



Barwon  
Health

# Establishing a volunteer based Dignity Therapy service

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**Barwon Health Palliative Care**

PCA Conference 2 September 2015  
Concurrent Session A5 - Allied Health

# My colleague in absentia

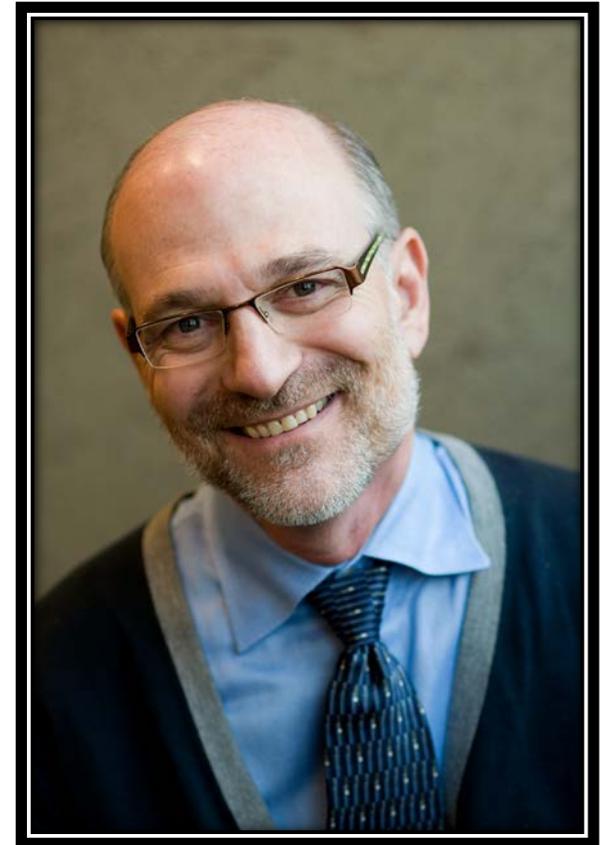


# Dignity Therapy - principles & praxis



# Dignity (and the work of Prof. Harvey Chochinov)

- Dignity a critical factor in patient perceptions of quality of life and thus will to live
- If dignity worth living or dying for, then worth researching
- ➡ Evidence based understanding dignity
- ➡ Model for how to enhance & protect dignity at end of life

