

## **Annual Report**

2018 - 2019



## Message from the Chair.

The past twelve months has seen plenty of productive change in our service. With change, often comes several sad farewells and new people to welcome to the organisation. Firstly, a heartfelt thank you to CEO Molly Carlile AM who resigned in September 2018 after two and a half years of service. Molly's passion and expertise contributed greatly to how we improve the quality of life of individuals, carers and families. Thank you also to Julie Murphy who stepped into the CEO role while our recruitment process took place. Julie's steady leadership during this period of adjustment was greatly appreciated by the team and the Board.

I am extremely pleased to welcome new CEO, Kelly Rogerson who joins Palliative Care South East with extensive health services management experience, a strong leadership background and a passion for top quality patient and family care. Kelly has only been with us since April and already we've felt her influence uniting our teams further and embedding a culture of excellence.

This year, a further two appointments were made to the Board which saw us welcome Michael Whelan and Kenneth Parsons. Michael is a director and financial executive with broad experience in all aspects of compliance, accounting, auditing and financial management. Ken is also a senior finance executive with extensive experience in financial leadership and management.

In governmental updates, we were pleased to be granted ongoing funding from Better Care Victoria to enable our Early Palliative Intervention Clinic to continue in 2018/19. This was in large part, attributable to the sustainable model of practice and positive outcomes demonstrated by our carers and reported by our families. Thanks to all involved, we look forward to the continuation of this important initiative.

Finally, without this team of dedicated people, our service would simply not function. An enormous thank you to our PCSE volunteers. Whether you contribute two hours of service or many days of your time each year, your support is invaluable. Your care contributes to family support at a time of great sadness, you drive our clients to and from appointments and amongst many other things, offer bereavement support alongside our trained clinicians. We are indebted to these generous people, all 54 of you. We look forward to working with you again in 2020.

On behalf of the team at Palliative Care South East, I wish you and your loved ones a safe and joyous summer break. I look forward to catching up with many of you in the new year.

Barry Small

Barry Small

Chair, Board of Directors



## Message from Palliative Care South East Chief Executive Officer Kelly Rogerson.

Firstly, thank you to Barry and team for the warm welcome to Palliative Care South East (PCSE). It's been a joy and privilege to meet and work with many of you since I joined back in April. To those I'm yet to meet, I look forward to doing so very soon. I'd also like to acknowledge that as a service, at PCSE we work on the traditional lands of the Bunurong and Wurundjeri People and pay my respects to elders past, present and emerging.

I want to take this chance to extend my gratitude to former CEO Molly Carlile AM and interim CEO Julie Murphy, whose collective leadership and dedication allowed the hardworking PCSE team to flourish.

2018/19 saw our service provided with continued funding thanks to the Department of Health and Human Services to support our workforce, operations and deliver care to the growing population in need of palliative care. In addition, we received funding in the form of infrastructure grants to support the purchase of new vehicles and IT equipment, both of which are vital to our daily operations.

A significant development for the sector occurred this year: the implementation of Voluntary Assisted Dying in Victoria in June. At PCSE we implemented practices to enable this choice for our patients, ensuring our community and staff were prepared to enable the process. We make many choices in life, and death should be no different. We are proud to be able to offer this option to our patients during a time of need.

Keeping our staff safe and well supported is at the centre of our organisation. We remain committed to providing the tools that enable PCSE staff to do their best work. This commitment is extended to the safety and wellbeing of our volunteers. Naturally, the dedicated workforce at PCSE are living examples of our values of respect, innovation, integrity and enablement. Our staff continuously put people at the centre of what we do, supporting those with life limiting illness to live well. I have seen this exemplified when staff and volunteers pour their attention into their work. Choosing to work in palliative care, to be with people at a time when they're most in need takes a special kind of person. And we're lucky to have a team full of them!

However we do not work in isolation. PCSE works in partnership with the community by interacting with general practitioners, acute public and private hospitals and aged care facilities every day. Our health care work also includes a focus on pastoral care, allied health and specialist nursing care; all of which are supported by a dedicated workforce of administrative support staff who enable the service to run smoothly.

