



Care Beyond Cure Inc. Evaluation Report 2019

Report Authors:

Dr. Kitty Vivekananda and Dr. Mayumi Purvis

FACULTY OF EDUCATION

MONASH UNIVERSITY

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Executive Summary of Evaluation of Care Beyond Cure Program

How the Care Beyond Cure (CBC) program has shaped participants' palliative care journeys was explored in this external evaluation conducted by researchers from Monash University. The evaluation covers 22 (from a possible 24) sessions conducted over a 10-month period of the CBC program. Feedback was gathered using post-session semi-structured surveys (N= 217); semi-structured interviews (N=6); and focus group interviews (N=6). CBC Committee and Advisory group members (N=3) were also interviewed to gain insights into the operation, vision and challenges associated with program delivery.

This evaluation sought to capture the reality of those people attending the CBC program, and in particular aimed to investigate the impact of CBC on their palliative care experience, and their life overall. The CBC program is open to participants with a progressive life-limiting illness and their carer/family member.

Impact on participants' wellbeing

The program had impact on all areas of wellbeing measured with the greatest impact on emotional and social wellbeing scores. On a 10-point scale where 1 indicated "no difference", 5 indicated "some difference" and 10 indicated a "big difference", mean post-session scores had the highest impact on Social Wellbeing (Mean = 8.5; range = 4 to 10), followed by Emotional Wellbeing (Mean = 8.2; range = 4 to 10). Interestingly, the program had an impact on Physical Wellbeing also (Mean=7.9; range = 1 to 10), which was slightly higher than mean ratings for Spiritual Wellbeing at (Mean=7.6; range = 1 to 10).

Many participants talked about the benefits of body/mind/emotions connection, explaining how some of the activities like massage, reflexology, yoga, mindfulness helped with managing pain, providing stress relief, and increasing mobility.

Key learnings from the qualitative evaluation data

The journey through palliative care is tough, both physically and emotionally. The most valued contributions of the CBC program were reported by participants as:

- ✓ Providing a **safe, nurturing, professional** and welcoming space where others accept you without judgement.
- ✓ Compassionate Community care is seen as something that **complements medical treatment** and emphasises the notion of palliative care into all of its domains (physical, social, emotional, and spiritual).
- ✓ CBC **promotes wellbeing** and provides a reprieve from otherwise unrelenting strain (attendees have a break, relax, catch their breath, feel happy and 'normal' for a short while at no financial cost).
- ✓ Comradery, laughter and friendship provide a **much-needed social support network** of acceptance and non-judgement (this social connection based on shared experience appears to ease the psychological and social pain associated with being ill or a carer).
- ✓ CBC has **enhanced death literacy** for participants (helping people understand and action end of life planning, e.g. Advance Care Plans).
- ✓ Carer **needs are strongly acknowledged and addressed** (CBC enables carers to receive attention for their own needs of relaxation and respite from responsibilities and being constantly vigilance for medical emergencies; along with the bereavement component of CBC extended the care for carers).
- ✓ The CBC activities often had a **valuable mind-body connection** (many reported the activities improved their physical symptoms related to pain and mobility).
- ✓ Participating in CBC reminded attendees that **they are more than their illness** or their carer role (therefore encouraging them to maintain their individual and social identities outside of patient or carer roles).
- ✓ CBC promoted new opportunities for **growth and learning, self-expression and continued enjoyment in life** (by helping attendees to develop new skills and interests that motivated them to live with purpose and meaning, as well as, boosting their self-confidence in their ability to engage in new activities and adventures).
- ✓ CBC **empowered attendees with a sense of freedom and choice** (many felt their lives and bodies were controlled by medical treatments and appointments, but CBC fostered autonomy by enabling attendees to choose at all stages regarding attendance and the nature and extent of their participation).
- ✓ Attendees' need for the above-mentioned positive gains was so great that they all expressed **a desire for more** (the sessions to go for longer or for sessions to be run at twice the frequency, that is, weekly instead of fortnightly program runs).

- ✓ The CBC Committee and Advisory Group play an **invaluable role as social connectors** within Compassionate Communities.

Conclusion

It takes more than a cup of tea to build a Compassionate Community that is a safe, welcoming and nurturing space at the end of life. This evaluation strongly indicates that Compassionate Communities offer something unique to formal palliative services that maintains people's social, personal, emotional, spiritual and even physical wellbeing. The participants in this program explained that they need space and freedom to be larger than their diseases and being carers of dying people, whilst at the same time, acknowledging that time and life is limited. This is the unique contribution of CBC in Tasmania to having good end-of-life care and support.

Whilst Compassionate Communities represent a necessary, essential and viable avenue for enhancing palliative care services, the researchers note that caution needs to be taken by governments and policy makers in simply shifting aspects of formal palliative care to communities and informal carers. Such initiatives and programs need to be well-supported and well-resourced, otherwise the risk of burnout and other mental distress associated with taking on an unmanageable burden of care may become exacerbated.

The present evaluation of the CBC Compassionate Community in action demonstrates the remarkable ability of 'grass-roots' community of care models to effectively cater for the diverse needs of its own local community. The findings show how communities, with adequate support and funding, have the potential to provide an extraordinary level of care and support from within themselves. Further, the research highlights the value in affording communities the opportunity to investigate their own needs and offer their own solutions and resolutions. The vision and leadership, not to mention the unpaid work provided by the CBC Committee and Advisory Group, should not be underestimated in the success of the program.

The results of this evaluation show that CBC has demonstrated meeting Kellehear's (1999) goals of Public Health Palliative Care, namely, creating supportive environments; strengthening community action; and developing personal skills. Having wider social networks increases the possibility of influencing place of death and use of palliative services. Our findings support the Compassionate Communities perspective that communities

experience end-of-life as a social event, not solely as an event primarily managed by professional health services (Grindod & Rumbold, 2018).

This community in north-west Tasmania deserves to be proud of its achievements thus far. There is much that other Compassionate Communities within Australia and around the world could learn from the CBC model. Congratulations to the Tasmanian Government in recognising and supporting the value of a grass roots community centred approach in palliative care. Recommendations for further research are provided at the end of the report.

Background to Evaluation

Broader research context

Care Beyond Cure (CBC) is a community-centred psychosocial palliative care program, which strives to provide equity of access to complementary, therapeutic and self-care strategies. The program is aimed at enhancing quality of life for individuals with a diagnosed ‘progressive’ life-limiting illness, regardless of age or disease type, and their family carer/s. CBC is a grassroots community program based on the principles of Health Promoting Palliative Care (Kellehear, 2016; Abel & Kellehear, 2016), which has come to be more commonly known as the Compassionate Communities approach.

Kellehear (1999) described the goals of Public Health Palliative Care as:

1. Building public policies that support dying, death, loss and grief
2. Creating supportive environments (in particular social supports)
3. Strengthening community action
4. Developing personal skills in these areas, and
5. Re-orientating the health system.

Although, the hospice movement began in the late 1960’s as a grassroots movement with an emphasis on providing those at end-of-life and their families with more autonomy in regard to their treatment choices (Grindod & Rumsbold, 2018), in reality however, with the continued advance of medical technologies, the focus has been on extending the life of the human body, at the cost of the quality of the life of the whole human person (Grattan Institute, 2014). End-of-life care globally has continued to focus primarily on medical interventions and curative treatments rather than on interventions that can support the psychosocial aspects that affect a person at the end of life. Public Health Palliative Care understands that the current model of palliative care is not sustainable without the involvement of multidisciplinary teams including voluntary participation from the community. Abel and Kellehear (2015) argue that palliative care services need to reach all patients who are living with life-limiting illness not just those with cancer, in order for the level of care to be accessible and equitable to all. A compassionate community model is not only more financially sustainable, it would also deliver home-centred services to those who are dying and so would reach beyond the traditional hospital-based settings (Abel & Kellehear, 2016).

The evidence for Compassionate Communities is beginning to emerge in the research literature with Australia a world leader in the research in this field. A systematic review of public health approach to end-of-life care (Sallnow, Richardson, Murray and Kellehear, 2016) identified eight articles with half of these studies arising from Australian work. The review found three overarching positive outcomes resulted from community engagement in end-of-life care:

- i) a practical difference was made in end-of-life care that decreased carer isolation and fatigue;
- ii) individual and personal growth was promoted; and
- iii) community capacity was developed.

The reviewers concluded community engagement increased the size of caring networks and that wider social networks had the potential to influence the place of death and the involvement of palliative care services.

The most significant study that has measured the economic benefits of utilising a complex Health Promoting Palliative Care intervention has taken place in Frome, Somerset, England which has a population size of 112,500. Using an enhanced model of primary care within a Compassionate Communities social approach, the intervention was able to reduce the rate of unplanned hospital admissions by 14% over the 44-month period, whilst the comparable rate within the control group population in the rest of Somerset increased by 28.5%. This represents a substantial health care cost saving to the Frome intervention, whilst the health spending substantially increased in the control group area.

Several other recent Australian studies not covered in the systematic review are worth mentioning as they indicate that health services require re-orientation to embrace a community approach. Grindod and Rumbold (2018) identified a prevalent social norm where carers are reluctant to ask for, or even accept, offers of help from family, friends and community networks despite their evident need for support while providing end-of-life care at home. Further, whilst comprehensive caring networks were essential for dying at home, the researchers found that “they are not widely supported by service providers. At worst, services are obstructive of peoples stated preferences for place of death and caring and often adopt a paternalistic approach” (p.S73). Grindod and Rumbold concluded that: “Service systems need re-orienting to place caring networks as central to the caregiving process. This can be achieved by putting systems in place which initiate and maintain such networks and enable service providers to work with informal networks as equal and respectful partners” (p.S81).