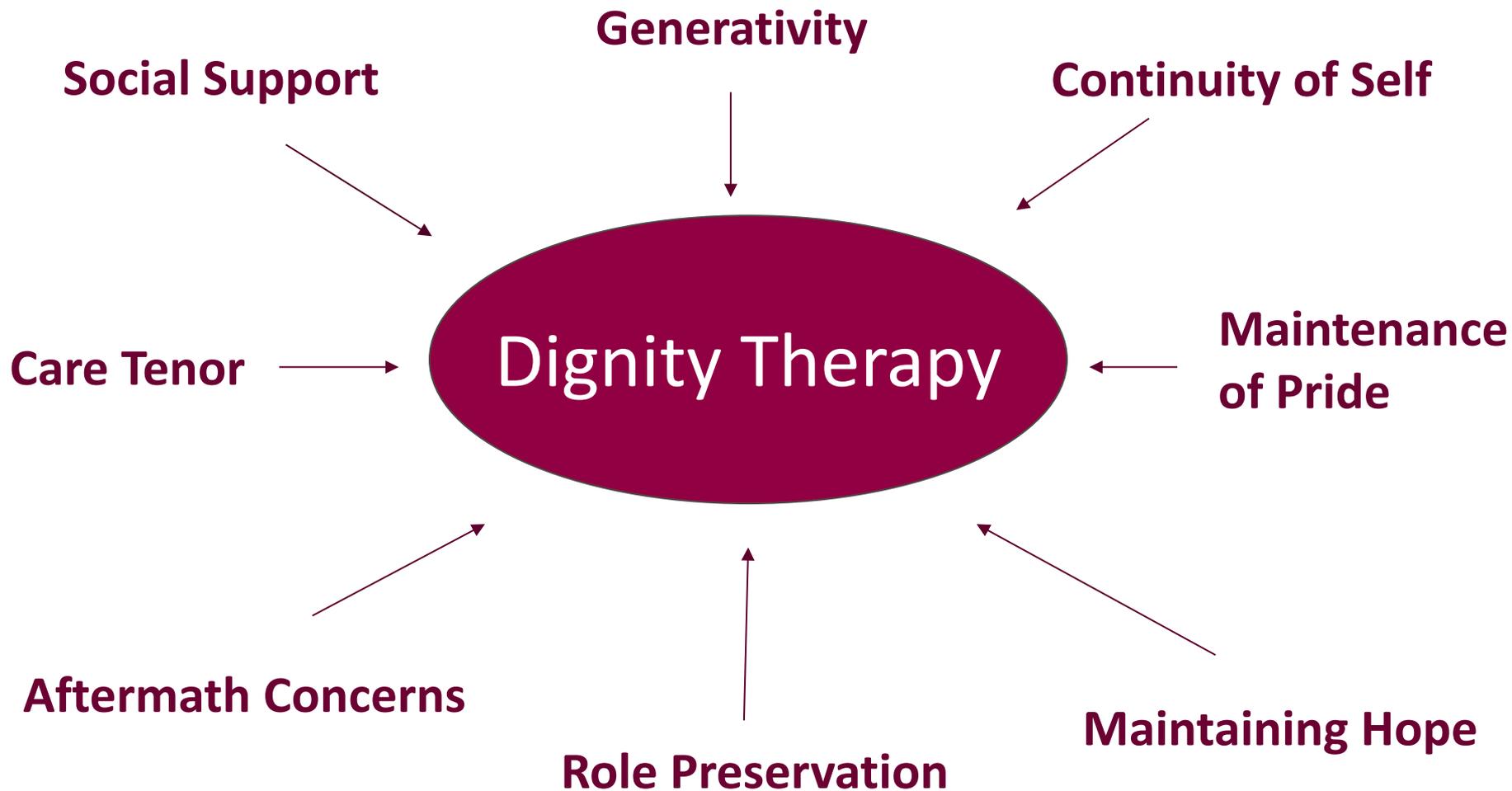


# Major dignity categories, themes and sub-themes

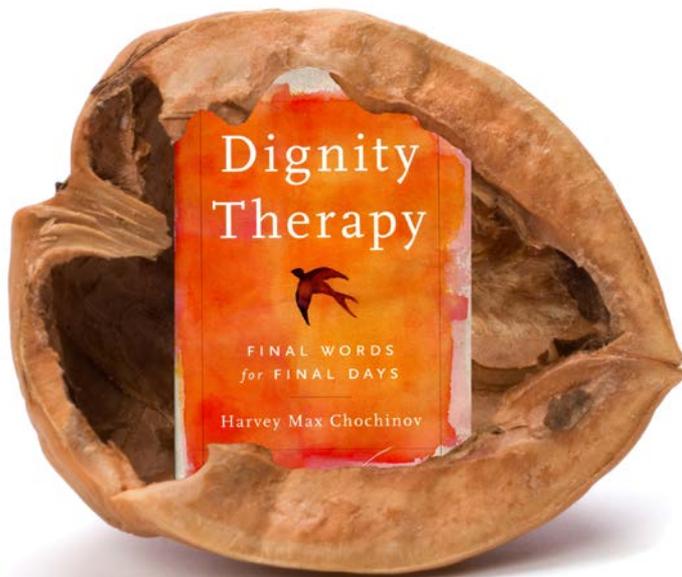
Illness related concerns	Dignity conserving repertoire	Social dignity inventory
<b>Level of independence</b>	<b>Dignity conserving perspectives</b>	<b>Privacy boundaries</b>
<ul style="list-style-type: none"> <li>• Cognitive acuity</li> <li>• Functional capacity</li> </ul>	<ul style="list-style-type: none"> <li>• Continuity of self</li> <li>• Role preservation</li> <li>• Generativity/legacy</li> </ul>	<b>Social support</b>
<b>Symptom distress</b>	<ul style="list-style-type: none"> <li>• Maintenance of pride</li> <li>• Hopefulness</li> </ul>	<b>Care tenor</b>
<ul style="list-style-type: none"> <li>• Physical distress</li> <li>• Psychological distress</li> <li>• Medical uncertainty</li> <li>• death anxiety</li> </ul>	<ul style="list-style-type: none"> <li>• Autonomy/control</li> <li>• Acceptance</li> </ul>	<b>Burden to others</b>
	<ul style="list-style-type: none"> <li>• Resilience/fighting spirit</li> </ul>	<b>Aftermath concerns</b>
	<b>Dignity conserving practices</b>	
	<ul style="list-style-type: none"> <li>• Living in the moment</li> <li>• Maintaining normalcy</li> <li>• Seeking spiritual comfort</li> </ul>	



