



COMPASSIONATE COMMUNITIES CONVERSATION SERIES

Townsville

Comparative Report 2019 and 2021



An initiative of
PalliativeCare
QUEENSLAND
PALLIATIVECAREQLD.ORG.AU

Project Initiative

The Compassionate Communities Conversation Series project is an initiative of the Palliative Care Queensland program Queensland Compassionate Communities.



2019 Compassionate Communities Conversation Series

Project Partners

PCQ would like to thank and acknowledge our partners for the 2019 Compassionate Communities Conversation project: Health Consumers Queensland, Council on the Ageing Queensland (COTA-Queensland) and Carers Queensland.



Project Funding

PCQ wishes to acknowledge the generous funding from the Queensland Government in funding the Compassionate Communities Conversation Series 2019 project.



2021 Compassionate Communities Conversation Townsville

Project Funding

PCQ would like to acknowledge Northern Queensland Primary Health Network (NQPHN) who funds the Connecting End of Life Care in Townsville (CELC-T) project, responsible for delivering the 2021 Townsville Compassionate Communities Conversation event.



Acknowledgements

Palliative Care Queensland (PCQ) acknowledges the Traditional Custodians of the lands and seas on which we live and work, and pay our respects to Elders past, present and emerging.

PCQ wish to thank all the interested stakeholders who have taken the time and energy to help guide and participate in this project and the development of this report. We understand that time is precious, and life is busy, and we appreciate everyone who has contributed in sharing experience, knowledge and time with us.

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www.palliativecareqld.org.au

hello@palliativecareqld.org.au | 07 3842 3242

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Background



About Palliative Care Queensland

Palliative Care Queensland (PCQ) is an independent not-for-profit peak body with charitable status representing the people who care for Queenslanders living with life-limiting conditions. Queensland Compassionate Communities (QCC) is the community arm of Palliative Care Queensland.

Our belief: The way we care for our dying is a significant indicator of our society's values

Our mission: Quality care at the end of life for all

Our vision: to hear Queensland community members say *"I live in a community where everybody recognises that we all have a role to play in supporting each other in times of loss, ageing, dying and grief. We are ready, willing and confident to have conversations about living, ageing, dying and grieving well, and to support each other in emotional and practical ways."*

PCQ has been operating for over 30 years with more than 400 members and is a founding member of Palliative Care Australia. PCQ members include health professionals across all sectors of health, specialist and generalist palliative care services, aged care, disability care, peak bodies, as well as consumers and interested members of the Queensland community. Collectively, the PCQ membership body holds tremendous knowledge and wisdom about the challenges the sector faces and the opportunities those challenges can bring.



About the CELC-T Project

The CELC Townsville project is administered by Palliative Care Queensland and supported by funding from Northern Queensland Primary Health Network (NQPHN) through the Australian Government's PHN program.

The Connecting End of Life Care in Townsville (CELC-T) project aims to improve the capacity of health, social and community palliative care services and supports within the Townsville Area. This will be achieved by improving systems, developing practice and building community capacity in relation to serious illness, dying, death and grief.¹

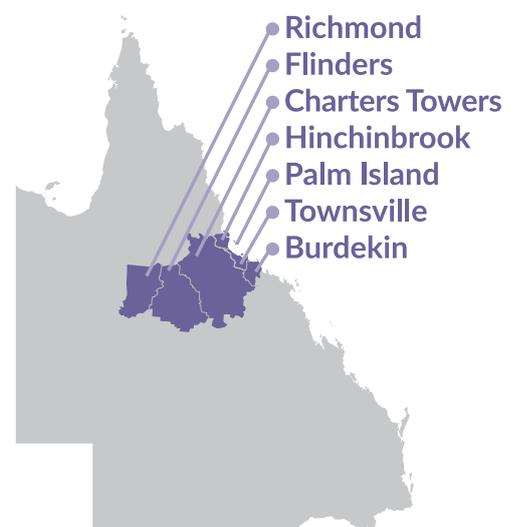


Figure 1: The Townsville Area



About The Compassionate Communities Conversation Series Activity

The Compassionate Communities Conversation Series (CCCS) events focused on the principles of Compassionate Communities and encouraged participants to consider individual and collective strategies for nurturing compassionate community activities. The CCCS events provided information and resources about local services and supports available to people who are experiencing loss, ageing, dying or grief and improved death and compassion literacy. The purpose of this report was to compare results of the 2021 CCCS with the 2019 CCCS.