So thank you to you all, and bring on more challenge and success supporting clients and their families in 2020.

Best wishes,

Kagaza.

**Kelly Rogerson**Chief Executive Officer

### Corporate Governance Statement.

Each Director has the skills and experience necessary for the oversight and leadership of the company. As a team, the Board of Directors brings together a broad range of qualifications and experience in health care service delivery/management, finance, accounting, sales and marketing, information technology and community development.

The Chair is responsible for leading the Board, ensuring Directors are fully briefed in all matters relevant to their role and responsibilities, facilitating Board discussions and managing the Board's relationships with the Chief Executive Officer.

The Chief Executive Officer's role is to implement the Board's strategic plan and drive the organisation's performance, ensuring we are always providing the best possible care for our clients and the best possible work environment for our staff.

#### Role of the Board

The Board of Directors provides strategic guidance and oversight of our organisation playing a key role by setting the vision, mission and values by which we operate. The Board play an integral role in setting the future direction of PCSE, mindful of the constantly changing environment in which we provide care. Our Directors are all volunteers and commit a large amount of time, effort and energy for the benefit of our local community.



Board Chair – Barry Small GIA (Cert) Board member since October

A broad perspective of organisational governance, strategy and risk management built over many years' experience in government and private enterprise.



Catherine Lengyel GAICD, AFCHSM, MAASW Board member since October 2017

Experience in development and implementation of clinical governance frameworks in human services and health care organisations. Substantial experience in the governance of mission based and notfor-profit organisations.



Emeritus Prof. Margaret O'Connor AM

RN, FACN, MAICD, MPCNA

Board member since April 2018
Lengthy experience
in palliative care
with a wide range of
skills including clinical
management, leadership
and governance,

education and research.



Kenneth Parsons CPA. BComm

Board member since May 2018

A senior and commercial finance leader with extensive experience in all areas of finance combined with excellent operational business understanding.



Michael Whelan CPA, GAICD

Board member since May 2018

A highly motivated professional director with extensive experience at both board and senior management level.



Natalie Sullivan

Joined as Board member October 2017. Resigned October 2018.



**Alison Smith** 

Joined as Board member April 2018. Resigned February 2019.



Tanya McParlane

Joined as Board member April 2018. Resigned March 2019.

## Service Operations Report

#### CONTACTS







**GENDER** 

**AGE** 

23% 71% 4%

0 - 34



Australia

**United Kingdom** 

Italy

Vietnam

India

Sri Lanka

Croatia

Cambodia

Germany

**Mauritius** 

**Netherlands** 

Greece

China

**New Zealand** 

Indigenous Australian

## **DIAGNOSIS**

MALIGNANCY

NON-MALIGNANT

#### **TOP REFERRAL SOURCES**

Acute Hospitals (Public)

Acute Hospitals (Private)

0%

**Palliative Care** Inpatient Unit

#### **LGA**









#### Volunteers

Our volunteers are the glue that helps keep Palliative Care South East together. This year was no different with the volunteers contributing right across the organisation.

Whether it be family support for bereaved families, promoting palliative care in the community or preparing folders for clients and carers, we could not work with the community to the level we do without their support.

Our volunteers come from a range of backgrounds and have been with the organisation for different lengths of time, but they all bring energy and shared passion for helping our clients and providing this important service for the community.

Pleasingly, our numbers are growing. This year we have a total 54 registered volunteers, many of whom contribute to family support, drive our clients to our clinic and appointments, as well as assist our clients and carers in the clinic with concierge services and support.

One of our volunteers, Natalie Irvine is this year celebrating 16 years as a Palliative Care South East volunteer.

A trained nurse by profession, Natalie is the embodiment of our volunteer program - a multi-talented, empathetic and hard-working person who has been an ambassador for our organisation, a driver, a companion for clients - she even sings in our choir at remembrance services.

Natalie decided to volunteer after seeing the care given to her sister-in-law through palliative care. She provides valuable support as a client support volunteer, visiting clients and families in their homes, taking clients out on 'little adventures' that often end up in a new location.