# Dignity themes and Dignity Therapy



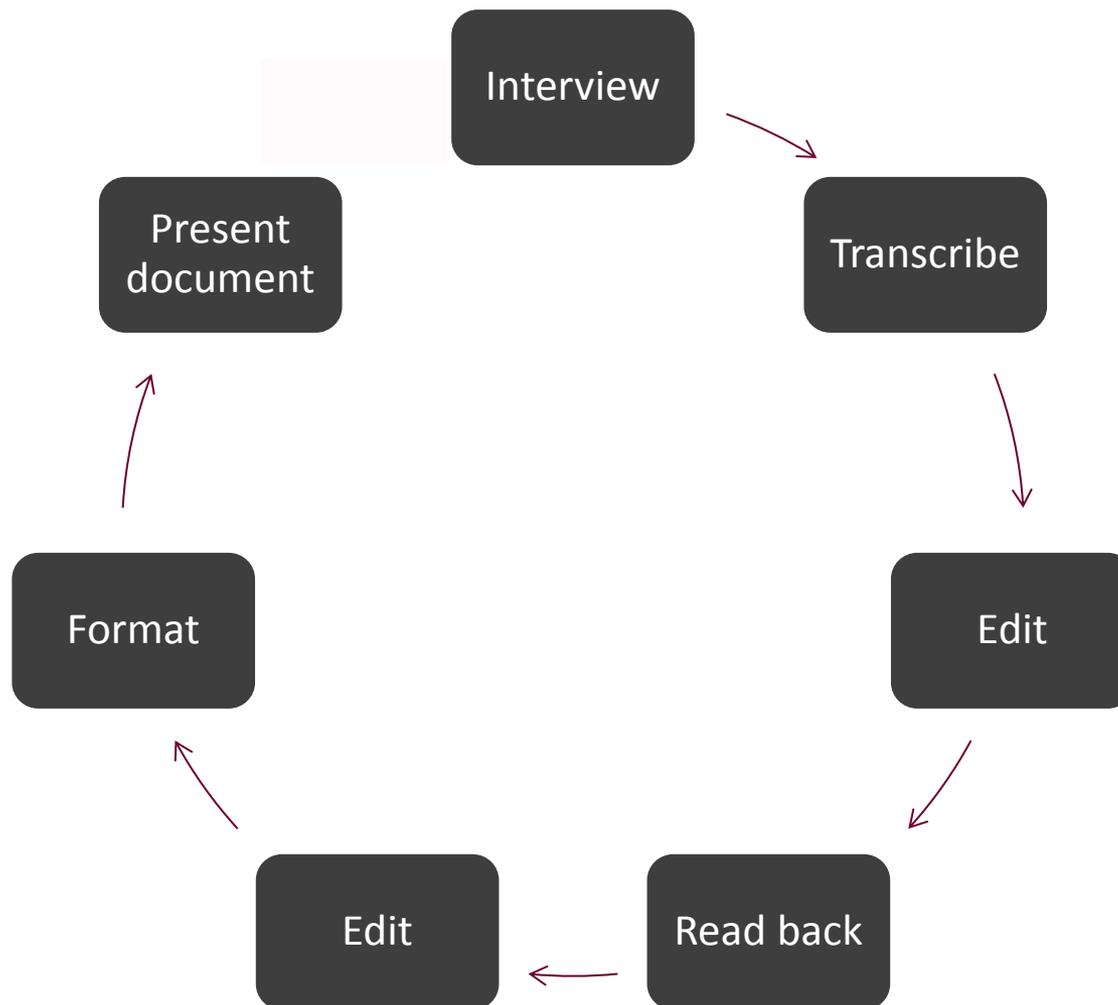
# Dignity Therapy in a nutshell



- Evidence based
- Semi-structured and individualised
- Serves as a guide to
  - elicit memories
  - offer wisdom and provide comfort to loved ones
- Allows participating patients to
  - recognise legacy they leave
  - identify unfinished matters they may wish to address
- Designed to be brief, esp. for patients with fatigue and low concentration



# The Dignity Therapy Process



# The Dignity Therapy protocol 1

- Tell me a little about your life history; particularly the parts that you either remember most or think are the most important?
- When did you feel most alive?
- Are there specific things that you would want your family to know about you, and are there particular things you would want them to remember?
- What are the most important roles you have played in life (e.g. family roles, vocational roles, community service roles). Why were they so important to you, and what do you think you accomplished within those roles?
- What are your most important accomplishments, and what do you feel most proud of or take most pride in?



# The Dignity Therapy protocol 2

- Are there particular things that you feel need to be said to your loved ones, or things that you would want to take the time to say once again?
- What are your hopes and dreams for your loved ones?
- What have you learned about life that you would want to pass along to others? What advice or words of guidance would you wish to pass along to your [son, daughter, husband, wife, parents, other(s)]?
- Are there words, or perhaps even instructions, you would like to offer your family, to help prepare them for the future?
- In creating this permanent record, are there other things that you would like included?