The CCCS activities focused on the following areas:



Closing the feedback loop

Feedback was gathered via surveys from the participants of the 2019 and 2021 events of their experience. This data will be examined and will be used to ensure that our future events continue to meet the needs of our community. This report will be made available on the PCQ website, shared in our E-news and our other networks, and with those that participated in the activity.

About Compassionate Communities

What are Compassionate Communities?

“A city is not merely a place to work and access services but equally a place to enjoy support in the safety and protection of each other’s company, in schools, workplaces, places of worship and recreation, in cultural forums and social networks anywhere within the city’s influence, even to the end of our days”²

Compassionate Communities are communities where everybody plays a stronger role in supporting each other in times of loss, ageing, dying and grief.³ The Compassionate Communities model focuses on the empowerment of communities to harness their assets and to contest the trend of health care being solely an institutional undertaking. The Compassionate Communities’ movement challenges the notion that death and dying should be contained within the clinical setting and aims to normalise conversations about death and dying by promoting death and grief literacy and dialogue in public spaces. One of the key elements of the Compassionate Communities model is equity: that all people – regardless of age, diagnosis, ethnicity, socioeconomic status etc., can access quality end-of-life care.⁴ Compassionate Communities is a globally recognised approach to improving the end-of-life experience for people by mobilising local networks, groups and services to be more conscious, aware and equipped to offer support.⁵

Compassionate Communities are a core part of public health approaches to palliative care, end of life care and bereavement. Compassionate Communities may be able to help their community members to:³

- Find the services and supports that they need
- Stay in touch with people they care about
- Be less socially isolated
- Communicate their wishes
- Care for their neighbours
- Offer transport assistance to their neighbours/friends
- Share their stories and legacy

Why compassionate communities are important

The overarching aim of Compassionate Communities is to improve the quality of life for people who are at their end of life, including family members and carers, health and social care professionals, communities and the health and social care systems. This can be achieved through increasing community development and capacity building. Some of the benefits of Compassionate Communities that are commonly cited include:

- Improved quality of life and wellbeing⁶
- Reduced stress and anxiety, which is linked to reduced experiences of pain⁷
- Reduced fatigue and feelings of isolation
- Increased death literacy and willingness to have conversations about death and dying⁸
- Increased awareness of and access to palliative care and other services, including for marginalised populations⁹
- Increased confidence in asking for assistance and the ability to find resources⁷
- Reduced palliative care-related hospital admissions and reduced length of stay in hospital¹⁰
- Increased likelihood of being cared for and dying in the place of choice, including at home¹¹
- Personal growth and learning, including greater appreciation of self and identity, and improved sense of belonging¹²
- Improved cultural responsiveness and appropriateness of care

Findings

About the CCCS Morning Tea in Townsville events

2019

The Compassionate Communities Conversation Series (CCCS) project in 2019 was a roadshow of 15 open community conversations across a 3 month-period throughout Queensland about life, ageing and death. One CCCS morning tea event was held in each Hospital and Health Service (HHS) jurisdiction, including Townsville.

The Townsville event was held on May 1, 2019 at the Carlyle Gardens Retirement Village, Condon. The event was hosted by Health Consumers Queensland (HCQ) and Palliative Care Queensland (PCQ). There were 46 attendees with 36 people completing surveys.

In 2019 demographic data was not collected in relation to the age, gender or background of attendees. Including if they were from a minority population group, a Culturally and Linguistically Diverse (CALD) background or a person with a disability.



Wednesday
May 1, 2019



Carlyle Gardens Retirement Village, Condon



46 attendees



36 surveys completed

2021

A subsequent morning tea CCCS event was hosted by PCQ in Townsville on 23 November 2021, once again at the Carlyle Gardens Retirement Village. At this event, 29 people attended and 20 people completed surveys.

