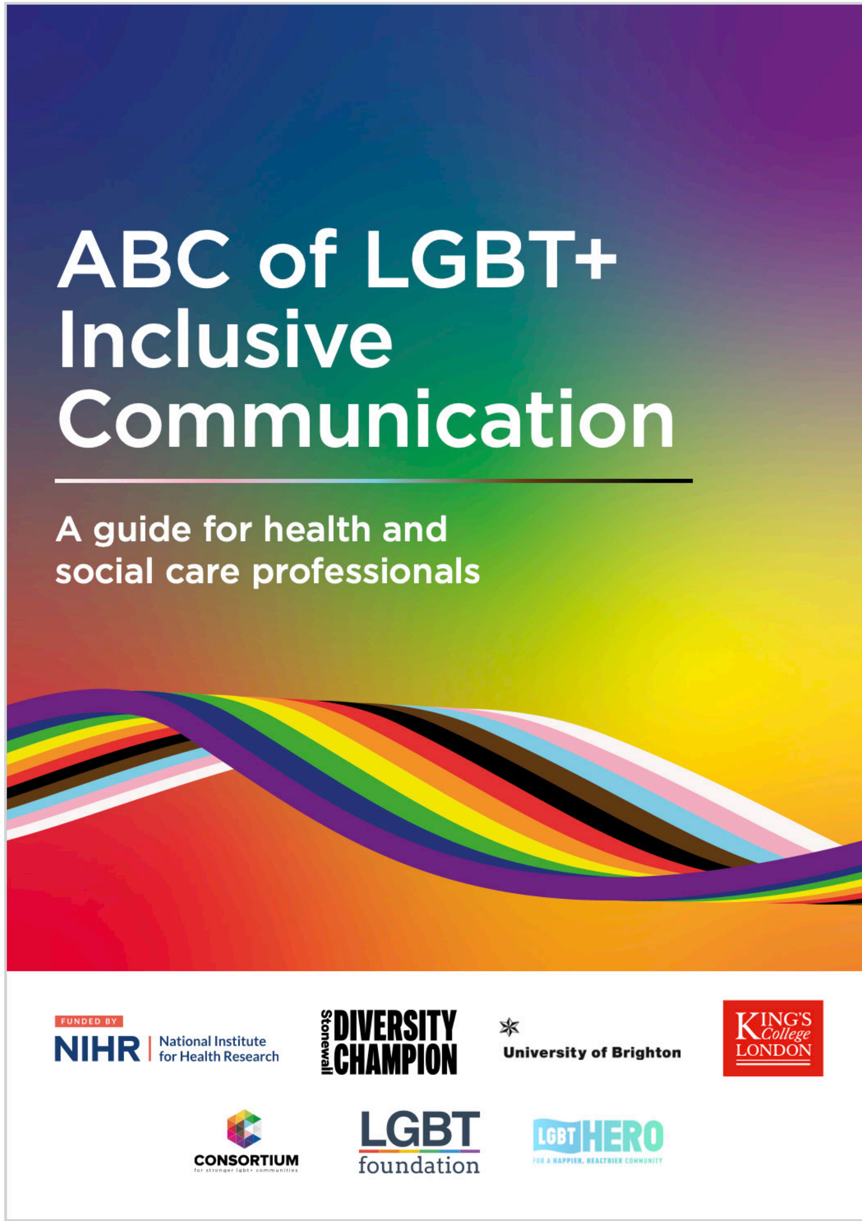
DR KATHERINE BRISTOWE

SHE/HER

DR DEBBIE BRAYBROOK

SHE/HER

CICELY SAUNDERS INSTITUTE
KING'S COLLEGE, LONDON



ABC of LGBT+ Inclusive Communication

A guide for health and social care professionals

FUNDED BY NIHR National Institute for Health Research
Stonewall DIVERSITY CHAMPION
University of Brighton
KING'S College LONDON
CONSORTIUM
LGBT foundation
LGBT HERO

HAVE A LOOK AT THEIR INFORMATIVE GUIDE

Katherine and Debbie's work alerted me to just how important communication is to interactions between clinicians and people in the Rainbow community seeking healthcare. Good communication is central to the establishment and maintenance of trusting relationships, informed decision-making and person-centred care. Bad communication can exacerbate people's unwillingness to share aspects of their identity which can have serious implications for their health. They may choose to defer or skip treatment rather than face yet another experience of discrimination.