# Editing the legacy transcript

## Some life reflections of Jenny

RA: Jenny as a start I'd like to invite you to tell me a bit about your life story, and particularly the episodes that have been most significant for you or the memories that are strongest for you.

It's funny isn't it 'cause because you kind of, I guess where consider your life story starts I-guess is different for everybody. And mine Mine: I think tends to be start more in my teens and and early twenties when I can really sort of remember things that were special or you know wonderful in my life at that time. And I suppose meeting my husband Ron and going on our big trip around Australia which was six months and um full of wonderful expeditions and crazy things that we did um - we didn't go the whole way around Australia, - but just some of the way - and it was just wonderful, - just it was just like we were the only two people there, - And and we were just having a ball. And um, yeah I suppose after that we kind of tried to settle down, and but it was hard after a great holiday like that.

Um, yeah and um, yeah then we moved out here to Anglesea and my family followed us (laughs) which was nice. Um, Mum & Dad and my brother he's out at Lara.

Nah, that's right, Ron and then there is my daughter I've haven't spoken about yet is Evie - and my Mum is Mary and my Dad Bill, and - My brother Tony he's been in Lara for a long, long time so we're all fairly close, which is great.

RA: -And so some names, your husband's Richard?

Ah, Ron

RA: -Ron sorry

Nah, that's right, Ron and my daughter I've haven't spoken about yet is Evie and my Mum is Mary and my Dad Bill - My brother's been in Lara for a long, long time so we're all fairly close which is great.

RA: -and his name?

- 'Give back' to client voice she/he had when healthier
- Ensure accuracy of content
- Enhance readability, flow and chronology
- Protect client and recipients of final legacy paper from hurt
- All while preserving uniqueness of client's voice



# The impact/benefit



# From a participant



“When I was told that you could help me record some reflections on life my heart leapt, because it was something that I’ve always wanted to do, but I thought that I’d run out time because I no longer had the strength and energy to do it myself. I was just delighted with the result, which was beyond my wildest dreams, and sharing it with my family the other day was very special.”

-Trish



# From her husband

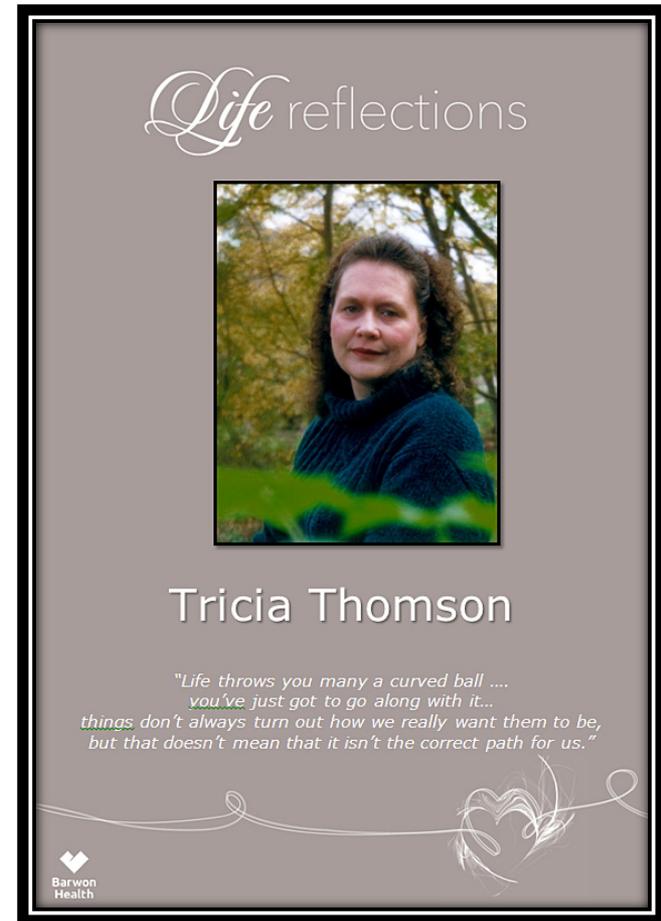


“It is a real blessing and source of comfort to me, as Tricia’s husband, to have in print, in her own words, her life’s journey and future desires for me and our three children. Often I have reached for it, looked at the photos, read it and drawn comfort, strength and emotional release through her heartfelt answers on these pages, holding her thoughts close to my heart.”