At the 2021 CCCS event, the largest portion of the attendees were over 65 years of age (45%) and female (90%). In terms of minority population groups, 10% identified as First Nations; 15% were from a Culturally and Linguistically Diverse (CALD) background, 5% were Lesbian, Gay, Bisexual, Trans, Intersex and Queer (LGBTIQ+) and 10% identified as a person with a disability. Please refer to Figure 2.



Tuesday
Nov 23, 2021



Carlyle Gardens Retirement Village, Condon



29 attendees



20 surveys completed

2021 attendee demographics

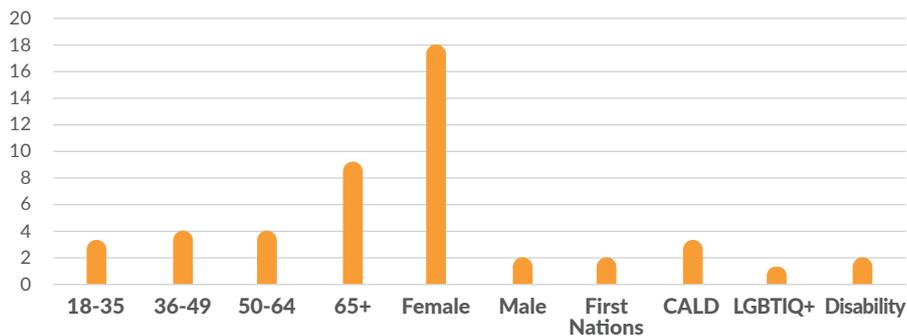


Figure 2: Demographic details of the 2021 CCCS attendees

When comparing the backgrounds of the attendees between 2019 and 2021, we found that the largest portion of attendees in 2019 were community members interested in palliative care (66.7%, compared to 40% in 2021) and volunteers (55.6% compared to 15% in 2021), alongside 30.6% were carers (compared to 10% in 2021). In 2021, the largest portion of attendees were those who work in health, social, or community services (50%, compared to 19.5% in 2019) and community members.

In 2021, we collected information on two additional groups, which we did not collect in 2019. This includes people with a life-limiting illness (10%) and people who have had someone close to them die or is dying (25%). Please refer to Figure 3.

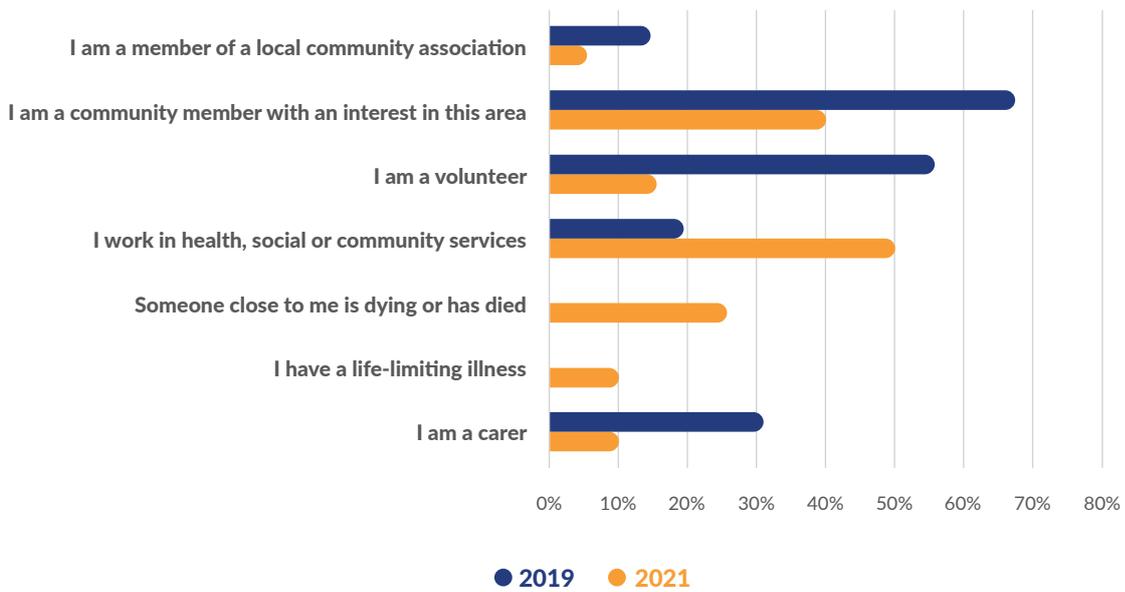


Figure 3: About the attendees, 2021 compared to 2019

*Data was not collected on all variables **Note: people could select more than one option and therefore, the variables do not add up to 100%



Photo: Compassionate Communities Conversation Series 2021, Townsville

What we learnt

Are current supports and services meeting the needs of the Townsville community?