Another Australian study by Rosenberg, Horsfall, Leonard, & Noonan (2018) also made similar findings. Where service providers were most helpful, they recognized the caring network and facilitated good communication, sharing of expertise and relationship building between formal and informal carers. However, this was often not the case. The researchers recommended three principles to guide the reorientation of health services and enable their transition from hindrance to help: re-evaluation of organizational values, recognition of the primacy of caring networks, and realignment of the inherent paternalism in health care provision. Horsfall (2018) describes this as “moving from a predominantly individualised care model to a network, community centric, model of care” and that, “operationalising public health approaches to palliative care requires moving to a place-based network centred model of care comprising formal and informal carers. Service systems need re-orienting to place caring networks as central to the caregiving process.” (p S42)

This section of the literature will mention public health approaches to bereavement. The needs of carers and bereavement support from a public health perspective has also been explored by Australian researchers (Breen, Aoun, O’Connor, & Rumbold, 2014). Essentially these research studies show that carers and families need support in both the pre-bereavement caring and the post-bereavement phases. However, such support was found to be frequently missing within formal palliative care services and when it occurred was described as “not personal”, “generic”, “just standard practice” (Aoun, Rumbold, Howting, Bolleter, & Breen, 2017). The researchers propose a universal grief support program that is community-based and caters for the majority of those who are bereaved. They further state that palliative care services should build relationships with local communities and resources and build community capacity, instead of offering specialised bereavement services themselves (Rumbold and Aoun, 2015).

Death Literacy

In this final section of the literature we will discuss Australian research into Death Literacy. It has been argued that society’s increased dependence on medical technologies within the health care system (Rosenberg, 2011) has resulted in a deterioration of community knowledge and a decrease in familiarity with the death and dying process (Horsfall, Leonard, Noonan & Rosenberg, 2013). With the aim of refocusing EOL care in Australia to think around public health approaches to palliative care, Noonan, Horsfall, Leonard and Rosenberg (2016) coined

the term *Death Literacy* which they define as, “a set of knowledge and skills that make it possible to gain access to, understand, and act upon end-of-life and death care options.” It is their understanding that for a community to improve its ability to support the caring of those at EOL, it needs knowledge and experience, a sense of empowerment and supportive social structures (Noonan, et al., 2016). *Death Literacy* encompasses four key areas:

1. Knowledge,
2. Skills,
3. Experiential Learning, and
4. Social Action.

In 2018, a national benchmarking of Death Literacy was undertaken by Western Sydney University and The Groundswell Project to determine current levels of Death Literacy at a whole of population and local levels in Australia (Noonan, Horsfall, & Kelly, 2018). This first benchmarking exercise found Tasmania has the highest Death Literacy compared with the national Death Literacy average (unpublished data from DLI). The survey also found that Australians generally are a caring bunch with 54% of participants knowing a carer of someone, 90% had provided emotional support, 78% bereavement support and 63% had sat with dying person. Overall, 46% have been involved in caring for someone dying with 15% taking place with a patient dying in hospital; 15% in a private home and 10% in aged care facilities. It is anticipated that the Death Literacy measure can be used to measure the impact of local and community-wide scale initiatives to contribute to scholarly, policy, practice and public knowledge of, and debate on, successful strategies and interventions in the end-of-life field.

Tasmanian State Government Policy Context

Within its *Communities of Care Strategy (2016-2019)*, the Tasmanian State Government adopted this public health approach to palliative care. The *Strengthening Communities of Care: A strategy of building the capability of all Tasmanians in palliative care (2018-2021)* further consolidates this public health approach and emphasises the need for connection and integration of formal and informal community care networks. Further, communities are viewed as critical in the delivery of sustainable, high-quality, and accessible palliative care services in Tasmania. As such, the definition and development of these palliative care services is required to stretch beyond traditional workforce structures, into a community capacity building approach.

Part of the impetus for change arises out of economic imperatives in that current models of palliative care are unsustainable given changing patterns of death and dying. There is an increase in life expectancy where two-thirds of Australians are now dying at a later stage (between the ages of 75 and 95) and this is estimated to double by 2055 (Commonwealth of Australia, 2015). Improvements in medical care mean that sudden deaths have decreased over the last century, therefore increasing the time we spend living with progressive chronic illnesses, often with a gradual decline prior to death (Abel, Kellehear, & Karapliagou, 2018; Swerissen & Duckett, 2014). Dementia now is the leading cause of death in Australian women and second leading cause for all Australians (Australian Bureau of Statistics [ABS], 2017).

In 2016, Tasmania recorded 4595 deaths, the majority of which were due to a terminal illness (ABS, 2016), with a large percentage of people dying on the North West Coast each year for whom quality of life could have been vastly improved. The *Communities of Care Strategy* recognises the importance of community engagement and community development strategies in palliative care and end-of-life.

CBC sought to address the apparent need for a community of care in the North West Coast of Tasmania and ran a single ‘Taster Day’ in the township of Penguin, in October 2015. Based on the success and enjoyment of this day, a pilot program followed in 2016, which was held across three areas, Penguin, Smithton and the West Coast. Following the successful pilot, the program was incorporated in September 2017, and funding was gained from the Tasmanian State Government to conduct a 12-month trial of CBC. Additional funding was also sought to undertake a formal evaluation by external evaluators to ascertain the benefit for participants of CBC.

Description of the Care Beyond Cure Program

CBC is a community-care model of support designed to enhance people’s quality of life, and reduce stress and suffering associated with living with an advanced ‘progressive’ life limiting illness. Through fortnightly 4.5-hour sessions, the program aims to put the ‘social’ back into the psychosocial, during which individuals with an advanced progressive illness and their family carer/s can access a wide range of complementary therapies and do so in the supportive caring company of both professionals and peers.

The CBC program offers a range of core services delivered each fortnight in addition to selected services that are offered on specified program runs. A total of 24 sessions were scheduled across the 2018-2019 trial period. Table 1 provides a list of the activities offered and the number of corresponding sessions for each activity over the course of the 12-month trial.

The name ‘Care Beyond Cure’, was chosen by Dr Thiru Thirukkumaran, who at that time was employed with Specialist Palliative Care Services North West. Dr Thiru Thirukkumaran is also part of Care Beyond Cure’s Advisory Committee.

Table 1: CBC Activities and Corresponding Number of Sessions

Activity	Number of Sessions	Session Type
Neck and shoulder massage	24 sessions	Core
Art ‘Try Me’ Activities	24 sessions	Core
Reflexology	24 sessions	Core
Oncology massage	24 sessions	Core
Manicure/pedicure	24 sessions	Core
Mindfulness	24 sessions	Core
Music – Acoustic Guitar	24 sessions	Core
Delta dogs	24 sessions	Core
UFO drums	24 sessions	Core
Gentle yoga	12 sessions	Alternate Fortnights
Tai chi	12 sessions	Alternate Fortnights
Concertina book	8 sessions	Selected Dates
Wrap Me in Memories	4 sessions	Selected Dates
Motor cycle ride	3 sessions	Selected Dates

CBC also incorporates a bereavement program that aims to provide continued post-care access for the family carer/s who had been attending CBC with their loved one. Former family carers will be eligible for twelve sessions (equivalent to six months of the program) which will be valid for a twelve-month period. Following the utilisation of the 12 sessions, former carers are welcome to attend CBC on a social basis at any time.

Evaluation Methodology

The CBC program trial was conducted across 24 sessions between July 2018 – June 2019. This evaluation covers 22 program sessions that ran between 3 July 2018 – 30 April 2019. Ethics approval was granted for this research by the Monash University Research Ethics Committee.

Participants and Eligibility

Participants in this evaluation were largely those persons who attended the CBC program for the purposes of receiving the associated care and services. Participants are either people with progressive life-limiting illnesses, or carers/family members of people with progressive life-limiting illnesses. In addition, three organisational members (from the committee and the advisory group) of CBC are also included as participants in the semi-structured interviews.

Voluntary participation in the completion of post-session questionnaires was open to any participant who had attended CBC that day, however participation in semi-structured interviews and focus groups was restricted to those persons who had attended at least six sessions with CBC. This eligibility requirement was set to ensure participants were able to adequately consider the impact that CBC had had in their palliative care experience and their life more generally.

A total of 217 post-session questionnaires were completed during the course of this evaluation. As questionnaires were undertaken anonymously at each session attended, it cannot be determined how many people in total completed questionnaires.

Semi-structured interviews were undertaken with three people with a progressive life-limiting illness, three carers, and three CBC committee or advisory group members. A total of six people participated in the focus groups, comprising three carers and three persons with a progressive life-limiting illness.

Evaluation Modalities and Procedure

The evaluation sought to answer the research question via three approaches to data collection: post-session questionnaires, semi-structured telephone interviews, and face-to-face focus groups.

Post-Session Questionnaires

Post-session questionnaires (see Appendix A) were available at the conclusion of each CBC session and attendees were invited to complete the questionnaires prior to leaving. Completed questionnaires were then deposited into a questionnaire collection box for analysis by the researchers.

Semi-structured Interviews

Two different semi-structured interview schedules were constructed to gain a more detailed understanding of the effects and impact that CBC was having on the lives and experiences of attendees. One interview schedule was tailored for carers and persons with a progressive life-limiting illness (see Appendix B) and the other for CBC committee and advisory group members (see Appendix C).

Those attendees who had participated at least six sessions with CBC were invited to share their experiences and reflections via the semi-structured telephone interview. Upon reading the research statement and signing the informed consent form, those who agreed to be interviewed by telephone were done so by Dr Mayumi Purvis. Interviews generally lasted approximately 20 minutes and were recorded and transcribed verbatim for thematic analysis.

Focus Groups

Three small focus groups were conducted with one carer and one person (unrelated to one another) with a life limiting illness at each group. Photo interviewing was used to facilitate conversations in the focus groups, which were conducted by Dr Kitty Vivekananda. Interviews generally ran for 30 minutes and were recorded and transcribed. Participants were asked what role CBC had in that transition from being focussed primarily on cure, to one focussed on care.

Results of Evaluation

Registrations

Fifty-two people registered for the program on 26 registration forms. A large variety of diagnoses were identified: cancer (N=8); motor neurone disease (MND) (N=3); dementia (N=3); Parkinson's disease (N=1); heart/lungs disease (N=2); multiple sclerosis (N=2); Chronic Obstructive Pulmonary Disease (N=5).

Referrals

The majority of referrals came via the Coffin Club or CBC word of mouth N=14. Three referrals came from an MND support group talk; N=2 Dementia Australia; N=2 Uniting Age Well; N=2 Penguin Market; N=2 posters.