# And her daughter

“I am so thankful for this resource, and for the time and effort put in by the palliative care team. After losing mum I have often found myself turning to this book for comfort; I can almost hear her voice speaking the words to me. It has definitely helped in the grieving process. I also know that in the future I will use it to help others understand who Mum was and the amazing life she led.”



# The problem - sustainability



# The sustainability issue



# The volunteer solution



# 'Take off' in Geelong – The Geelong Advertiser 21 June 2014



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38

weekend extra

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## The final chapter



**“God, I think it’s so unfair. I get the most beautiful little girl and then I’m not going to be able to be around her. I know I’ll watch over her, and I will. I won’t let her out of my sight.”**

A KISS GOODBYE: Sharon Clegg held her very first Dignity Therapy session with her daughter Bella, who was only seven months old when her mother died. Photos: Kate Phillips, Inge Hogen

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A Geelong program is helping the terminally ill to die with dignity, knowing their story will live on after their death, writes MANDY SQUIRES

LEE Osborne swept over her keyboard as she typed the life and death story of Shannon Clegg.

“She was this young vibrant person, a new mum and she was dying. She had a lot to say,” Lee says. “It was my absolute privilege to help her say it.”

In the fortnight before she died, Shannon wanted to leave her mark on the world, Lee says. She wanted her baby daughter to know how much she loved her, and how very, very much she wanted to stay. She wanted baby Isabella Rose (Bella) to know that her mother — taken by cancer when she was seven months old — had loved the beach in Torquay, the Tumor Brides in London and the vibrant blue and red. She wanted Bella to keep in mind that her dad would make mistakes as he tried to raise a little girl alone, but that he was doing his best.

Shannon wanted to pass on to her daughter the knowledge that life was too short to live alone, little by little, and for too precious to take for granted. She wanted to tell Bella it was important for her to be independent and stand up for herself in life — never to be “a walk-over”.

Most of all, she wanted baby Bella to know that she would always watch over her but she would “be the good one on her shoulder”.

“God, I think it’s so unfair. I get the most beautiful little girl and then I’m not going to be able to be around her. I know I’ll watch over her, and I will. I won’t let her out of my sight, poor thing. I don’t know exactly how I’ll be watching over her. I just know that I will,” Lee typed through tears.

The message had come from Shannon — aged just 38 — on her deathbed at Barwon Health’s McKellar Centre via recorded interviews with palliative care specialist worker and Dignity Therapy advocate Russell Armstrong.

The interviews have now been turned into a booklet called *Some Life Reflections of Shannon Clegg*, which Shannon’s mum, Gae Fleming, and sister, Veronica Clegg, describe a gift more precious than gold.

Quite simply, it helped Shannon die more at peace, they say.

It was easier for her to leave Bella, knowing her love and life was recorded in black and white. It has also helped the family process their grief.

“We pick up the book now and we read it, and we can hear Shannon speaking. That’s such a comfort because we still have part of Shannon now. That has helped us so much, it really has,” Gae says.

The booklet — in which Shannon answers a number of pertinent, leading questions from Russell — will be even more important to Isabella as she grows up, Veronica says.

“She will be able to read her mum’s exact words to her and find out what her favourite things in life were and what was important to her. Shannon was so happy about getting that opportunity,” Veronica says.

For Russell, recording Shannon’s story was a priority.

It was also among the most confronting of the 30-plus interviews he has conducted since Dignity



LIFE’S REFLECTIONS: Palliative care worker Russell Armstrong has been collecting the stories of dying patients.

Photo: HEIDI HARR



SOMETHING TO REMEMBER: Shannon Clegg’s sister Veronica Clegg and mother Gae Fleming.



LASTING LEGACY: John McQueen hopes his book will “set things right” with his family before he dies.



BRINGING THE STORY TO LIFE: Volunteer Leanne Osborne.

Therapy was introduced to Barwon Health’s palliative care program in August, 2012.

When the interviews started in Shannon’s McKellar Centre room, there was a cry in the corner and, at times, a baby crying, Russell says.

Later, when Shannon was extremely sick, she sat in the corner when she was pregnant with Bella. Shannon had not been able to have surgery or treatment until after the baby was delivered by caesarian section at 33 weeks, Veronica says.

“There was hope at the start, but it turned out to be more aggressive than anyone thought,” she says. Shannon died on November 6, 2013.

Dignity Therapy — in the form of interviews resulting in a booklet with favorite photographs — is something Russell would like to offer other people to talk about their achievements for the first time and possibly address unresolved matters, he says.

Sometimes, it’s an opportunity for other people to talk about their achievements for the first time and can give great purpose to life at its very end, Russell says.