When comparing responses to the question 'are current supports and services meeting the needs of the Townsville community?' between 2019 and 2021, we found that in terms of cultural and spiritual needs there wasn't a great difference. In 2019, 25% of attendees said yes and in 2021 30% of attendees said yes. Concerning social needs, 36.1% of attendees said yes in 2019 and 25% said yes in 2021. These two categories raise concern if only 25-36% of people feel that the supports and services in Townsville are meeting the cultural, spiritual and social needs of people who are experiencing ageing, dying, death and grief. In 2019, 50% of attendees said that medical and other care needs are being met in comparison to 40% in 2021. In 2019, only 19.4% of attendees felt that supports and services in Townsville were meeting emotional needs, compared to 30% in 2021. Although the sample size is low, this raises concern and warrants further investigation. Please refer to Figure 4.

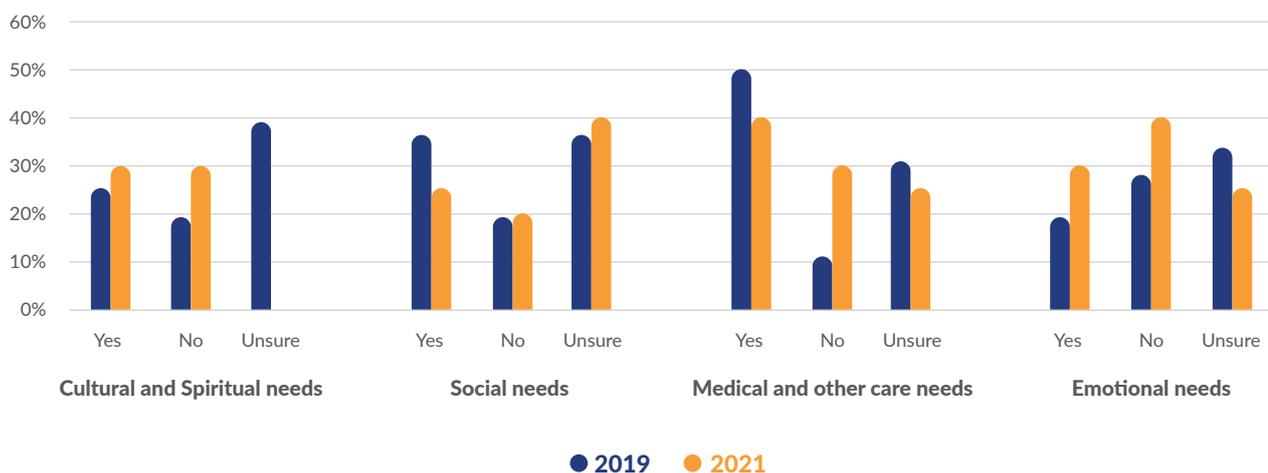


Figure 4: Did the attendees feel that local services and supports for people in the community experiencing loss, ageing, dying and grief meet their needs? CCCS 2021 compared to 2019

Where do participants look for information?

When we asked the CCCS attendees 'where do you look for information in relation to serious illness, dying death and grief?' we found that there wasn't a great difference in responses between 2019 and 2021. The major sources in both years include friends, family, neighbours or colleagues; General Practitioner (GP), google search; asking someone who has experience with this, community groups and organisations and health care websites. Please refer to Figure 5.