Description of Participants

Age

Attendees at CBC represented a wide range of age groups from childhood through to older adult. The majority of attendees represented the 50 – 59 years age category. For those who completed post-session questionnaires, the distribution of ages recorded are presented in Table 2. Note that on 36 questionnaires, no age was recorded (this data has been excluded from the following table).

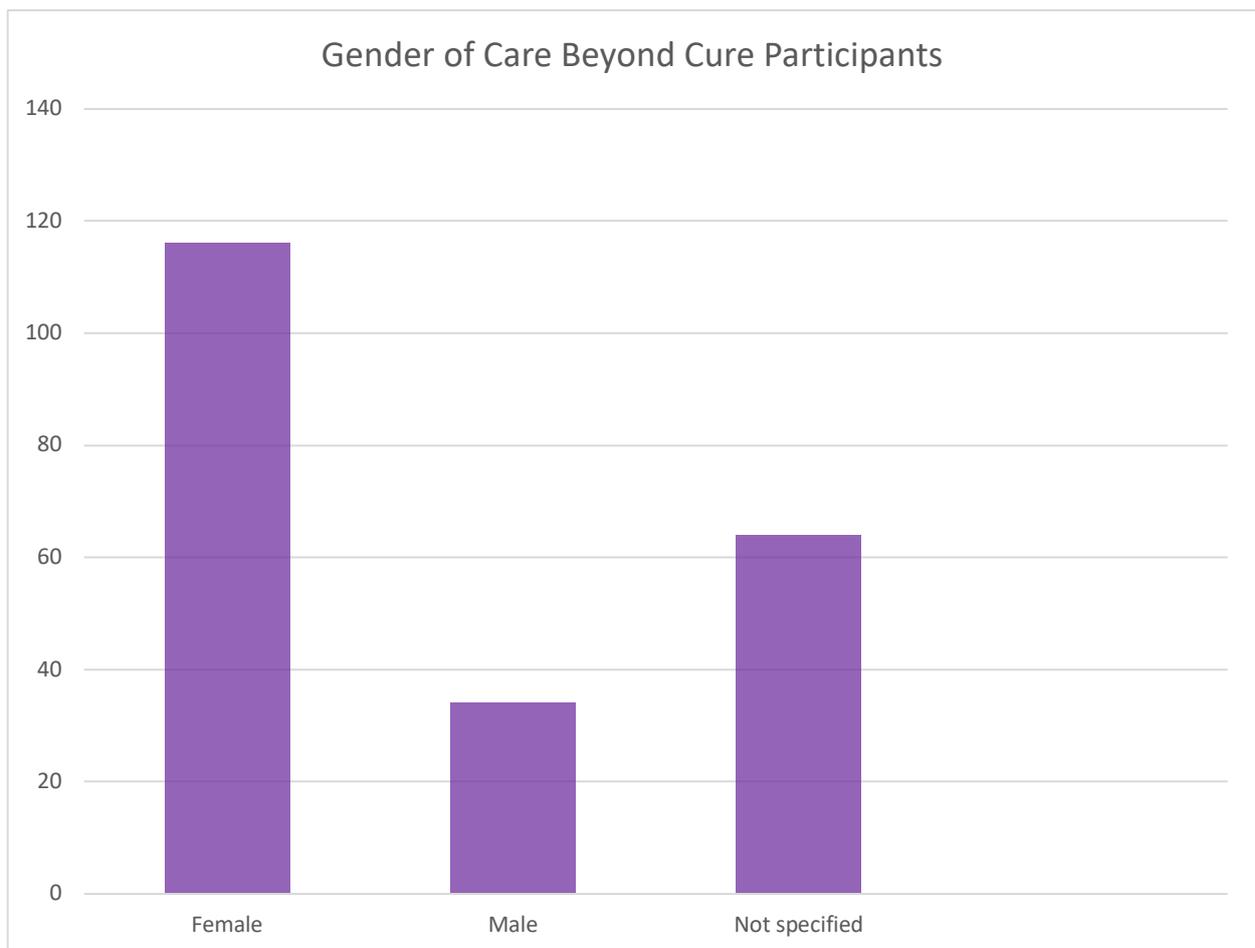
Table 2: Age category of CBC attendees

Age Category	Number of attendances
Child (under 18)	7
Young adult (under 40)	13
40 - 49	32
50 - 59	81
60 - 69	28
Older adult 70+	24

Gender

The gender of participants attending sessions who completed evaluation forms is reported below. Overall, 53.5% (N = 116) of participants reported being female, whilst 29.2% reported being male (N = 34). 17.3% (N = 64) of participants did not report their gender or indicated “other”.

Figure 1: Gender of Participants



The results of this evaluation are divided into three data sets: post-session questionnaires, qualitative data from attendees (incorporating both interview and focus group data), and qualitative data from the committee and advisory group members.

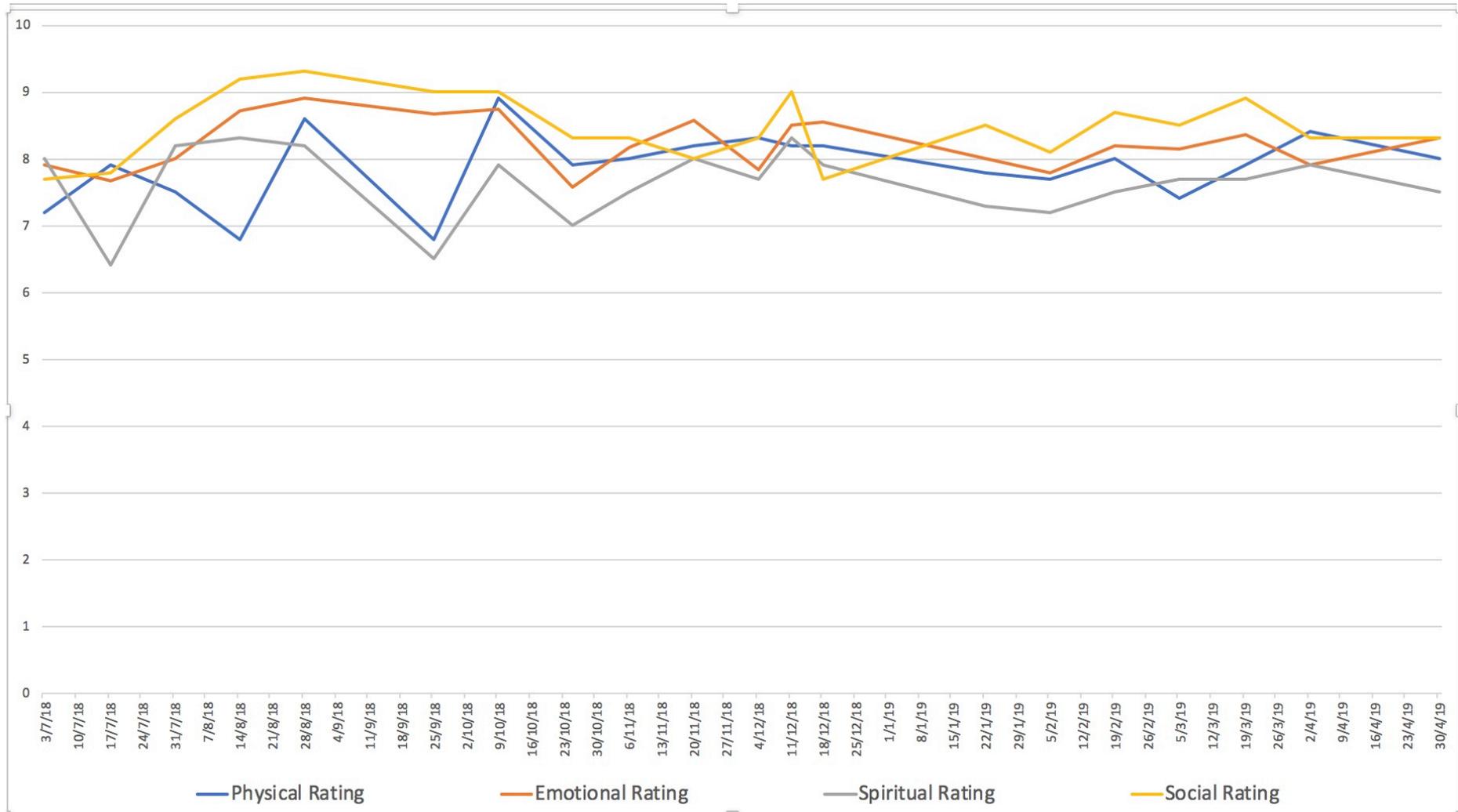
Post-Session Questionnaires

A total of 217 post-session questionnaires were collected. The data from the questionnaires was divided into four areas of analysis: post-session wellbeing ratings; reasons for choosing to engage with a particular activity; what participants liked *most* about their day at CBC; and what participants liked *least* about their day at CBC.