“I am having to walk away try and pick out the people I think will get the most benefit out of it, so for a period at the end of last year and early this year, they were nearly all young mums with tragic stories who

really wanted to leave something behind for the kids they were coming going to be saying goodbye to. I think I had about half-a-dozen youngish parents in a row,” Russell says.

But the program was also appreciated by older palliative care patients.

With a team of 30 well-trained and supported volunteers, he could estimate Dignity Therapy for 600 more patients every year.

Funding to train the volunteers — preferably through international expert Dr Harvey Chachinac — would also be needed, Russell adds.

Modelled on a Canadian program developed by Dr Chachinac, Dignity Therapy helps people who are dying identify their legacy, impact important messages to their loved ones, pass on life wisdom and possibly address unresolved matters, he says.

“It often helps the patient and the immediate circle of family and friends to explain what they’ve learnt about life and what they like to leave behind in a really positive thing for the patient and very helpful for the family,” Keith says.

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themselves and others that they are much more than their illness.

Russell has had the widow of an older Dignity Therapy recipient tell him that, through his interview, he managed to capture “the very essence” of her husband.

Another widow found about her migrant husband’s tough early life for the first time through the Dignity Therapy process.

Dignity Therapy volunteer, businessman and former Geelong Maroon Beils Faggs says many people don’t like to be seen as “dying” about their achievements but are happy to answer questions about their life when asked. Seeing these achievements recorded in booklet form can help them feel their life has been worthwhile, he says.

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“It’s an incident and father John McQueen is dying of Chronic Obstructive Pulmonary Disease (COPD).

His Dignity Therapy booklet has a picture of him grinning and holding a fish on the front cover.

For John, the booklet is about “setting it right” with his kids, years after things were said and done, people were hurt and the family broken.

He wants his kids to know that he loves them — that he has always loved them — and that he did the best in life he could.

Leanne Osborne, medical secretary and now Barwon Health palliative care volunteer, has typed up 11 of the deceased interviews Russell has conducted.

“The stories of people’s lives, and the circumstances of their deaths, have varied enormously but the messages have been remarkably the same, she says.

“It is people talking right at the end and straight from the heart,” Lee says. “They are saying all the things that matter most, and it’s so incredibly timely.” They leave messages for their children, parents and siblings and they talk about how much they love them. They talk about the things that really matter in life and all the peripheral stuff. It’s not about cars and houses and travel. In the end, it comes down to love.”

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# Setting up the Volunteer Program

Recruitment & Interviewing

Training

Ongoing Support

Development

Recognition



# Recruitment & Interviewing





# Our Recruited Team

- Professional background
  - Journalists
  - Teachers
  - Social worker
  - Former religious leader
  - Family support worker (and carer for dying partner)
- Office/Administration background
  - Medical transcriptionist
- Graphic Design background
  - Graphic Designer



# Presenting – our team! (at least part thereof)



# Training



# The Training Process

- Classroom training:
  - ½ day: Barwon Health volunteer orientation
  - 1 day: palliative care training
  - 2½ days: Dignity Therapy training
- Experiential training:
  - 1-2 interview as observer/assistant
  - 1-2 interviews as lead therapist (with support)
- On-going training & support:
  - 2 hours support/supervision/education each month



# Ongoing Support



# Ongoing Support

- Informal Support
  - Regular phone calls/ emails
  - Open door policy
- Formal Support
  - Formal briefing and debriefing
  - Monthly support sessions, whole team
  - Notification of death of patient
- Peer Support
  - Volunteer-to-volunteer support and mentoring