To learn more, they referred me to the journal article they and their co-authors wrote that explored communication best practice in clinical settings. They condensed their study's results into 10 recommendations that I am including here with their permission as they will be useful for healthcare professionals in Aotearoa New Zealand interested in connecting more authentically with their patients from the Rainbow community.

Creating positive first impressions and building rapport

1. Use neutral language, such as neutral pronouns or neutral terms for significant others. Neutral pronouns such as they/them, and neutral terms like 'partner' or 'person'.

2. Use the words your patients use to describe themselves and significant others. If your patient refers to a significant other as 'they/them' or as a 'partner' or 'friend' use the same words.

3. Consider the messages your non-verbal signals might send. When discussing sexual orientation and gender identity, be mindful of the impact of potential non-verbal signals of discomfort. For example, your facial expression or volume/tone of voice may be suggestive of surprise/disapproval, or physical expressions such as shifts in posture/eye contact may be suggestive of discomfort. Enhancing care by actively exploring and explaining the relevance of sexual orientation and gender identity.

> "BAD COMMUNICATION CAN EXACERBATE PEOPLE'S UNWILLINGNESS TO SHARE ASPECTS OF THEIR IDENTITY WHICH CAN HAVE SERIOUS IMPLICATIONS FOR THEIR HEALTH."

Enhancing care by actively exploring and explaining the relevance of sexual orientation and gender identity

4. Create a safe space by making your questions about sexual orientation and gender relevant to care. Explicitly state why you are asking these questions, and give an option not to answer, so that patients can make an informed choice. This will vary depending on clinical specialty, for example, you may be asking to ensure they are receiving required screening invitations, or because you want to ensure patients' significant others are being included appropriately.

5. Respect gender. Routinely introduce questions about gender identity and pronouns into your practice so you provide opportunity for patients to share and ensure you refer to them correctly. You could try saying 'I want to make sure we are using your names and pronouns correctly. My name is XXXX and my pronouns are YYY/yyy. What about you?'. Only ask about gender history in private, using specific, justified questions.

6. Incorporate significant others and sexual orientation appropriately. Ask about significant

others inclusively, with neutral language. You might say ‘So I can look after you the best I can, can you tell me who’s important to you?’. If asking about partners or spouse, avoid gendered terms (such as wife or boyfriend). Instead, you could ask ‘Do you have a partner?’.

7. Consider your surroundings and who else is there. Ensuring that patient preferences are known before discussing sexual orientation and gender identity where other people, including significant others, might overhear is vital.

Visible and consistent LGBT+ inclusiveness in care systems

8. Standardise how LGBT+ related discussions are approached. Asking LGBT+ related questions consistently, regardless of social, cultural, religious and political backgrounds, makes discussions easier and more acceptable.

9.Having LGBT+inclusive processes and systems in place. Digital clinical records are central structures which, when designed inclusively, can bolster care for LGBT+ people. With patients’ consent, recording sexual orientation and gender identity in clinical records avoids repetition and prevents mistakes in correspondence.

10. Visual markers of LGBT+ inclusiveness. LGBT+ inclusive policies, inclusive organisational materials and indicators of relevant training received should be in place, visible and easily accessed. Wearing a badge/lanyard in LGBT+ related colours shows inclusiveness and offers additional comfort.

For a more comprehensive guide, download the booklet they and their colleagues created: ‘ABC of LGBT+ Inclusive Communication: A guide for health and social care professionals’.