Post-Session Ratings of Physical, Emotion, Social & Spiritual Wellbeing

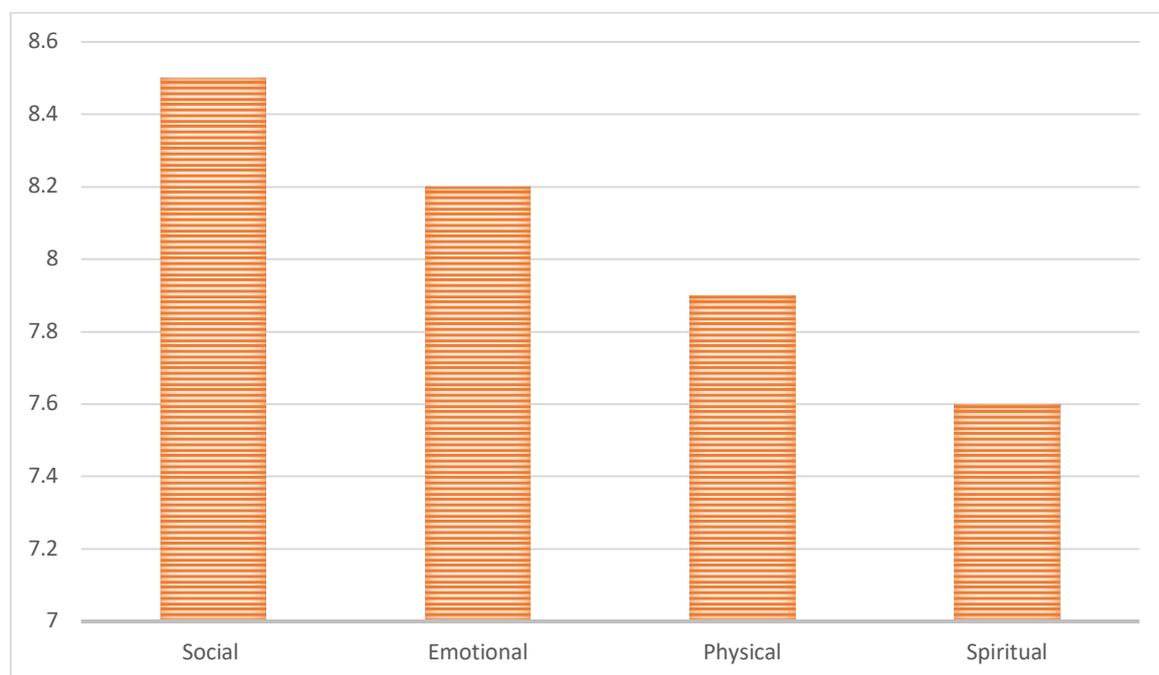
At the conclusions of each session, participants were asked to consider how they were feeling *before* they came to CBC and then rate the impact that attending CBC had had on their physical, emotional, social and spiritual wellbeing. This rating was done on a 10-point scale where 1 indicated “no difference”, 5 indicated “some difference” and 10 indicated a “big difference”. The CBC program had a positive impact on all domains of wellbeing (physical, emotional, social and spiritual) across all 22 sessions. Figure 2 shows ratings across all 22 sessions evaluated.

Figure 2: Wellbeing ratings across all 22 sessions



It can be seen that CBC had an impact on all dimensions of wellbeing including physical wellbeing. The highest impact was on social wellbeing with a mean rating of 8.5 (range 4 to 10), followed by emotional wellbeing with a mean rating of 8.2 (range 4 to 10). Interestingly, the mean physical wellbeing rating is 7.9 (range 1 to 10) slightly higher than mean ratings for spiritual wellbeing at 7.6 (range 1 to 10). It is clear that all dimensions of wellbeing were rated highly by participants as a result of their attendance at CBC. Figure 3 shows a graphical illustration of the mean wellbeing scores.

Figure 3: Mean wellbeing scores for CBC participants post session



Reason for choosing activity

Participants were asked an open-ended question about why they chose to participate in various activities. Their responses were coded into categories and it can be seen that participants indicated a range of benefits involving physical outcomes such as helping with pain management, soreness and increasing movement and mobility; psychological benefits such as stress and worry relief; mind body integration; and enhancing emotional wellbeing by doing new, fun, interesting, pampering and enjoyable activities. Table 2 sets out the identified categories for choosing participation in certain activities and the corresponding participant quotes. The number of responses collected in reference to each them is also provided (N).

Table 2: Participants' reasons for choosing certain CBC activities

Categories	N	Quotes from participants
Joy: Fun, interesting, creative, pampering and enjoyable	124	'Always enjoyable.' 'Because it was fun.' 'Great therapy.' 'Creating is fun.' 'Share stories.' 'Therapeutic'
Emotional: Stress/tension relief, break from worry/relaxing	94	'It has shown up on my sleep app. I am sleeping better after the session.' 'Great place to relax.' 'Relieve pressure and tightness.' 'To release tension in the body.' 'Need to give my mind a rest.' 'Relaxing.' 'Drums make me happy.'
Physical: Pain, soreness, fatigue, relief, mobility	71	'Back massage saved me.' 'For pain relief & increased mobility.' 'Control pain and fatigue.' 'A lot of people define you as a cancer patient but forget what troubles me the most is my scoliosis and fibromyalgia. The massages help tremendously.' 'Tired, sore, scared of hospital tomorrow.'
Novelty: Trying something new, interesting, motivational	14	'Having my nails painted for me. I can't do it myself.' 'Feel better. Pamper. Look good. Feel good.' 'Good for the soul.' 'Not able to treat this area myself.' 'Spoil myself.' 'Can't reach feet myself.' 'Helps my crumbling nails since my chemo.' 'Relaxing and good for my dry hands.' 'My feet feel neglected, so it was soooo nice.'
Personal control: Mind-body control, increasing focus	12	'Learning body-mind control.'

What participants liked most about their time at CBC

Participants were asked an open-ended question about what they liked most about the day. Table 3 provides a list of themes and the illustrative quotes. The number of responses collected in reference to each them is also provided (N).

Table 3: What participants liked most about CBC sessions.

Theme	N	Quotes from participants
Professional Care: Feeling welcome, friendliness, safe, relaxing, professional space	23	'I love this place." (from one of the child participants) 'I have seen such positive outcomes from this service for my brother and his family.' 'Everyone was very helpful' 'This space was so amazing/healing.' 'Meeting new people.' 'Feeling welcome.' 'The time out." 'Just being here.' 'Knowing that my brother is surrounded by such care, compassion, love is so important to me and I am truly grateful to you all.' 'Belonging."
Connections: Conversations, laughter, & people	35	'The atmosphere and people attending are great.' 'Sharing stories.' 'Chatting.' 'Making connections and relaxing.' 'Friends. The company.' 'Just being with friends who care.' 'All of the people' 'Feeling comfortable.'
Overall enjoyment	20	'All of it'
Quality Care: Being looked after & support	19	'Having my nails painted for me. I can't do it myself.' 'Feel better. Pamper. Look good. Feel good.' 'Good for the soul.' 'Not able to treat this area myself.' 'Spoil myself.' 'Can't reach feet myself.' 'Helps my crumbling nails since my chemo.' 'Relaxing and good for my dry hands.' 'My feet feel neglected, so it was soooo nice.'
Freedom: Choice and autonomy	2	'No pressure.'
Self-Authenticity: Being yourself	5	'Feeling very vulnerable today - good to rest.' 'Just being here'. 'Not being so great.'
Simple pleasures: Joy attached to ordinary events	5	'Watching mum do activities.' 'Watching [family member] dance.' 'Today's dog was Bruce – he is such good value – the gentlest large dog.'

What participants liked least about their time at CBC

Participants were also invited to share what they liked least about the day. Table 4 provides a list of themes and the illustrative quotes for these responses. The number of responses collected in reference to each of them is also provided (N).

Table 4: What participants liked least about CBC sessions.

Theme	N	Quotes from participants
Wanting longer sessions: Not enough time, missing out on an activity	12	'Wish it could be longer.' 'Ran out of time for all I wanted to do.' 'Time flew.'
Not wanting it to end: regrets that sessions came to an end	14	'Leaving.' 'Just wish it could carry on forever or until I die.'
Only positives: no negative feedback	9	'All good.' 'Love it all.' 'Nothing.'

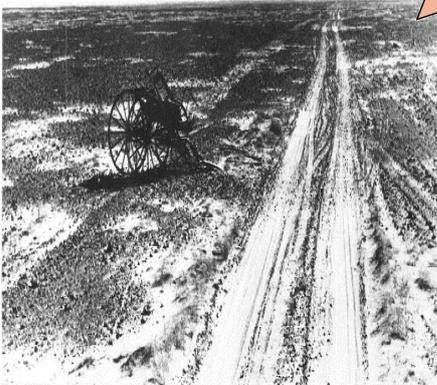
Final comments from questionnaires

A word cloud was constructed from descriptive words used by participants to describe any final comments about participating in the program (see Figure 4). The words express the great sense of gratitude for CBC community and the positive experiences and feelings evoked by involvement in CBC.



“It’s a tough journey”

Focus Group Participant

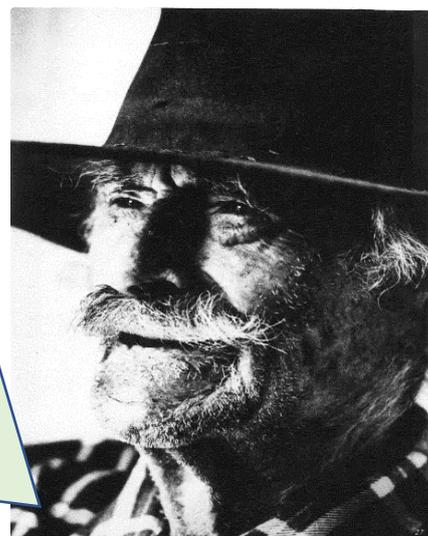


“The road, the journey, going into the unknown, from being somewhere where you know the terrain and you know what is going on, where you’re in control to a certain degree and then you are going out onto this dirt road which looks like it is leading to nowhere but clearly it is leading somewhere. Having that feeling that I don’t want to get to the end because you know what is there at the end but you really don’t have any choice but to continue putting one foot in front of another and going with it. It is all that desolation, fear of ‘oh my god where am I going?’”

Focus Group Participant

“This reminded me of my husband. There was this kindness in this person’s eyes. I’ll be there for you. I don’t know where I’d be without him. He’s funny. He makes me laugh when I want to cry. He’s not patronising or dismissive. He has that ability to make me laugh. And then I think, oh well. It’s not that bad. Everyone has got to die. This is a man when I was sick who would change my urine bag during the night so that I could get some sleep (crying). Who does that? He is just there. And then he says, ‘Are you well enough for sex yet?’ [I say] ‘Oh for god’s sake is that all you have on your brain?’ He says, ‘Come on darling, we love each other.’ So, he is really funny.” (laughing)

Focus Group Participant





“Chemotherapy is pretty harrowing and then it takes me weeks to get over it and then it is almost time for the next one. I can’t go to bed at night without looking at my diary for medical appointments. In between all the medical appointments, in that little space, I feel there is a cloud over the top of me, but I have got some freedom, I can do some flying. Soaring above the medical appointments. We went to Spain for six weeks. They couldn’t get to me. There was no one prodding me and poking me and sticking needles in - there was that breath that I could take. The freedom to be not a patient, a victim, - to be just yourself. We are more than our illness.”