"I've been to all different places of Melbourne, places I wouldn't' ever have gone to. If we see a road I don't know what is down there, I say 'let's go down there'. It enviably ends at a lovely cafe, with coffee and cake. We chat and just have a good time," Natalie explained.

Natalie says she sees her role as being the steady presence for clients as they go on the journey together.

"Most people are very stoic about the situation they are going through. They can talk about things they can't talk about with their families, their fears or the situation they are currently in. When families say, 'oh you can't talk about that', we provide a listening ear, we are there to listen and talk about what is on their mind."

As well as providing support to clients, our volunteers also provide PCSE with a variety of support through regular bereavement groups, providing office assistance, preparing folders for clients and carers, as well as capturing the life history of our clients through the Sharing My Story program.

Without the support of our volunteer team, we could not provide the complete service offered to clients and their families.

After 16 years of helping her community, Natalie says she knows she is making a difference.

"People often say, 'I don't know how you could do that'. Well its very rewarding and the range of roles we do is immense."

"It's something I knew that once I started volunteering, I would never stop."

"I know I'm useful, I know what I'm doing. I get satisfaction from it, and I know people appreciate it," Natalie concluded.





#### Remembrance Service

Twice a year, Palliative Care South East conducts a Remembrance Service to provide support and comfort to the loved ones of Palliative Care South East's clients.

Led by our Pastoral Care worker Barry Whelan with the assistance of our Music Therapist, Cherie Baxter the services are held in May and November, for invited family and friends to remember their loved ones and celebrate their lives in a supportive environment. Both our staff and volunteers play an integral role in supporting client families at these services and throughout the year.

During 2018-19 we were able to make a number of improvements to the service including formalising registrations with name tags for attendees, updating and reformatting the service booklet, and for the first time provided introductions to each live music performance.

We are excited to see the continual evolution of the Community Singing Group, providing a focal point for the proceedings. Based on participant, staff and volunteer feedback we also continued to improve the readings and songs delivered.

Our services continue to be well supported, with a total of 52 people attending the May 2019 service, representing 14 client families.

We were pleased to receive overwhelming positive feedback from guests. At May's service guests told us;

- 66 Keep up doing the things you do; it means so much to us. Big Thanks! 99
- 66 Just keep it up.
  Thank you for your efforts and the good work you have done.
- 66 As human beings, we need a constant reminder to move on, and these services are very helpful to take us out of our state and remind us that the deceased will never be forgotten.





Art and music therapy are two important parts of our service at Palliative Care South East, in line with our vision to help people with life-limiting illness to live well. Both art and music therapy have been shown to relax patients and their loved ones while also enhancing quality of life. Many people reporting less pain symptoms and improved sleep when they have enjoyed this kind of gentle activity.

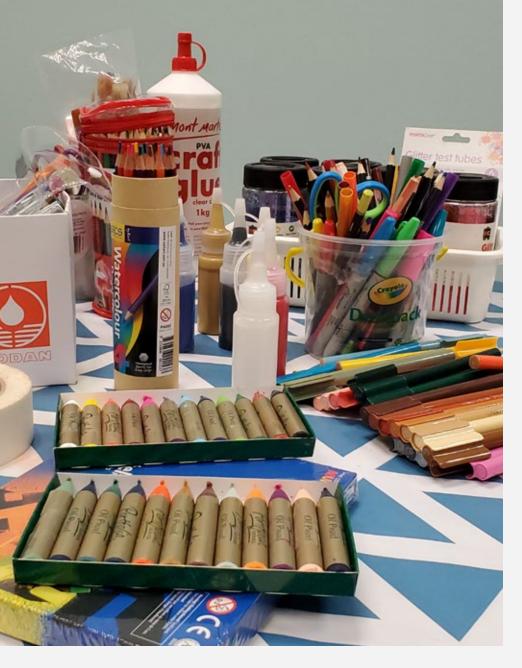
In these articles, we catch up with our Art Therapist Susanna Wyers and Music Therapist Cherie Baxter to hear first-hand why both professionals are so passionate about their work, and how their careers led them to join PCSE.