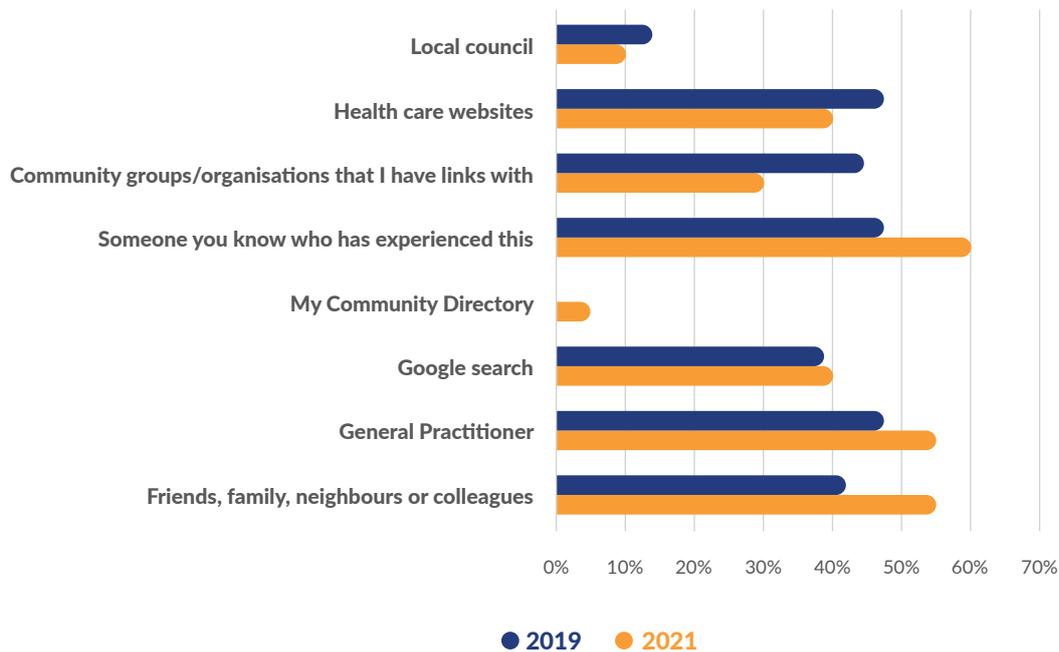


Figure 5: Where do people look for information in relation to serious illness, dying, death or grief? CCCS 2021 compared to 2019

*Data was not collected on all variables

What are the local places where communities connect?

When we asked the CCCS attendees 'what are the local places where communities connect?' we found that there were similarities between the 2019 and 2021 groups (see Table 1). The common places that were listed include Men's sheds; sporting groups/gyms/fitness groups; art & crafts groups; schools; churches; community groups and associations; cafes, restaurants and pubs; shopping centres; retirement villages; libraries; and markets. Some new places that were listed in 2021 and were not listed in 2019 include university groups; parks (including dog parks) and kids sports and activities. These differences may be explained by the differences in the people that attended the 2019 and 2021 events.

2019	2021
<ul style="list-style-type: none"> Community Centres Community Gardens Sporting Organisations Churches Cafes, restaurants and pubs Bus stops Neighbourhood Community groups and associations (CWA, rotary, RSL, Lions Club) Shopping centres Retirement villages Cowboys Leagues Sporting groups/gyms/fitness groups/yoga/Tai Chi Singing and dancing groups Library Men's Shed Fishing Art & craft groups Bingo Markets Dying with Dignity Aged care groups Schools Service groups/computer group City Council arranged gatherings Respite Centres Neighbourhood community centres District community centres Workplaces Senior citizens and Seniors expo Community Support Services PCYC Community information centre Entertainment centres Townsville Aboriginal & Islander Health Services Department of Veteran Affairs 	<ul style="list-style-type: none"> Magnetic Island Care Centre Men's Shed Churches Choir Sporting groups/gyms/fitness groups Art & crafts groups Schools Community groups and associations (CWA, rotary, RSL, Lions Club) Cowboys leagues club Cafes, restaurants and pubs Shopping centres Retirement villages Library Markets University groups (sporting, cultural and student associations) Dog parks Dancing groups Park Kids sports/activities

Table 1: What are the local places in the Townsville community where people collect? 2021 compared to 2019

What supports already exist in the community for people experiencing ageing, loss, dying and grief?

