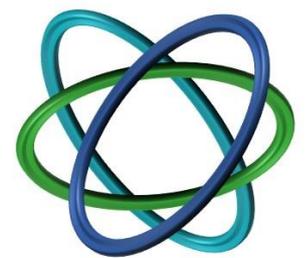
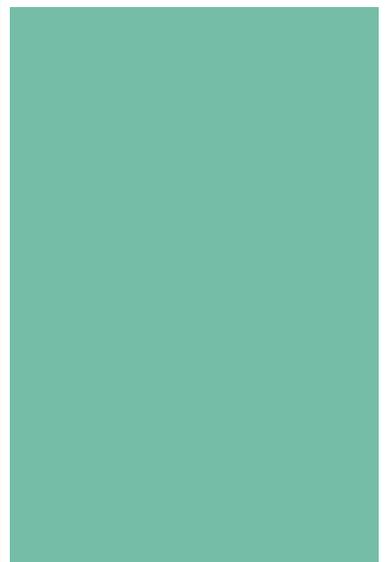
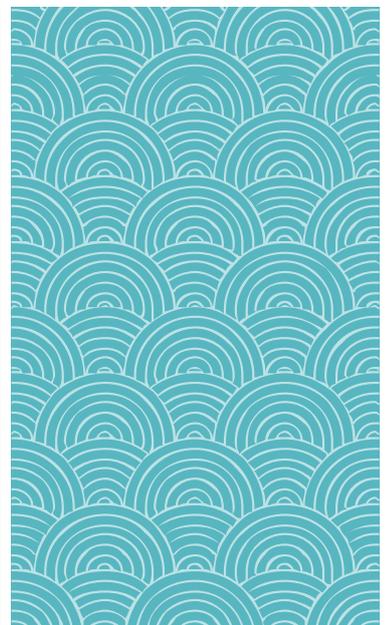


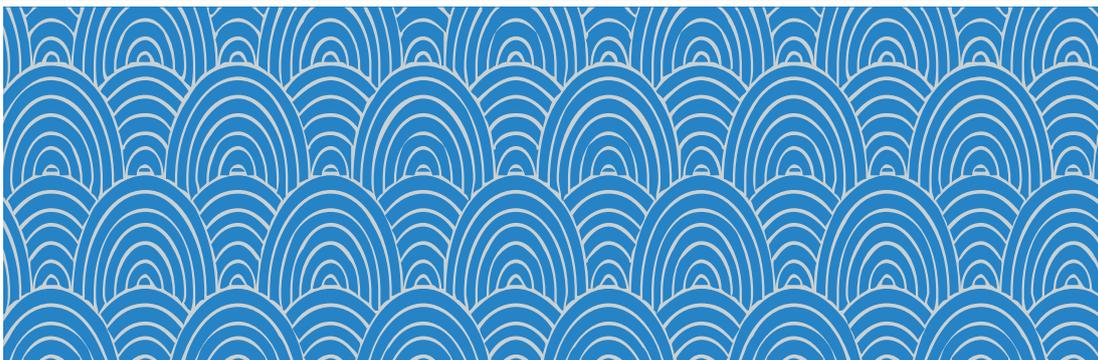
PALLIATIVE CARE CONVERSATIONS

A Train-the-Trainer resource to teach
referral to palliative care

Southern Metro Palliative Care Consortium, Melbourne 2022



SMRPCC



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To obtain a copy of the resource, please contact Tanja Bahro, consortium manager on tanja.bahro@smrpcc.org.au

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Introduction

Welcome to Palliative Care Conversations. This resource has been developed to support palliative care specialists to deliver an information/education session to equip generalist health professionals with sufficient confidence, skill and resources to make appropriate and timely referrals to palliative care while maintaining the patient's trust and supporting their well-being.

The Southern Metropolitan Palliative Care Consortium (SMRPCC) has developed this resource as a practical tool to deliver information sessions which will:

- Define palliative care and the setting in which it takes place
- Explain the process and criteria for referring to a palliative care service
- Promote communication skills for effective palliative care conversations
- Provide details for further training and skill development opportunities

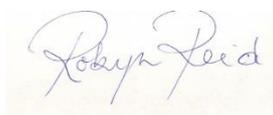
It is our expectation that the information in this resource is delivered by a palliative care specialist with extensive knowledge of local palliative care referral processes and pathways and familiarity with the *Clinical practice guidelines for communicating prognosis and end of life issues with adults in the advanced stages of a life-limiting illness, and their caregivers*.

The Palliative Care Conversations Train-the-Trainer resource is available free. Please contact us for a copy.

Thank you,



Tanja Bahro
Manager, SMRPCC



Robyn Reid
MND Shared Care Worker, SMRPCC

Using this resource

This Palliative Care Conversations information/education resource includes all the information and resources you need to deliver a 90-minute session to generalist health professionals. The resource includes:

- Facilitator's Guide
- PowerPoint presentation (with notes)
- Participant hand-outs
- Running sheet
- Evaluation template
- References for additional information and resources

Please read through both the Facilitator's Guide and speaker notes prior to delivering the program. This Facilitators Guide provides background information and explanations for delivering the program content and activities. The presentation notes are included with the PowerPoint presentation and provide supporting information related to the specific slide/content being delivered.