## **Art Therapy**

My original interest in Art Therapy stems from my own background in art. I have been a practicing artist for 25 years and understand how art can be a soothing and therapeutic experience. In my artwork I use symbolism to explore personal narratives. This led to an investigation of psychoanalysis and seeing the importance of visual language to better understand ourselves and the human condition.

This lived experience of knowing the therapeutic potential of art making and my exploration of symbolism with its links to psychoanalysis resulted into a lightbulb moment; I wanted to be an Art Therapist to bring these two keen interests together!

This epiphany drew me to study a Master of Art Therapy at La Trobe University. The course involved studying counselling skills alongside art therapy for adults, children, groups and



families. A crucial element underpinning each of these disciplines is the use of a Trauma Informed Art Therapy Practice, that is how someone's lived experience may impact their daily life.

Terminal illness and impending death can be a traumatic experience for both the patient and their loved ones. This experience can bring up previous or unresolved traumas. Most traumas are non-verbal and are registered within the body through the senses. Art making requires no words and the actual art materials offer a sensory experience which can gently access and help to heal trauma. Art therapy is unique in that it can offer both an escape from and exploration of thoughts and feelings during palliation. My main role is to develop a trusting therapeutic relationship with clients through art making.

My role involves working with adults, families and children using a client-led approach. The type of art intervention varies greatly based on the individual and may include, painting, drawing, clay modelling, craft, knitting and crochet. Occasionally a client may prefer not to create art themselves but instead watch me paint. These clients report that watching the painting process as a soothing experience, providing an opportunity for quiet reflection.

Many people find talking about illness and death confronting, especially when children are involved. I use art making to help develop and sustain therapeutic relationships between children and parents. Art also provides a safe space for children to express themselves. What someone may struggle to say verbally is often easier to express creatively.

Working as an art therapist with palliative care clients is emotionally taxing but also incredibly rewarding. I feel honoured that clients trust me to share their experiences during a vulnerable and special time of their lives. It is satisfying to witness how the art making process can provide therapeutic assistance during challenging times.

I recall working with a terminally ill young mother who spent her last weeks in a palliative care ward. She was coming to terms with her death, however, her husband could not accept the situation and he did not want their children to know the reality that awaited their family. I had worked with this patient for about month. She enjoyed art therapy and reported that it offered her a pleasant escape and gave her some relief from her pain while she created art.

During what would be her last art session she asked if we could create an artwork together, as her illness had left her partially paralysed and she needed help with the finer details. This final piece was a calm and peaceful painting. It was a water scene. On the shoreline stood a female figure looking out over the water with her back towards the viewer. The figure cast a long shadow back on shore, which subtly replicated a ghost like shape. When the session finished, the patient's husband entered the room, he sat next to his wife and looked at the painting. The next day he brought their children in to the hospital. He softly expressed his deep sadness that his wife was leaving them.

After her death, the husband told me that the painting is now framed and displayed in their home so he and the children see it often. He explained that the artwork gently allowed his wife to express that she was dying and that she was ready to die, and it provided the opportunity for them to say goodbye before her death.

\*Thank you to the patient's family who generously granted permission for us to tell their story.







## Music therapy

I was an active musician playing piano, cello and singing in choirs, with a separate interest in allied health when I attended a University of Melbourne open day in late high school. It was a formative time which would shape my future. It was exciting to find out about music therapy, a profession that combined my passion for both music and health.

I went on to complete a four-year music degree at the University of Melbourne, majoring in music therapy. The degree spanned performance, ensemble, music language, music history, group music education and music psychology in addition to music therapy subjects and practicum. I later completed a Graduate Diploma in Guided Imagery and Music and the Graduate Certificate in Specialist Palliative Care.

These days, my work involves visiting clients and their families at home to provide individualised music therapy sessions. Together, we discuss their current needs and music preferences, select what kinds of music we will share and the ways we will each participate. This may involve live music making such as singing and playing instruments or listening to recorded music together. I am always informed by where the client and family members are at in their illness and bereavement trajectory and whether they are aware of the next steps. Music therapy can involve discussion, reminiscence, learning relaxation skills, creating lyrics, writing a new song, recording music and documenting life experiences in a music biography.