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INFORMATION & RESOURCES

University of Virginia

Documenting Death: Her Wife’s Death on Social Media. Link

End of life care for transgender elders: Priorities for clinical practice, research and health policy. Link

The Handbook of LGBTQIA+Inclusive Hospice and Palliative Care. Link

Little Star Link

UVA Nurses Study the Needs of Transgender Senior Citizens. Link

UVA Nursing Professor Discusses Hospice Care for Older Transgender People. Link

Seattle, Washington

Thinking Differently, Charlie Blotner: Transgender Patient Preferences When Discussing Gender in Health Care Settings. Link

Establishing Trust in Healthcare: How the Transgender Community is Building a New Ecosystem for Health. Link

Washington Portable Orders for Life Sustaining Treatment. (POLST) Link

University of Victoria

‘Reach and impacts of a 2SLGBTQIA+ Liaison Nurse: Report of preliminary findings’. Slemon, A., Handlovsky, I., Schmied, S., and the ADJUST Research Collective (2024). Link

Verbatim Theatre. Link

HIV in My Day Link

'In My Day Uses Community Storytelling to Remember the HIV Epidemic in Vancouver.' Link

Videos highlighting LGBTQIA+ experiences of inequity in aged care
Never Married Link

'It Still Hurts' Link

Special Occasion Link

Academic articles
Amato, A., Wonsiak, T., Handlovsky, I., Ferlatte, O., Kia, H & Oliffe, J. (2024). Cultivating Psychological Well-Being amongst Older Gay Men: A Qualitative Exploration. SSM-Qualitative Research in Health. Link

Beringer R, Gutman G, & de Vries B. (2021). Exploring and Promoting Advance Care Planning among lesbian, gay, bisexual, transgender, and queer (LGBTQ) older adults living in non-metropolitan British Columbia. Journal of Gay and Lesbian Social Services, 1. Link

Beringer R, Gutman G, & de Vries B. (2017). Developing a web-based platform to foster end-of-life planning among older LGBT adults. Gerontechnology, 16(1): 48-55. Link

Handlovsky, I., Amato, A., Ferlatte, O., Kia, H., Gagnon, M & Worthington, C. (2023). Examining the Influence of pre-HAART experiences on older, self-identifying gay men's contemporary constructions of Quality of Life (QOL): a Canadian perspective. Journal of Homosexuality. Link

Handlovsky, I., Marcellus, L., Newton, L., Zakher, B. & Mussell, J. (2023). Clarifying contemporary conceptualizations of allyship with LGBTQ2S+ groups in the context of healthcare/health settings: a scoping review protocol. JBI Evidence Synthesis. Link

Handlovsky, I., Wonsiak, T. & Amato, A. (2023). Older, self-identifying gay men's conceptualizations of psychological well-being (PWB): a Canadian perspective. Nursing Philosophy, 25(1). Link

Lintott, L., Beringer, R., Do, A., & Daudt, H. (2022) A Rapid review of end-of-life needs in the LGBT community and recommendations for clinicians. Palliative Medicine. Link

Website helping the Rainbow community age with dignity
Dignity Supporting Seniors: Supporting BC's (British Columbia's) 2SLGBTQIA+ seniors. Link

University of Kent

Care Home Guide for Creating Inclusive Residential Care for LGBTQ+ Elders. Link

Creating Inclusive Residential Care for LGBTQ Elders (Circle) Link

Keemink, J. R., Hammond, J., Collins, G., Price, J., Wells, M., Johnson, S., Rugg, S., Parish, M., King, A., & Almack, K. (2025). The CIRCLE care home guide: a co-designed resource on LGBTQ+ inclusion for care homes. Health Expectations. doi: 10.1111/hex.70309 *(in press)*

Goldsmiths

Pentaris, P., Patlamazoglou, L. eds. 2023. Bereavement in older age in LGBTIQ adults. Psychology & Sexuality, 14(4). 1941-9899 Link

Pentaris, P., Petricola, M. Gender, Age and Identity. In: Douglas J. Davies, ed. 2024. A Cultural History of Death: Volume 6: A Cultural History of Death in the Modern Age. London: Bloomsbury Academic. Link

The Mary Stevens Hospice

It's more than rainbows in reception. Working with LGBTQ in Palliative and End of Life Care. Link

No Barriers Here website. Link

Cicely Saunders Institute/King's College

ABC of LGBT+ Inclusive Communication: A guide for health and social care professionals, (2022). Link

Braybrook D, Bristowe K, Timmins L, et al. Communication about sexual orientation and gender between clinicians, LGBT+ people facing serious illness and their significant others: a qualitative interview study of experiences, preferences and recommendations BMJ Quality & Safety 2023;32:109-120. Link

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