Focus Group Participant

Although there were some similarities in the data between carers and those with a progressive life-limiting illness, there were clear distinctions in their experience, and so the data sets between carers and palliative care recipients were separated in order to highlight the perspectives of each group.

Carers

Carers clearly shared in the challenges and complex emotions associated with being a carer but expressed joy in simple family-related activities.



“My mum has lung cancer. Reminds me of mum at home when we were kids. I was always wanting to help her in the kitchen. We bonded over that. She always made special birthday cakes every year. So, I now do that for my daughter. She is 27 but she still wants me to make her a birthday cake. The last time I made a cake I felt it was therapeutic, I lost myself in making the cake.”

Carer Focus Group Participant

Most valuable part of the CBC program for carers

Carers identified a range of positive aspects of CBC, including social connection, non-medical togetherness in a safe environment, and giving meaningful structure to their schedule. The fact that these benefits were gained in a service that was free for participants added immense value of the CBC program for carers. The uniqueness of this offering meant that there was something safe and enjoyable that they could do together, without incurring financial burden.

No cost service with meaning: Carers placed great value on being able to attend CBC at no cost, whereas this was not raised as a factor for palliative participants. This may indicate that

carers carry more stress and worry over financial burden. The no cost service of CBC allowed them to enjoy the therapeutic benefits of CBC activities and services without the carer-guilt associated with spending money or doing something for themselves.

“It was probably that (1) it was free, and (2) it was available for both of us to attend and equally participate in. Some of the services that get offered to [loved-one] are just designed for the person with the illness, they are not set up for carers as such. But this is something that we can both do together.”

- Carer Interview Participant

“It's given me an opportunity to take time for myself when I would otherwise feel guilty about doing that for two reasons, financially and time wise, you know, um, I should be doing better as a Mum, you know, like I should be putting that towards the kids, at the time it was the kids or [loved-one]. So I guess it's, it's giving me the opportunity to do that without guilt and to actually have treatment, you know, like I'm having a massage or reflexology and actually being able to relax and not feel bad about having it as well.”

- Carer Interview Participant

Non-medical togetherness in a safe environment: Carers noted the importance of being able to enjoy the benefits of CBC together with their palliative loved-one. They also emphasised the incredible sense of comfort they found in being able to relax, knowing that their palliative loved-one was being looked after should they suddenly need extra care. This offered an opportunity for respite from caring in an otherwise relentlessly stressful carer role that is full of worry for the ongoing wellbeing of another.

“that we can both do it together, that's the most important part.”

- Carer Interview Participant

“Oh, it's really, really great ... everyone sort of is able to just relax a little bit. I guess I feel relaxed because I know that I'm not having to watch (loved-one) all the time and I get a bit of a break and I get a massage which is great.”

- Carer Interview Participant

“... and I know that she’s got support there, so if she has a panic attack or has any difficulties, I know she’s got people there to support her, while I’m busy having a massage.”

– Carer Interview Participant



“A chance to talk with people. I don’t get out much. I really like the art. Doing things that you haven’t done before. I find it quite freeing to be able to relax and not think too much about stuff. Express yourself without having to talk. Good having the dedicated time. It’s good to be around people. I go to manicurist lady to get some pampering. It is good having a massage. I hadn’t had one till I came here. Lots of new growth. Otherwise I would not have had the opportunity to do. Massage is very beneficial. We usually only go out for mum’s medical appointments. They are focussed on mum’s physical health. Here it is about wellbeing. It is a very different focus here from what we were used to at the hospital with the doctors. It’s more personal.”

- Carer Focus Group Participant

Social connection: Social connection had two general aspects. The first related to the building of friendships with peers who like them, did not want to have conversations focussed on illness. The comfort in socialising with people who were not going to ask, feel sorry for them, or treat them as an illness themselves was highlighted.

“Just that it's not about the sickness. No one mentions anything about that really, it's just something else that's different to focus on as opposed to being in hospital or at home.”

– Carer Interview Participant

“We are all going through a similar journey, so there's a shared experience”

– Carer Interview Participant



“This is what I want in my life. I want unity. I saw that as people together in unity. CBC is such a great organisation.”

- Carer Focus Group Participant

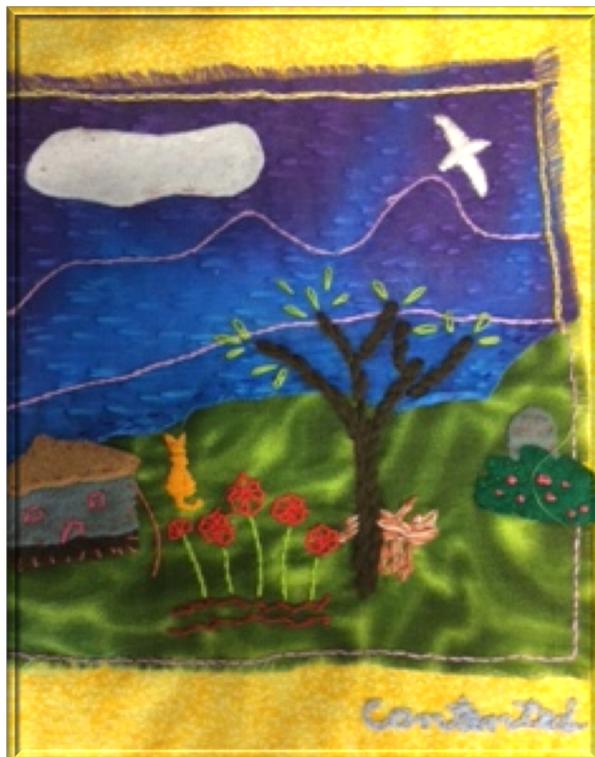
In addition, some carers described themselves as either shy and reserved, or socially avoidant and experiencing social anxiety. As a result of attending CBC, these carers noted that the program had helped them personally with their social shyness or anxiety, thus enhancing comfort with social connection. This further highlights the mental health risks associated with being a carer, particularly for those who are socially isolated or not linked in with support services. Other participants noted that CBC helped them to feel more than the sum of their caring role as it reminded them that they are a person with needs too.

“It’s been very positive. I was a bit shy, and I’m generally a shy kind of person anyway, so I was a bit reserved when I first started. I’d never had a massage or any of those touchy things, so I was a bit cautious to start with but now I’ve stepped right into it and I’ve really enjoyed participating in the activities.”

– Carer Interview Participant

“I guess I still, well, there are days when I maybe don't want to be around people or go out ... once I get here I’m okay, because the atmosphere's so light and no one is talking about anything miserable ... generally it helps me on those days, it makes me feel a lot better about things, especially if I've got my own stuff going on, like my world seems to get a bit small sometimes and then I come here and I get a bit of perspective. It's feels nice to see everyone having a good time.”

– Carer Interview Participant



“Everyone is in the same position at Care Beyond Cure. So, we are not different. Here you are accepted for who you are and what you’ve got. A place where you can be yourself. You don’t have to hide anything. I am more than a carer. I am a person.”

- Carer Focus Group Participant



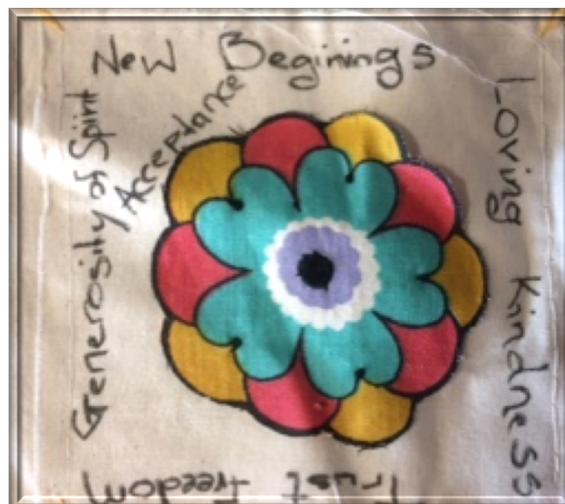
Structure and building confidence: Attendance at CBC helped carers to recognise the need to incorporate non-medical activities into their lives, given that medical appointments tended to capitalise on most of their time and outings from home. The day at CBC also helped participants to realise that they are physically capable of going on enjoyable outings, and this prompted them to venture out of the home for non-medical daytrips more often.

“I don't have much structure. [My loved-one] does because of the medical appointments, but it's nice to have something to look forward to as opposed to just knowing you have to go to the hospital every Friday ... it's just having somewhere to go.”

– Carer Interview Participant

“[My loved-one] didn't really like going out much ... she wasn't really interested in travelling anywhere before, but now we sometimes go out to other places just because she knows she's okay to go out for the day, that she'll be okay to be out of the house for the day.”

– Carer Interview Participant



Most challenging part of the CBC program for carers

Some carers indicated that going to CBC for the first time was anxiety provoking due to the unknown but communicated that they quickly found comfort in the space and with the people there.

“It was challenging probably the first day, because we didn’t know what we were going to experience – it was probably anxiety I guess, but once we got through that door and started participating in the activities, we couldn’t wait to go next time.”

– Carer Interview Participant

“Everyone is happy at CBC and very welcoming, they don't make you talk if you don't want to ... so we are comfortable enough to be coming, when usually we've avoided social things in the past.”

– Carer Interview Participant

Some participants also noted that they wished CBC either operated weekly, offered longer sessions (more than 4.5 hours) or was not run on the same weekday each fortnight. These perceived opportunities for improvement were reflective of the participants’ desire for more time in the sessions or more opportunities to attend CBC. For carers who happen to work one or two days per week, for instance, if CBC was on the same working day then this would preclude those carers from attending.

“Initially I wasn't going to it because I was working on the day. So, I mean if there had been one day one week and one on a different day of the following week. At least you could access one.”

– Carer Interview Participant

“I guess that's really what I'm saying is that there's not enough time in the time that we have. I would like more time ... I guess once a fortnight is a good amount of time ... but if it was weekly, we would come weekly.”