A document which includes a copy of each slide and the accompanying presentation notes has also been included for your reference.

The presentation, running sheet and evaluation template can be altered to reflect the particulars of a specific service or to target the message to a particular audience.

This program has been designed in accordance with active learning techniques and adult learning principles to maximise participation and self-learning. The program is divided into 6 learning sessions (plus introductions, icebreaker activity and summary/close). In each session the theory is presented in point form using a PowerPoint presentation, followed by discussion and finally a group activity designed to re-enforce learning and maximise participation.

Delivery of this program requires you to have access to the following resources:

- PowerPoint program
- Laptop & data projector
- White board & markers
- Printer to provide participants with copies of
 - evaluation forms
 - the Referral to Palliative Care activity
 - participant handouts including:
 - training programs and resources
 - additional handouts selected (by you) from the handouts & resources table

If, after reading through the program you have any questions or comments, please contact the Southern Metro Region Palliative Care Consortium.

Information for Facilitators

There are many reasons why your palliative care service might ask you to give a talk or presentation to health care professionals. There are points in a person's illness where health professionals need to communicate effectively and compassionately and engage the person with the issues that impact upon their decision-making. These conversations can be daunting and make health professionals uncomfortable and worried that they may say the 'wrong thing' or create distress.

The Palliative Care Victoria (PCV) Communication Strategy states:

'There is a strong expectation in the general community that medical professionals (and hospitals) will introduce palliative care when it becomes necessary. However, interviews with health care professionals and stakeholders confirmed that the current palliative care messages are often inconsistent, the patient is told 'very little' and referrals are occurring quite late. This suggests that health care professionals either don't know a great deal about palliative care or are uncomfortable discussing palliative care.'

The aim of this program is to equip people with sufficient confidence, skill and resources to be able to make appropriate and timely referrals to palliative care while maintaining the patient's trust and supporting their well-being.

Learning Outcomes

On completion of this program participants will:

- understand what palliative care is
- understand how to make an appropriate palliative care referral
- understand the settings in which palliative care takes place
- understand how to have difficult conversations using basic communication skills
- identify where to get additional training and skill development

Program duration

90 minutes

If the program is being delivered to a large group (20 or more participants) you may want to extend the program to 120 minutes to ensure sufficient time for discussion and completion of activities.

Workshop outline

Time (approx. only)	Content	Methods and Resources
5 minutes	INTRODUCTION <ul style="list-style-type: none"> • Introduction to the facilitator • Introduction to training • Program objectives • Introduction of participants 	Slide 1
5 minutes	SESSION 1 <ul style="list-style-type: none"> • Icebreaker • Euphemisms for death 	Slide 2 Group Activity
15 minutes	SESSION 2 Overview of palliative care <ul style="list-style-type: none"> • What is palliative care? • What are the different settings for palliative care? • Who can make a referral? • Making an appropriate referral 	Slides 3-13
5 minutes	SESSION 3 Barriers to end of life conversations <ul style="list-style-type: none"> • What prevents health professionals from having palliative care conversations • Before the conversation • Preparing for the conversation 	Group Activity Slides 14-22
15 minutes	SESSION 4 Engaging with the patient/family/carer <ul style="list-style-type: none"> • Creating rapport • Effective communication techniques • Eliciting preferences • Barriers to effective communication 	Slides 23 - 28
20 minutes	SESSION 5 Managing the conversation <ul style="list-style-type: none"> • Dealing with intense emotion • Managing the flow of conversation • Ensure understanding & provide information Case study role play	Slides 29 - 37 Group activity
20 minutes	SESSION 6 After the conversation <ul style="list-style-type: none"> • Monitoring quality and outcomes • Further skills 	Slides 38 - 41
5 mins	SUMMARY & EVALUATIONS	Slides 42

Session details

Introduction – Slide 1

Aim:	At the end of this session participants will know: <ul style="list-style-type: none">• the name of the facilitator,• where they are from• their role• housekeeping• the content and goals of the presentation
Duration:	Approximately 5 minutes
Resources:	Participants' Packs (optional and needs to be prepared by session organiser) <ul style="list-style-type: none">• a printed copy of the presentation,• document with relevant links/references and training programs, palliative care myths & facts• evaluation forms

Process:

- Welcome participants.
- Introduce yourself.
- Tell participants about your position your qualifications and work experience as this helps establish credibility.
- Talk about housekeeping issues such as:
 - duration of training and anticipated finish time
 - break times
 - location of toilets
 - car parking
 - turning off mobile phones
- Ask participants to introduce themselves:
 - Depending on the length of time allocated to the training and the number of participants the facilitator can decide on how much of the following information should be shared by participants as an introduction:
 - their name
 - a brief description of their job (if not all from the same organisation)
 - any communication challenge they have faced in working with patients with a life-threatening illness

Use this information to moderate expectations of the session. If you choose to record responses on the whiteboard, you can review their list of challenges at the end of the workshop to check whether they have been addressed.