# Development

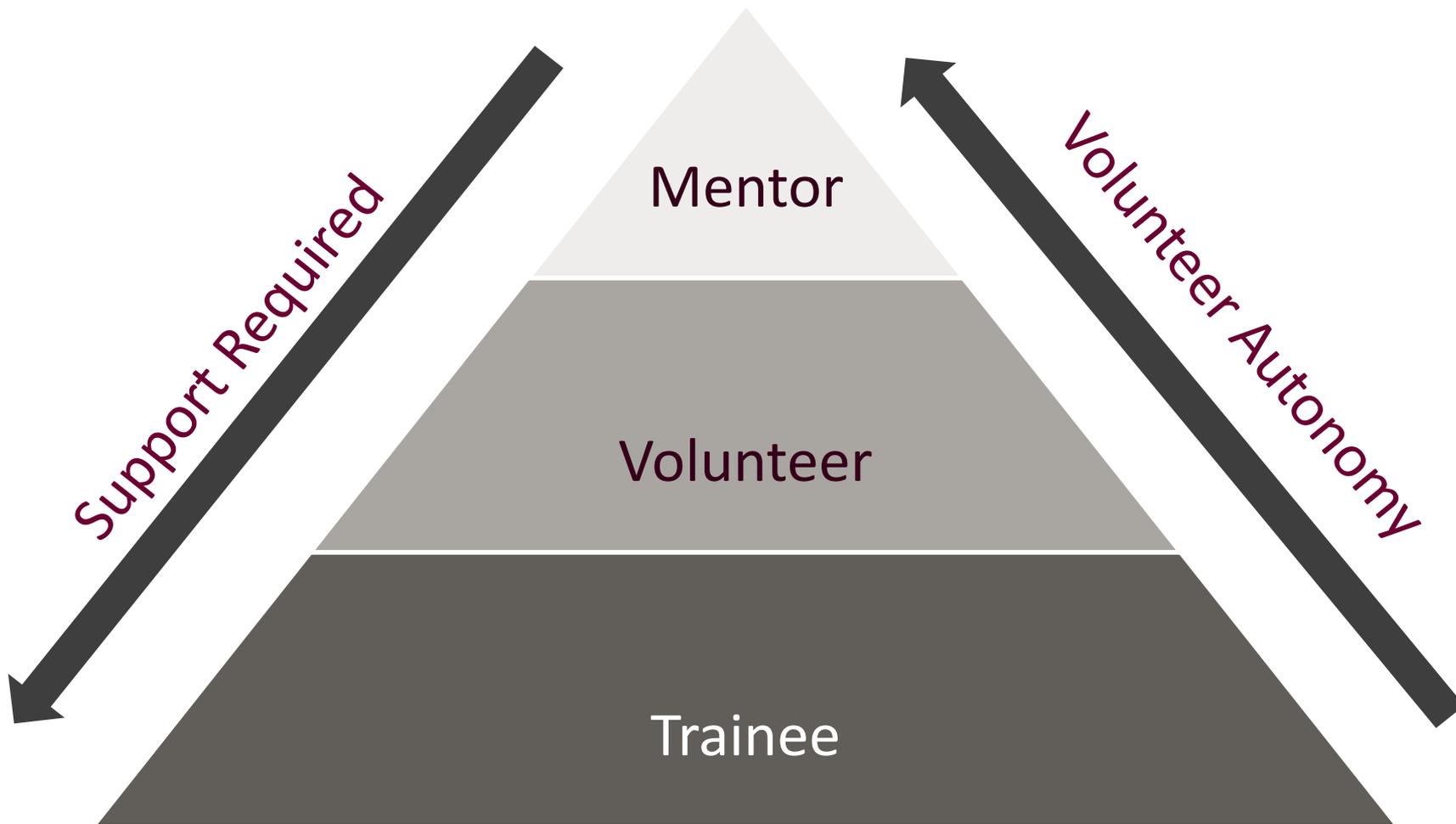


# Development

- Volunteers have a “volunteer career”
- Volunteers seek development opportunities
- We created 3 volunteer roles within Dignity Therapy:
  - Trainee
  - Volunteer
  - Mentor



# Volunteer Roles



# Recognition



# Recognition

- Informal Recognition
  - Regular encouragement and recognition of good work
  - Volunteers profiled in newsletter
- Formal Recognition
  - Including in National Volunteer Week events
  - Mentor Volunteers offered attendance to PCA pre-conference session
  - Thank you cards