– Carer Interview Participant

It was also noted that waiting one's turn for the more popular activities (the physical therapies such as massage and reflexology) was problematic (participants sometimes missed out), and it was suggested that more than one therapist be available for providing these services.

How CBC shaped the palliative care journey for carers

Carers reported that CBC had a notable influence on their palliative care journey, and further, that CBC had a way of adding value and meaning to their lives beyond the actual time spent at CBC. Specifically, carers stated that CBC had balanced out an otherwise entirely medical experience and ushered in meaning and purpose to daily living, had relaxed the tone of palliative care making it more social, and had led participants to feel empowered to make autonomous decisions about death and dying, thereby increasing their death literacy.

“Care Beyond Cure, along with the Coffin Club has had a big impact, it's given us a better understanding of death and being prepared, so you start to make plans and get organised, so it's all really helped in that regard. It's given us back the power and control, and whilst we don't get to decide the death side of it, we get to decide how we want things to work out in terms of the funeral and things like that, and that has given us the freedom and power to make choices for ourselves.”

- Carer Interview Participant

“Well, it's sort of shaped it in the sense that it has put a more relaxed feel to it. There's a couple of ladies we know that go as well, and we sometime drive there together, and that has given her different reasons to contact them – you know 'are you coming next week?', so it's become a real social thing.”

– Carer Interview Participant

“He [husband] also goes to coffin club which is part of this group. He loves it. That’s freedom for him and it is freedom for me as well. I get a bit of alone time. He knows that I am safe for that couple of hours. He can be himself with a couple more of the fellas. He’s made me a coffin. We have accepted that death isn’t bad. He has his own time with his own friends. ... We’re prepared. The coffin club taught us to prepare. I don’t want my son to go through what I went through with mum. He will know what I want. He doesn’t have to run around like a headless chook thinking what song does she want? I think that is one thing this has taught us. Don’t be scared of death. It can be very daunting for some people. We need to talk about it more. I think death is still going to be traumatic for the people we leave behind but they don’t have to run around doing all these tedious things like what coffin does she want; does she want to be buried; does she want to be cremated? If that is all done, it is not so stressful for them. It needs to be talked about.”

- Carer Focus Group Participant



“It has had an impact. It would have been all medical otherwise, just medical every week. That's how it would have been ... [my loved-one] really likes the art aspect of this group, and the teacher there was encouraging her, gave her an art book to take home, and now she's started doing it at home as well because she's having so much fun doing it at CBC. So it's changed the way we are at home as well. Now she's got more purpose during the day when she gets up and decides to do her art for the day.”

- Carer Interview Participant



People with a progressive life-limiting illness

Those participants of CBC who are living with a progressive life-limiting illness (referred to here as ‘palliative people’ for brevity) indicated that their connection to CBC came via varied means, for example via the Coffin Club, seeing a flyer at a private service provider’s business, and via linkages with a therapeutic social support program.

Most valued components of the CBC program for palliative people

A number of benefits associated with CBC were identified by palliative people including the flexibility of the service, wellbeing promotion, and comradery and friendship.

Flexibility of the service: Palliative participants really valued the flexibility of the services and expressed great fondness for being able to choose and self-direct when attending. They liked the ‘no pressure’ approach of the staff and service and commented that this was a point of difference from other wellbeing programs for palliative people.

“I don't go to any of those other groups because they do things like ‘eating healthfully for cancer’. Would you be interested in that diet stuff? I want to eat cream cakes! Get the most out of life. Oh, I say blow that, I don't need that. I don't need somebody telling me how to live my life and that's what CBC doesn't do. At CBC, everything is very comfortable. You know you can walk in; you can do what you like. You don't have to do anything. I think that's one of the best things about CBC is that they've got a number of things that you can do, but nobody's trying to pressure you into anything. You can just come along and sit if you want to, you can probably come along and cry if you want to, but nobody does that, everybody is a bit too busy living.”

– Interview Participant



“Dolphins are very social, compassionate animals. They also help people. They are known for saving humans, saving dogs in the water. CBC is a social thing. Walk in and relax. First thing I do is to get a cup of tea and say hello to everyone. Sometimes I don’t want to do a lot of activities, I want to chat. Sometimes I want to switch off and do some art classes. It just depends on how I am feeling on the day.”

- Focus Group Participant



Wellbeing promotion: Palliative people attending CBC remarked at the notable sense of wellbeing they gained from both the CBC activities and the physical space within which CBC was held. This wellbeing was both psychological and physical in nature, providing a means for increased calm, greater happiness, and improvements in mobility as a result of the activities. Further to this, CBC was deemed a place that promotes a peaceful acceptance around death and dying.

“There is some sadness at Care Beyond Cure. We don’t all have good days but we are still accepted. That’s the time when you feel a little bit down. You come here and you are uplifted. Sometimes I feel that I am in a dark place and I come here and there is light and Care Beyond Cure can pick you up.”

- Focus Group Participant



“This one represents when you come to CBC you don’t feel alone. We are all growing. We are not withdrawing. We have come alive when we come here. People say, ‘You are dying.’ I say, ‘No everyone is going to die.’ At the moment I am living. I’m not dying. I try to stay positive every day, look to be positive. I don’t think about death. I’m not scared of death. So, at the moment I am living.”

- Focus Group Participant



“Medical is helping you physically. This is helping me mentally. This has taught me acceptance. We don’t all need psychiatrists. We need insight into what is happening to people. It is OK to feel down. Everyone has a bad day. If it is physical the doctor will give you a pill. This is uplifting for your mind. I do mindfulness. I found that a journey to open my mind. There is a light at the end of the tunnel. I have never believed in that sort of thing before. I find it relaxing. When I feel down, I do what she has taught us, because I suffer depression, so I don’t go to that dark place as often as I used to

I look at things differently now. I don’t see it as doom and gloom anymore. She’s taught me to bring things back to what is happening now. Not to worry about what happened last week or what is going to happen next week but living for today. Tomorrow is a bonus. I live in the day. Today is a good day, so enjoy it and don’t let outside doom and gloom come in and upset today. That has been a positive thing in my life. We are just here for a short time. We are on a journey of learning. Death is not doom and gloom.”

- Focus Group Participant

“It’s just nice to know you can get some peace”

– Interview Participant

“So, it's really nice to have a supportive place to go to, you know, just forget about all that other stuff ... it takes my mind off other stresses I guess. Everyone's really supportive and caring. It's a really nice space and atmosphere to be, to be in. It's been good to just get that feeling of wellbeing.”

– Interview Participant

“People are coming along, and they are happier, that could be a better outcome in as much that they're not taking anti-depressants etc. You don't have to be happy about dying, but you don't have to be unhappy about dying either”

– Interview Participant

“Because I'm finding that my fine motor skills are sort of declining, in that even when I'm eating a meal, I get food on the fork and then lose it before I get to my mouth. So, I've been trying to do craft activities that sorta keep my hands mobile. So, the art side of it's really good in that way.”

– Interview Participant

“...being able to get a massage. And yoga, but I’m the white man so it’s hard for me to do all that stuff. I’m a white man but I do what I can. But it’s really good.”

– Interview Participant

Comradery and friendship:

The sense of the common-bond palliative people found in sharing a space and activities with one another created a strong sense of comradery and friendship. Participants seemed to implicitly acknowledge illness as the commonality but recognised in each other the desire to keep on going and keep on enjoying things.



“They are very warm and kind and you can call them for help. That is everyone. The people who run it. The carers. The people who are sick. These represent freedom.”

- Focus Group Participant

“If you’re sitting at home on your own you think too much, but if you’re out there seeing other people who are having a harder time than me, then I think, ‘pick it up mate’.”

- Interview Participant

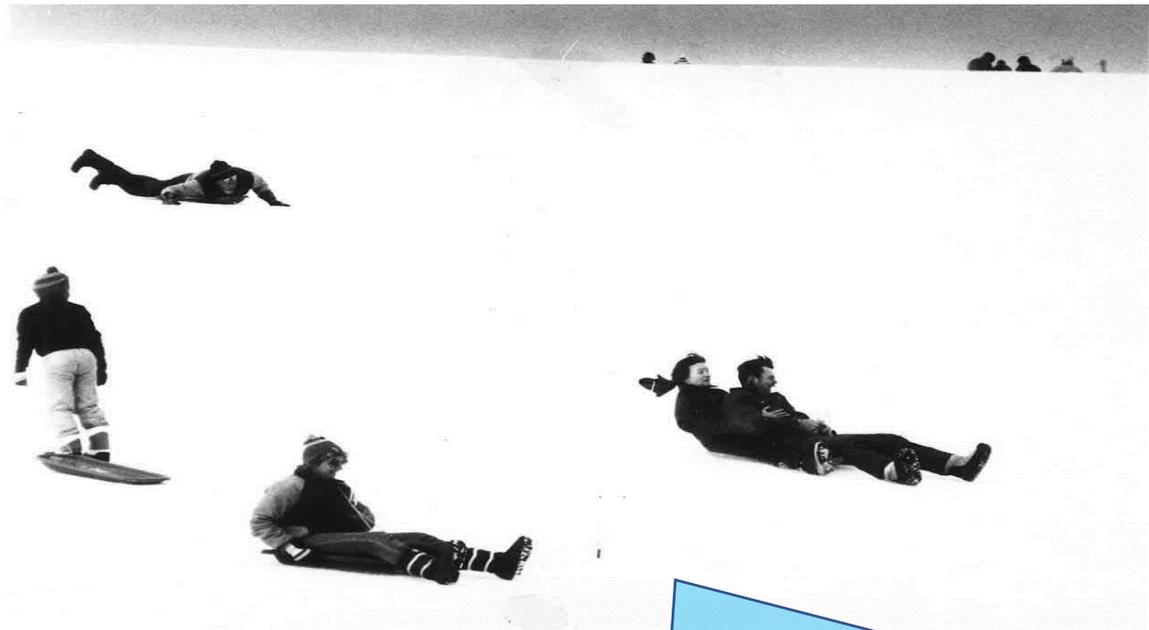
“The people there are just beautiful. You know, the people that go there, we are all on the same boat. And it’s a good boat. It’s a happy boat. And there’s dogs, and there’s a man singing.”