My work is most satisfying when I receive feedback from family members saying they will treasure a music biography and used sections of it in their loved one's eulogy. I once worked with a client who had Motor Neuron Disease (a progressive neurological condition) helping him to sing when he could no longer speak. I've enjoyed moments of fun, play and interaction with people who had previously been withdrawn and demoralised by illness and loss. A bereaved parent I worked with learnt to relax and sleep better following our music therapy sessions.

A highlight of 2019 was the Music Matinee Concert presented by PCSE in collaboration with the Centre of Care and Wellbeing to enhance the community of support for bereaved people. Ron Webb, an 81-year-old gentleman and current PCSE client sang with me and my guitar accompaniment. Ron was very nervous about performing but reported he was very glad he did it.

Speaking about his experience of music therapy, Ron said: "At the end of the day I thought "I may as well give it a go. I don't know anybody". I heard some good artists there on the day. I always thought I could sing when I was a kid. When I first started the singing lessons [as part of his music therapy] I had no idea of doing any such thing. I have never performed before in my life. I follow the music at church and sing all the songs, but music therapy has helped me slowly but surely. I feel like I'm starting to achieve something that I've always wanted to do. Singing makes me relax. It takes away any inhibitions. It takes away the quietness of the room. It's been good. It's dug me out of a hole." You can't ask for much more job satisfaction than that!

<sup>\*</sup>Ron kindly gave us permission to share his experience of music therapy.



## Dr Ruth Redpath Scholarship

Thanks to funding from the Dr Ruth Redpath Scholarship, named in honour of Dr Ruth Redpath AM who was the founder of our service, PCSE was proud to support our staff member, Collette Chaplin, to complete two modules within her Post-Graduate Diploma in Palliative Care at Flinders University 2018. The topics studied were Paediatric Palliative Care and Oncology for Palliative Care.

Collette found the first module stimulating learning about the ways in which palliative care is different for children. For starters up to 30 per cent of paediatric palliative patients have cancer, compared to the spectrum of disease with adults. Parents and siblings are more involved as decision makers and care-givers, The developmental factors such as age influence the child's ability to understand illness and death, contributing to their ability to communicate and actively participate in decisions about their end of life care. Many doctors wish to stay involved with their child patients who end up in palliative care and the needs of the extended family must be considered when planning care for child patients. Finally, grief in parents who've lost a child is understandably expected to be severe, complicated and often prolonged.

Upon completing this module, Collette joined the Victorian Paediatric Palliative Care Programme at Royal Children's Hospital (RCH), led by Jenny Hynson. She was invited to spend a voluntary day per week for three months embedding with the team to better understand their service, taking these learnings back to colleagues at PCSE.

Within the catchment area serviced by PCSE we have young clients in our service, and Collette reported "this experience (at RCH) was invaluable to enable me and my colleagues to support this unique group of patients".

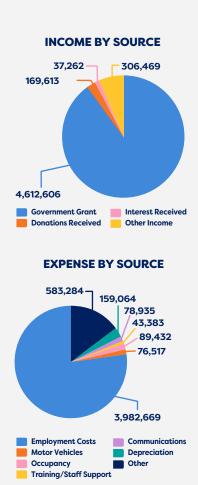
Collette's second module focused on oncology for palliative care, looking at the staging of varying cancers and at their different chemotherapy/treatment regimens that are offered for metastatic cancers.

Speaking about her experience, Collette said, "This module enhanced my understanding of the classifications of many of the cancers that patients supported by PCSE are diagnosed with. I now have greater knowledge of the treatments they are offered which has helped me to understand why each patient has their unique treatment plan and why some are not offered certain treatments. This has helped me to be able to more effectively give informed answers to the questions that many of my patients have after visiting their oncologist."

Dr Ruth Redpath Scholarships are open to all PCSE staff to further their education in areas that support PCSE's service. We look forward to continuing this initiative in 2020 and beyond to recognise the power of knowledge and history in the palliative care journey.