When we asked the CCCS attendees 'what supports already exist in the Townsville community for people experiencing ageing, loss, dying and grief?' we found that there were some similarities between the 2019 and 2021 groups. Please refer to Table 2 for all responses. The similarities between the two years include the Palliative Care Centre at the Townsville Hospital and Health Service (THHS); social workers; meals on wheels; charity organisations such as Red Cross and the Salvation Army, and aged care facilities. Some supports that the 2021 group listed that weren't mentioned in the 2019 CCCS were aged and palliative teams at the THHS, including the Frailty Intervention Team (FIT), the Specialist in Palliative Care in Aged Care (SPACE) team, and Specialist Palliative Rural Telehealth (SPaRTa). This could be due to these services being relatively new.

2019	2021
<ul style="list-style-type: none"> Churches Counselling Local organisations for bereavement Palliative Care Centre (Townsville Hospital) General Practitioners Social workers Volunteer groups Ozcare/ Blue Care/ Anglicare Ambulance Aged Care Facilities Family and friends RSL Department of Veteran Affairs Pastoral care workers My Aged Care Funeral homes Lifeline, Beyond Blue, Carers QLD, the Salvation Army My Community Directory Palliative Care QLD NDIS Bereavement support group Seniors Week - Expo's Home Assist Community Visitor scheme Meals on Wheels 	<ul style="list-style-type: none"> Support groups for individual diseases Primary health care Hospitals Hospice for Townsville residents Funeral homes Aged and palliative teams at the Townsville Hospital: Frailty Intervention Team (FIT), SPACE, SPaRTa Red Cross, Salvation Army Palliative Care Centre (Townsville Hospital) Social workers Meals on wheels Community transport Aged care facilities – permanent and respite

Table 2: What supports already exist in the Townsville community for people experiencing ageing, loss, dying and grief? 2021 compared to 2019

What's not working well in the Townsville community?

When we asked the attendees 'what's not working well in the Townsville community?' we found that most of the responses in 2021 were new. Please refer to Table 3 for the full list of responses. The new responses include support for distant residents of THHS such as Magnetic Island; a lack of knowledge of statement of choices and advance care directives; a lack of knowledge and understanding of the length and breadth of palliative care; income support; difficulty getting doctors, dentist and allied health appointments, and a lack of supports for carers. One common response between the two years was My Aged Care, where people go to access government-funded aged care services. In 2019, there was a strong theme around voluntary assisted dying, which was not present in 2021. This could be due to the introduction of voluntary assisted dying legislation in Queensland, which comes into effect in 2023.

2019	2021
<p>Aged Care</p> <p>Living at home in the last stages of dying without proper care and assistance</p> <p>Rural and remote areas have no palliative care or home care</p> <p>My Aged Care</p> <p>Lack of communication between departments</p> <p>Providers taking advantage of aged and frail consumers</p> <p>No choice for end of life/assisted dying.</p> <p>Staffing levels at care providers</p> <p>General Practitioners only give you 5 min appts (not holistic)</p> <p>ED provides pain relief only</p> <p>Hospital bed space</p> <p>Navigation on online community sites e.g. My Aged Care</p> <p>A lack of conversations from early on with doctors</p> <p>Centrelink systems - too complex</p> <p>NDIS</p> <p>Sensitive communications</p> <p>Information sharing</p> <p>Too reliant on technology to get messages out (too impersonal)</p> <p>A lack of face-to-face care</p> <p>Inadequate carer to patient ratios</p> <p>A lack of Government funding</p> <p>More counselling for grief.</p> <p>Hospital (resources stretched)</p> <p>Regional areas do not have the help they need</p>	<p>Support for distant residents of THHS</p> <p>Lack of knowledge/understanding of the length/breadth of palliative care</p> <p>Lack of knowledge of statements of choices, advanced health directive</p> <p>Income support</p> <p>My Aged Care</p> <p>No capacity for new clients to receive in-home care</p> <p>Getting doctors and dentist appointments</p> <p>A lack of allied health</p> <p>A lack of support for carer organisations and families</p>

Table 3: What's not working well with health and community services in relation to ageing, dying, death and grief in the Townsville community? 2021 compared to 2019

What are the gaps in the Townsville community?