- Interview Participant



“I say friendship is the main thing. Everybody is just so comfortable with each other. Everybody has got life-threatening illnesses and it doesn't matter. Nobody worries about it, which is good. And no one whinges there.”

- Interview Participant



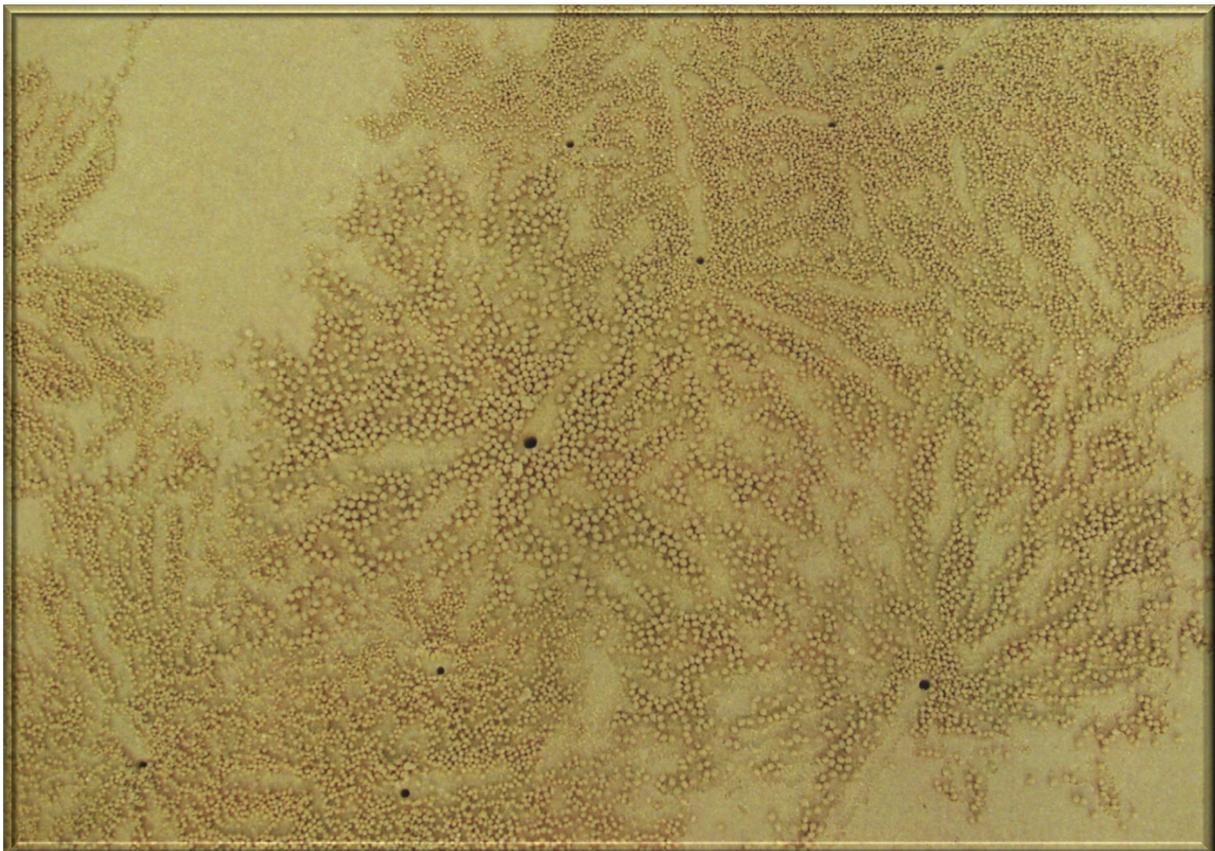
I didn't tell a lot of people that I was sick, for a lot of time. I kept it to myself. But here I feel comfortable. I know no one is feeling sorry for me. We're all in the same boat. It has helped me to grow and to accept that I am not the only one going through this. There is no judgement at Care Beyond Cure. Everyone is accepting of who we are. I am usually a very private person. This has opened me a little bit. It's been good. You know there is someone there for you other than immediate family. You don't want to tell immediate people how you feel because you don't want to upset them. Burdening them with your worries. Sometimes you lash out at the people close to you because you can't do things. Dependency is a very hard thing to accept because I have been very independent, used to do everything for myself and now he [husband] has got to do it for me.

Here I feel that you can talk to people and open up about how you feel. It's all learning. Care Beyond Cure has helped with that. It's all part of acceptance. You are not vulnerable any more. You are not alone. I am learning to accept help whereas before I didn't.

- Focus Group Participant

Crabs you can't see them. But under the sand they are all working together. They (CBC) represent individuals working together.

- Focus Group Participant



Most challenging part of the CBC program for palliative people

Palliative people struggled to find fault with the CBC program, however like carers noted that they would like the sessions to run longer to increase accessibility to more activities. Further, one participant commented that whilst the internal space of CBC was beautiful, accessibility of the building from the outside for people with mobility issues was somewhat fraught.

“I'd like to get into the mindfulness because I think that mind body thing, something I believe in, but I don't know a lot about, and with mindfulness it goes from 11:00 for about an hour sometimes, I just find it's hard. It's a balancing act. If you do mindfulness then you're probably not going to fit in some of the other services. So it's just juggling I guess, CBC is 10 till 2:30, but some days it just doesn't seem long enough.”

– Interview Participant

“The actual program is fantastic, but actually parking and getting in and out is a bit tricky because I can't walk very far. There's a long drive. And we're situated at the back of the building. The driveway is in quite bad condition, so I have to be really careful getting in and out of the car that I don't trip and that sort of thing but it's a beautiful space once you're in there.”

- Interview Participant

How CBC shaped the palliative care journey for palliative people

Participants remarked at the positive impact that CBC was having on their experience of being a recipient of palliative care. The shift of focus away from medical curing of illness, avoidance of death, to mere enjoyment of living was notable.



“CBC is just part of my life, And I enjoy it and um, I appreciate it. I really do appreciate it. It helps me and makes me feel wanted and cared for and that the services are there for me. You know, for once it's for me. Usually everything you do in the health system has to have a cure outcome, well this doesn't have a cure outcome and it's just for you to go along, enjoy it. It's just simply making my life a lot nicer.”

– Interview Participant

“[CBC] has eased it [the palliative care experience] and it's also made it possible to keep going. Even though I can't do a lot, I just love it.”

– Interview Participant

Participants also noted the sense of care and safety they felt in being in a supportive, non-medical environment with skilled helpers.



I know if anything happened, I know people would know what to do so my daughter wouldn't have to cope on her own. Here is an escape valve.

- Focus Group Participant

Cows getting a lick – a herd – you do get the help you need – it is very emotional, mental and spiritual. At Care Beyond Cure you'll get the love that you need and help. Playful. People being together. This feels like family. You feel like you have bonded. It represents a circle of friends that are all in the same position. We accept each other and don't feel sorry for each other. We are all going to die one day. I might get there quicker.

- Focus Group Participant



CBC Committee and Advisory Group

Members of the CBC Advisory Group (N = 1) and Committee (N = 2) were interviewed about their views on, and vision for, CBC. Collectively, their feedback and ideas described the rationale for CBC, its key characteristics and value, perceived barriers to broader and long-term implementation, and the future vision for CBC.

Rationale

The CBC group viewed the services of CBC as needed, highly relevant and of great benefit to the broader community. The program runs in the northwest of Tasmania which reportedly holds 22% of the state's population but is geographically isolated in terms of access to medical services. The group highlighted that CBC operationalised the non-medical dimensions of palliative care (emotional, social, and spiritual care) but also emphasised the care it provides to carers themselves, who were identified as often suffering more than the person with the life-limiting illness.

Characteristics and Value:

Committee and Advisory Group members underscored the non-medical element of care that CBC offers and suggested that the friendly, grass-roots, non-judgemental nature of the service was key to the level of joy and acceptance felt by its attendees. The grief care component of CBC (bereaved carers can continue to attend CBC for a further 12 sessions over a 12-month period) was also considered a significant community contribution and a much-needed resource. One of the successes of CBC was viewed to be the physical space within which it exists, as this was deemed to be a forum for the community to meet and support each other. Essentially, the idea was that CBC actioned the "community" in "community palliative care" and created a place and an avenue for forming and fostering connections. It therefore produced an opportunity to bring people together to share concerns, ideas, hopes and fears, and by doing so opened up the doors for conversation and change. Those changes may be emotional, attitudinal, or social. The central idea is one of providing a space for the community to come together and learn about each other's needs and seek to meet those needs from within its own informal structures. CBC therefore took a 'bottom-up' approach to meeting the needs of the community.

Furthermore, the ability of the service to meet the needs of a diverse group of people (everyone can, and does, walk away with something different) was considered a notable achievement. When discussing the value and contributions of CBC, the CBC group (committee and advisory members) shared the following comments:

“For every single symptom like this (referring to symptoms of medical illness) ... there is a psychosocial component. So, without fulfilling the psychosocial components we are never, ever going to satisfy the person. That is not going to be 100 percent good end-of-life care. So, Care Beyond Cure is fulfilling that part.”

- CBC Group

“It’s hard to quantify. I think the need for it is shown in the number of people who keep coming back, session after session, because if it wasn't worthwhile for them, they wouldn't come back.”

- CBC Group

“It's just fantastic that we're able to offer some comfort to people in their time of need and if someone walks away with a smile on their face, we've done our job for that session and for that person.”

- CBC Group

Barriers:

A number of barriers to the growth and success of CBC were identified. First, whilst the CBC group did not view themselves as existing in competition with anyone or any services (but in fact complementary to existing palliative care services), the group expressed surprise and dismay at the “gatekeeping” demonstrated by other organisations or services that might otherwise make referrals to CBC. Specifically, when CBC reached out to other services to offer their support and care for palliative people and carers, those services made decisions about the value and relevance of CBC on behalf of their patients/clients *without passing the information on* to these individuals for their own autonomous decision making. This

experience by the CBC group is reflective of the research detailed earlier, which described the paternalistic approach within many palliative care services (Grindod and Rumbold, 2018).