### **Financials**

Revenue	FY2019	FY2018	FY2017	FY2016
Government Grant	4,612,606	4,480,012	3,822,368	3,560,030
Donations Received	169,613	31,822	41,983	35,003
Interest Received	37,262	42,439	41,576	63,494
Other Income	306,469	297,125	273,809	66,600
	5,125,950	4,851,398	4,179,736	3,725,127
Expenses				
Employment Costs	3,982,669	3,551,351	3,303,074	3,166,246
Motor Vehicles	76,517	65,816	66,408	71,072
Occupancy	89,432	85,916	88,388	83,415
Training/Staff Support	43,383	28,883	32,484	62,514
Communications	78,935	69,450	55,553	47,919
Depreciation	159,064	126,148	102,187	85,511
Other	583,284	687,032	424,530	404,268
	5,013,284	4,614,596	4,072,625	3,920,945
Net Surplus/(Deficit)	112,666	236,802	107,112	(195,818)



#### **Donors**

Thanks to the generosity of our wonderful donors Palliative Care South East is able to extend the level of service we provide to our clients, carers and their families. We are most grateful for this support and encourage members of our community to help us in any way they can.

#### List of Donors

Rose Hall
Charles Choong
Don Moyes
Ashley Smith
Pauline Grey
Jennifer Jellett
Judy Wills
Trish O'Donovan
My Lan Ly
Molly Carlile
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Norman Remedios
Michael Green
Norina Giaccotto
Emanuele Busacca

## Clubs & Organisations

Dandenong Christian
Reformed Church
Narre Warren Uniting Church
Op Shop
Berwick Opportunity Shop
Inc
City of Casey
Casey Cardinia Foundation
Department of Health and
Human Services

# Family & Friends of the late:

Saide Haidar Chris Thomas George & Sharon Keady Gabby Moretti

#### How you can help

#### **Financial Donations:**

Your generous donation, no matter how big or small, will help us to continue to support our community by providing care to those living with a life limiting illness and their families and friends. Our services are provided free of charge. You will be helping us to:

- Provide in-home specialist nursing care
- Provide 24 hour support
- Grief and bereavement counselling
- Occupational Therapy
- Social Work
- Music Therapy
- Spiritual Care
- · Equipment
- Trained volunteers

Help us to do more by donating today. There are many ways to donate:

- Single donation
- Donation in memory
- · Regular donation
- Bequest in your Will

Go to our website – www.palliativecaresoutheast.org.au or call 03 5991 1300 to donate today.

Palliative Care South East is a registered charity. All donations over \$2 are tax deductible.

#### Volunteering:

PCSE was founded by volunteers back in 1984. The philosophy of the early founders lives on in our volunteers. We could not fully support our community without the help of our volunteers.

Become a PCSE volunteer and help your community. We provide full training for all volunteers, with regular meetings and outings to provide ongoing support.

To find out more or to join our team, contact our Coordinator of Volunteers:

T: 03 5991 1300

E: reception@pallaitvecarese.org.au

W: www.palliativecaresoutheast.org.au and follow the links to our Volunteers page.

#### **Corporate Sponsorship:**

PCSE wants to partner with you to make our community stronger. By providing financial support, you can support our scholarship program, sponsor an event or make a regular donation to help purchase much needed equipment.

As a local business, your organisation can also provide non-financial support. We provide services to our clients and their families in their homes. Families caring for people with a terminal illness often do not have the time to carry out day to day activities that we take for granted. It could be lawn mowing, a haircut, cleaning, odd jobs – anything that will help our community to feel cared for.

Contact our office to discuss how you and your staff can help us to help our community.

Email: reception@palliativecarese.org.au or phone 03 5991 1300



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Palliative Care South East acknowledges the support of the Victorian Government, South Eastern Melbourne Primary Health Network and Better Care Victoria.





Palliative Care South East acknowledges the Bunurong and Wurundjeri people as the traditional custodians of the land and we pay our respects to the Bunurong and Wurundjeri Elders, past, present and emerging.