When we asked the attendees ‘*what are the gaps in the Townsville community?*’ we found that the similarities between 2019 and 2021 were regional towns/areas. Some new gaps that were listed in 2021 include technology; clear access to Centrelink; advocacy; literacy and language barriers; services becoming “self-help” and having to relocate to another town for treatment and not having any supports.

2019	2021
<p>Communication between departments</p> <p>Regional towns/areas</p> <p>Lack of placements for age care individuals</p> <p>Lack of personal “face to face”</p> <p>Constant turnover of staff at care agencies</p> <p>Conversations about linking services</p> <p>Communication</p> <p>Information availability (printed information)</p> <p>Lack of funding and resources.</p> <p>Information sharing to the community</p> <p>Streamline processes</p> <p>Services for young age groups (carers or experiencing loss/dying etc)</p> <p>Workforce issues – shortages and a lack of trained staff</p> <p>Public transport limitations for elderly</p>	<p>Regional towns/areas</p> <p>Clear access to Centrelink</p> <p>Advocacy</p> <p>Literacy</p> <p>Language barriers</p> <p>Technology</p> <p>Services becoming “self-help” with no or limited assistance</p> <p>Relocating to a new city for treatments and not knowing any supports</p> <p>Information sharing</p> <p>Lack of networking</p>

Table 4: What are the gaps with health and community service in relation to ageing, dying, death and grief in the Townsville community? 2021 compared to 2019

What are some strategies that individuals could do to help grow a local compassionate community?

When we asked the attendees 'what are some strategies that individuals could do to help grow a compassionate community in Townsville?' we found that most of the answers to this question in the 2021 cohort were different to the responses in 2019. Please see Table 5 for the full list of responses.

2019	2021
<p>Have a voice & support assisted dying</p> <p>Become more involved</p> <p>Emotional and physical support</p> <p>Be present</p> <p>Accept help when we need it</p> <p>Educate the young people to be more connected to the elderly</p> <p>Bring more awareness to what's happening in local areas</p> <p>More phone communication</p> <p>Learning more about what is available in the community</p> <p>Get to know your neighbours and host regular gatherings with them</p> <p>Take more interest in what is happening in the community</p> <p>Volunteer</p> <p>Start conversations</p> <p>Establish a support group such as Death Cafe</p> <p>Be resourceful</p> <p>Churches could be more pro-active in the community</p> <p>Establish a community support group to identify our elderly</p> <p>Support for carers & families - provide respite, emotional support</p> <p>Be interested in people</p> <p>Spread information</p> <p>Take more of a vested interest in the services that are available to the community and knowing where to refer to people</p> <p>Welcome new people</p> <p>Offer lifts/rideshare</p> <p>Keep in touch and be willing to help</p> <p>Be sensitive to the needs of others</p> <p>Respect</p>	<p>Encourage service clubs and leaders of organisations to promote palliative care</p> <p>Continue positive advertising</p> <p>Communication</p> <p>Perseverance</p> <p>Raising awareness</p> <p>Friendly neighbourhood</p> <p>Create groups</p> <p>Involve kids and vulnerable groups</p> <p>Volunteer</p>

Table 5: What are some strategies that individuals could do to help grow a compassionate community? 2021 compared to 2019

What are some strategies that your community as a collective could do to help grow a local compassionate community?

When we asked the attendees 'what are some strategies that your community as a collective could do to help grow a local compassionate community?' we found that there were some new suggestions from the 2021 group. Some of these include 'value other people's skills, knowledge and lived experience' and 'accept other peoples traditions'. Please see Table 6 for the full list of responses.

2019	2021
<ul style="list-style-type: none"> Support legislation for assisted dying Create a list of available facilities More face-to-face interactions Be inclusive Be available Be interested Spread the word Community events/networking/interest groups Talk to neighbours/regular events Be more friendly and open Be compassionate and show empathy Make time Put yourself in other people's shoes Call out people who are doing the wrong thing Share information with others Reach out to people Join in community activities and welcome newcomers 	<ul style="list-style-type: none"> Be kind Make strategies Spread the word Raise awareness Be open-minded Value other people's skills, knowledge, and lived experiences Accept other people's traditions

Table 6: What are some strategies that the Townsville community as a collective could do to help grow a compassionate community? 2021 compared to 2019

Outcomes from the 2019 and 2021 CCCS

When comparing the outcomes from 2019 and 2021 CCCS, we found that in the 2019 cohort, 69.5% of attendees either strongly agree or agree that attending the CCCS increased their awareness of what community supports are available, compared to 100% of attendees in 2021. When we asked the attendees if attending the CCCS helped to increase the acknowledgement of the reality of death and dying to help people to prepare for end of life in ways that are meaningful to them, we found that in 2019 69.4% of attendees either strongly agreed or agreed, compared to 85% in 2021. Please see Figures 6 and 7.