The gatekeeping practice was evidenced by the fact that no referrals to CBC came from formal palliative care services despite CBC making dedicated efforts to outreach to other services. A further disconnect between formal services (those focussed on cure and medical treatment) occurred when CBC felt the need to withdraw from the use of treatment focussed space for running the CBC program, largely due to the perceived stigma (by treatment providers) of having dying patients on their premises.

Second, as the current funding stream is limited to only a 12-month period, the group needed to funnel the money into the provision of services and were unable to allocate funds for advertising, education and awareness, and this clearly impeded their ability to gain referrals and enrolments. Furthermore, the group highlighted the difficulty in gaining funding for programs that provide non-medical aspects of palliative care.

Finally, the group hypothesised that community discomfort about death and dying impeded the conversations that could support referrals for CBC. It is noteworthy that in the qualitative data, CBC itself appeared to have a positive impact on increasing death literacy within its attendees, and this was a valued and appreciated aspect of CBC by participants.

Vision:

CBC group members had three main aims for the future of the CBC program. First, that the program be funded with lengthier funding streams (e.g. a three-year funding cycle); second, that subject to positive evaluation the program be rolled out state-wide; and third, that CBC continue to contribute to strengthening death literacy within Tasmania, thereby improving end-of-life experiences for all Tasmanians.

Discussion and Conclusion

This evaluation report has highlighted the changing landscape of palliative and end-of-life care in Tasmania, as well as the emerging role of compassionate communities in this space. The CBC program operates as a compassionate community and is offering extremely positive experiences and outcomes for attendees, both carers and those with a progressive life-limiting illness. The qualitative data produced a range of findings with attendees reporting overwhelmingly positive outcomes as a result of their involvement with CBC, with possibly the only criticism being that there was not more of it available. The most notable results from the data analysis are summarised as follows:

Key Learnings from Qualitative Data

- ✓ The journey through **palliative care is tough**, both physically and emotionally.
- ✓ Compassionate Community care is seen as something that **complements medical treatment** and emphasises the notion of palliative care into all of its domains (physical, social, emotional, and spiritual).
- ✓ CBC provides a **safe, nurturing, professional** and welcoming space where others accept you without judgement.
- ✓ CBC **promotes wellbeing** and provides a reprieve from otherwise unrelenting strain (attendees have a break, relax, catch their breath, feel happy and ‘normal’ for a short while at no financial cost).
- ✓ Comradery and friendship provide a **much-needed social support network** of acceptance and non-judgement (this social connection based on shared experience appears to ease the psychological and social pain associated with being ill or a carer).
- ✓ CBC has **enhanced death literacy** for participants (helping people understand and action end of life planning, e.g. Advance Care Plans).
- ✓ Carer **needs are strongly acknowledged and addressed** (CBC enables carers to receive attention for their own needs of relaxation and respite from responsibilities and being on constant vigilance for medical emergencies; also, with the bereavement component extended the care for carers).
- ✓ The CBC activities often had a **valuable mind-body connection** (many reported the activities improved their physical symptoms related to pain and mobility).

- ✓ Participating in CBC reminded attendees that **they are more than their illness** or their carer role (therefore encouraging them to maintain their individual and social identities outside of patient or carer roles).
- ✓ CBC promoted new avenues and opportunities for **growth and learning, self-expression and continued enjoyment in life** (by helping attendees to develop new skills and interests that motivated them to live with purpose and meaning, as well as, boosting their self-confidence in their ability to engage in new activities and adventures).
- ✓ CBC **empowered attendees with a sense of freedom and choice** (many felt their lives and bodies were controlled by medical treatments and appointments, but CBC fostered autonomy by enabling attendees to choose at all stages regarding attendance and the nature and extent of their participation).
- ✓ Attendees' need for the above-mentioned positive gains was so great that they all expressed **a desire for more** (the sessions to go for longer or for sessions to be run at twice the frequency, that is, weekly instead of fortnightly program runs).
- ✓ The CBC Committee and Advisory Group play an **invaluable role as social connectors** within Compassionate Communities.

The research question, “*how does the Care Beyond Cure program shape participants’ palliative care journey?*” was answered in the results section of this report with the main finding being that CBC de-medicalised the experience of the palliative person and returned some sense of balance or ‘normalcy’ to their life. Although this evaluation was exploratory in nature due to the uniqueness of the program, the results nevertheless suggest that participants in a palliative realm (carers included) are seeking to retain autonomy, a sense of self, freedom in living, and joy (through bonding, engaging, novelty, and choice). CBC provided avenues for these things within the palliative care journey, thereby easing the stress and burden associated with the medicalisation of one’s life and ending.

The results of this evaluation show that CBC has demonstrated meeting Kellehear’s (1999) goals of Public Health Palliative Care, namely, creating supportive environments; strengthening community action; and developing personal skills. Having wider social networks increases the possibility of influencing place of death and use of palliative services.

Future Research

The current evaluation was exploratory in nature and as such a larger-scale evaluation would be ideal in order to capture a bigger and therefore more definitive data set. A comprehensive investigation could include changes in Death Literacy using the DLI Scale and network analysis within compassionate communities to assess their impact. The recent emerging literature on Compassionate Communities in Australia and barriers identified in the CBC research, indicates a need for greater service reorientation of formal palliative care services to engage with communities. There are still sections of medical services that feel they have failed if cure has not been successful and a silence exists about death and dying. The Compassionate Communities research reviewed at the beginning of this report suggests that professional power and expertise derived from the medical model undervalues the role of community members as having knowledge, lived experience and expertise to determine their own goals in end-of-life care. Further, traditional professional palliative models view referrals to community resources as “risky” (Rumbold et al., 2014). It could be argued that it is risky *not* to engage community resources in end-of-life care. The barriers identified in the previous section in this report require further investigation, in terms of how successful partnerships between formal services and informal grassroots care networks at end-of-life can be developed and promoted.

The researchers from this current evaluation report from Monash University propose that the Tasmanian Government consider funding a PhD scholarship to undertake this research. Australian researchers are world leaders into Compassionate Communities and this research has been greatly accelerated through PhD studies at University of Western Sydney and La Trobe universities.

Concluding Remarks

The present evaluation of the CBC Compassionate Community demonstrates the remarkable ability of ‘grass-roots’ community of care models to effectively cater for the diverse needs of its own local community. Our findings support the Compassionate Communities’ perspective that communities experience end-of-life as a social event, not as a medical event primarily managed by professional health services. The findings show how communities, with adequate support and funding, have the potential to provide an extraordinary level of care and support from within themselves. Further, the research highlights the value in affording communities the opportunity to investigate their own needs and offer their own solutions and resolutions.

The vision and leadership, not to mention the unpaid work, provided by the CBC Committee and Advisory Group, should not be underestimated. Their commitment to CBC has played an invaluable role as *social connectors* and contributed to the success of the program.

Nevertheless, the success of Compassionate Communities is dependent on broader support, backing, and engagement from formal medical and palliative organisations. Palliative care is a shared responsibility requiring involvement from both professionals and informal social structures. Further, there is widespread agreement that good quality care extends well-beyond merely providing medical treatments, but attends to the whole of the person, and that this is for the greater good and wellbeing of the individual, as well as, the entire community.

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Appendix A – Post-session Questionnaire

CARE BEYOND CURE EVALUATION 5/02/19AGE BRACKET: (PLEASE CIRCLE) Under 40 40 – 49 50 – 59 60 - 69 70 plus GENDER: _____

Service/Activity	if Tried	Why Did You Choose This Service/Activity?
Massage Neck & Shoulder		
Oncology Massage		
Reflexology		
Art – Try Me Table		
Manicurist		
Mindfulness		
Wrap Me in Memories		
Tai-Chi		
Delta Dogs		
UFO Drums		

Reflecting on how you were feeling before you came today, has attending Care Beyond Cure made a difference to how you are feeling now? - physically, emotionally, spiritually, socially?

	1= No difference 5 = Some difference 10 = Big difference
Physically	1__ 2__ 3__ 4__ 5__ 6__ 7__ 8__ 9__ 10
Emotionally	1__ 2__ 3__ 4__ 5__ 6__ 7__ 8__ 9__ 10
Spiritually	1__ 2__ 3__ 4__ 5__ 6__ 7__ 8__ 9__ 10
Socially	1__ 2__ 3__ 4__ 5__ 6__ 7__ 8__ 9__ 10

What did you like most about today?

What did you like least about today?

Any other comments or suggestions?

Appendix B – Semi-structured interview for CBC participants

Thank you so much for agreeing to participate in this interview, we are so grateful for your time and contributions to this research. I'm going to ask you a series of questions about your experience of Care Beyond Cure,

- If any of the questions don't make sense to you, please ask me to rephrase it for you or explain further.
- If at any time you feel too unwell or tired to continue, please let me know and we can schedule another time to talk or finish the interview.
- Are you okay to begin now?

Questions about CBC

1. What initially drew you to attend the Care Beyond Cure Program?
2. What has the experience been like for you?
3. What have been the most valuable parts of the program?
4. What has been difficult or the most challenging parts for you?
5. How has Care Beyond Care shaped your palliative care journey?
6. What effect has Care Beyond Cure had on other parts of your life?
7. What would you change to improve the program?
8. Is there any advice you would give others about Care Beyond Cure?
9. Is there anything I haven't asked you about, in terms of Care Beyond Cure, that you would want me to know or understand?

Appendix C – Semi-structured interview for CBC Committee Members

Thank you so much for agreeing to participate in this interview, we are so grateful for your time and contributions to this research. I'm going to ask you a series of questions about your experience with Care Beyond Cure,

- If any of the questions don't make sense to you, please ask me to rephrase it for you or explain further.

Questions about CBC

1. As a committee member, what vision did you/do you have for the Care Beyond Cure program? Why?
2. From your perspective as a committee member, what do you believe has worked well with regard to CBC?
3. What new things have emerged over the course of delivering the CBC program? What has surprised you?
4. What barriers and challenges have emerged and how have these been dealt with?
5. What value do you hope the program offers for end-of-life care?
6. Is there anything I haven't asked you about, in terms of Care Beyond Cure, that you would want me to know or understand?