# The program in practice

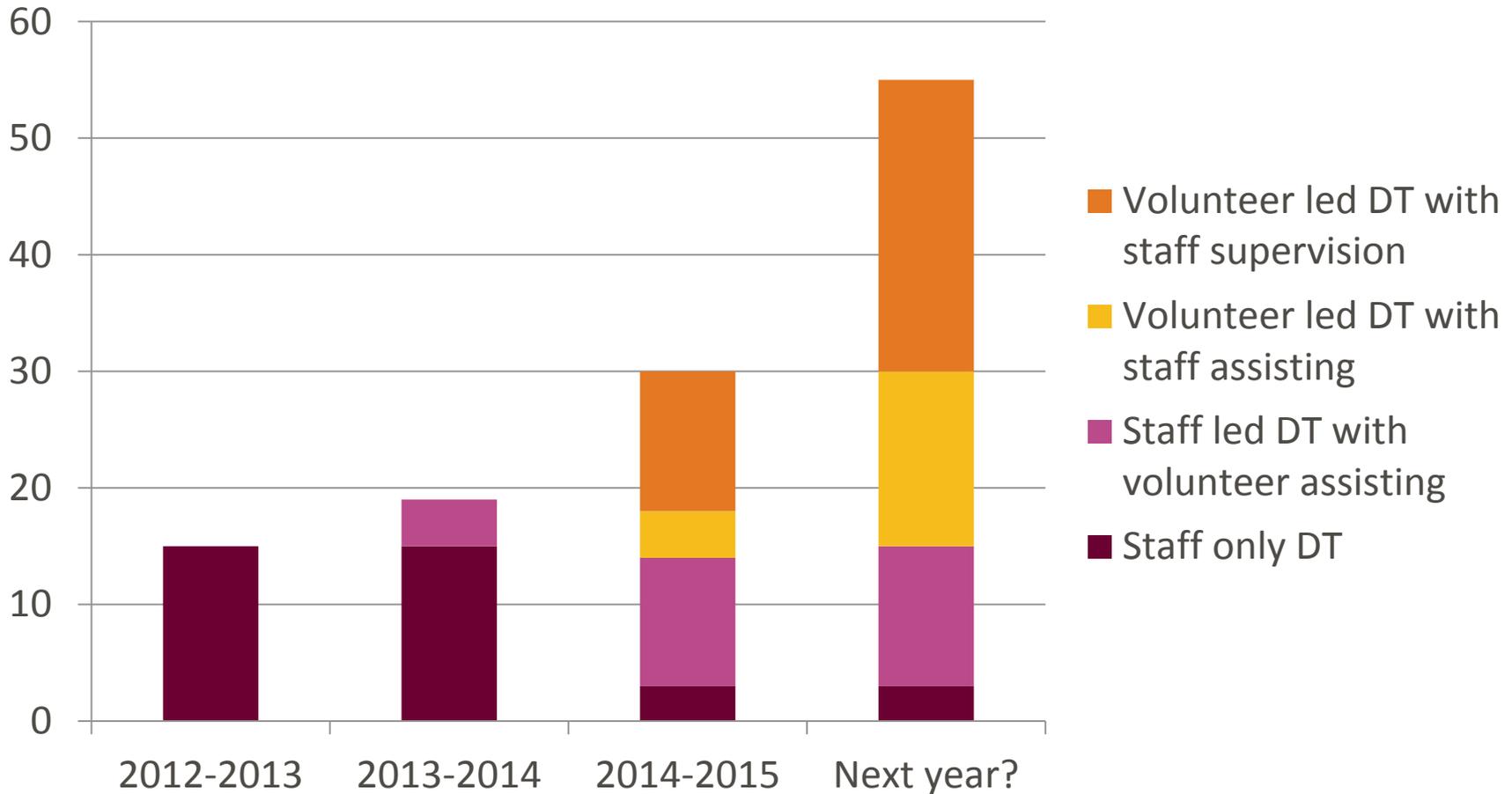


# First year of full volunteer program

- Guidance documents developed and reviewed
- Increased ability to offer Dignity Therapy to patients (already doubled first year with staff only, and still growing)
- High retention of volunteers



# The outcome (over 3 twelve month periods)



# The Unexpected - CHALLENGES

- Getting it Right!
  - Offering DT at the right time
  - Offering DT to the right patient
  - Matching the patient with the right volunteer
- Droughts & Floods of referrals
- Managing volunteer expectations
  - Workload for volunteers
  - Changing patient status
  - Fluid patient appointment times



# The Unexpected - BENEFITS

- Flexible Scheduling
  - After hours
  - Weekends
  - Multiple visits
- Quality improvement in response to volunteer feedback
  - Working in pairs
  - Introducing DT
  - The read back
- Dignity Therapy “+”
  - Companionship & Respite Support
  - Bereavement Support



# Closing reflections



# Volunteer perspective



Working with the Dignity Therapy Program at Barwon Health is an absolute privilege. To be allowed into the inner sanctum of a dying person's thoughts and last wishes, and knowing that you are helping them communicate a lasting legacy to their loved ones is so incredibly intimate and special.

I have consummate respect for the sanctity of my role and feel honoured to be a part of this incredibly worthwhile Program.

Lee, volunteer typist, pictured with client Jenny



# The reward!



Photo courtesy of Nigel Hallett



# Final words



Dignity Therapy participant Shannon with her daughter; Shannon participated in DT a fortnight before her death

“We pick up this book now and we read it, and we can hear Shannon speaking. That’s such a comfort because we still have part of Shannon here. That has helped us no end, it really has. What you have given us we will cherish forever. It’s a gift more precious than gold.”



# Questions

- Dignity in Care website
  - <http://dignityincare.ca/en/>