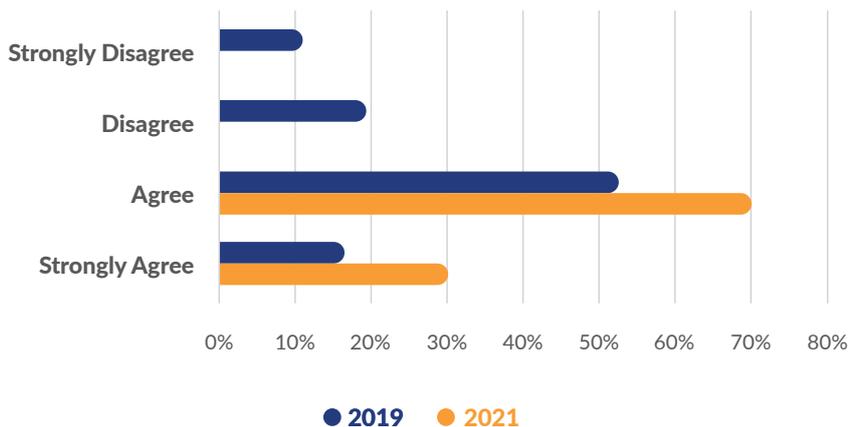


Figure 6: CCCS attendee's awareness of community supports, 2021 compared to 2019

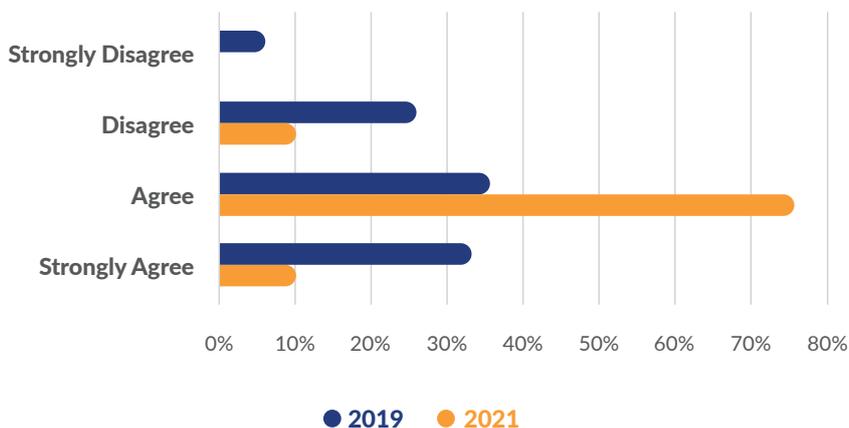


Figure 7: CCCS attendee's acknowledgement that the reality of death and dying can help people to prepare for end of life in ways that are meaningful to them, 2021 compared to 2019

Invitation to Action

To go forward, we would invite decision-makers to focus on the following:

- Recognise that the Townsville community has unmet cultural, spiritual, social, medical and emotional needs with regards to supports and services for people who are experiencing serious illness, dying, death and grief
- Work towards ensuring that the cultural, spiritual, social, medical and emotional needs of all people in the Townsville community are met
- Consider using a Public Health Palliative Care framework
- Consideration by the Local Government Areas to adopt the Compassionate City Charter¹³
- Foster communities to grow compassionate communities through partnerships and initiatives in locations and with groups identified in this report
- Consider strategies to improve or better support people needing to access services online, such as My Aged Care and Centrelink
- Increase the cultural safety of available information and resources and supports and services

How to activate compassionate communities in Queensland



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PalliativeCare
QUEENSLAND

 07 3842 3242

 hello@palliativecareqld.org.au

 palliativecareqld.org.au