Introduce the training topic:

- Facilitator needs to advise participants that the following session may trigger personal emotional responses due to the nature of the content.
- Explain that it is vital for health professionals in contact with people with a life-threatening illness to have the confidence and skills to provide information about end-of-life choices and settings. This workshop will provide some introductory information about having palliative care conversations with those patients and their families.

Session 1: Icebreaker

Aim: At the end of this session participants will have a humorous insight into the way in which society does not like to talk about death.

Duration: Approximately 5 minutes

Slide: 2

Process:

- use the Euphemisms for Death activity to kick-start the discussion on the death-denying aspects of our society.

Details of how to conduct the activity are provided on the following page.

Euphemisms for death activity

Ask the group for all of the examples they can think of for ways to talk about death. *e.g.*, kicking the bucket, pushing up daisies *etc.*

You should be able to get more than twenty and answers can be recorded on a white board.

Facilitate a discussion about:

- What these expressions tell us about how we handle death?
- How this affects our ability to have discussions about the end of life?

Draw out and summarize some of the following points:

- There is a lot of diversity within the group of participants and the types of ways to talk about death. Some euphemisms will be known to many, some will know only a few.
- Sometimes we do not want to talk about death *e.g.*, passed away
- Euphemisms are a way to 'soften the blow' when talking about death
- Sometimes euphemisms may be used in a common way within a cultural group
- Sometimes euphemisms are humorous in order to reduce fear
- Euphemisms may be used due to superstition or beliefs that talking about something can make it happen
- Our culture shapes our behaviour and interaction with others. Some difference may include:
 - common practices to use certain language at certain times
 - humour
 - avoidance

Summarise key points including:

- Euphemisms are often used to replace very direct language such as died, buried, dead, cremated, etc. This can help some people to feel removed from the fear or anxiety that death can provoke
- Euphemisms are commonly used by particular groups
- Euphemisms can be a way to use humour to reduce the solemnity of the topic of death

Session 2: Overview of palliative care

Aim: At the end of the session participants will have:

- An understanding of what palliative care is and the settings in which it occurs
- The difference between the palliative approach and specialist palliative care
- Who can make a referral and how to make an appropriate referral?

Duration: Approximately 10 minutes

Slides: 3-13

Process:

- Start with slide 3 to provide examples of when difficult conversations may have to occur. Continue with the presentation (*slides 4 – 11*) to provide participants with a definition of palliative care, an explanation of the different settings for palliative care and to identify who can make a referral.
- Information about what an appropriate palliative care referral is and the difference between the palliative approach and specialist palliative care is also covered in this section (*slides 12-13*).

Supporting Information:

The following information supports the delivery of information presented on the slides. Additional information is also included in the notes section of selected slides.

What is palliative care? (*slides 4 – 6*)

Health professionals often don't know that palliative care is specialised health care for people **living** with a serious, life threatening illness. They don't understand that it is not a last resort but a positive way to support families and individuals from the initial diagnosis through to bereavement.

Settings in which palliative care can take place (slides 7 – 9)

Community Palliative Care

- Palliative care in the community provides expert nursing, including help with management of pain and symptoms for people being cared for at home. Services vary from agency to agency but most provide nurses, counseling and pastoral care, and some also offer creative health therapies such as art and music therapy.
- Community palliative care may also have welfare assistance and trained volunteers to support patients who live in their catchment (geographical region).
- Community palliative care staff work in conjunction with relevant local agencies and treatment facilities to form a team of people providing support and services
- Local GPs are in consultation with Community Palliative Care staff and have access to specialist medical practitioners with palliative care experience and expertise.
- It is important that families are realistic in their expectations of support. Community Palliative Care services do not provide round the clock nursing care in the home, although they may broker-in respite care for the family/carer with volunteer support or other agency involvement, as appropriate. The family and carers provide the bulk of the day to day care in the home with continuous support from palliative care.

Inpatient Palliative Care

- Patients may be admitted to a hospice or hospital palliative care unit:
 - Because of difficulty with symptom management
 - For family/carer respite or because continuing to be at home is not an option
- This can be a short-term placement to stabilise or improve quality of life and control symptoms
- This could be a longer-term placement for ongoing care until death
- Hospice has much more flexibility in terms of visiting and pets and is a more home-like atmosphere compared to a hospital setting

Hospital Palliative Care Consultancies

- Palliative care consultancy services are located within acute care hospitals
- The consultancy team consists of nursing and/or medical and allied health professionals who provide specialist palliative care skills and education to hospital staff, patients with a life-limiting illness and their families/carers

How to make an appropriate palliative care referral (slides 12 – 13)

There is often a lack of understanding regarding the palliative care service system and how it operates. This can cause inappropriate referrals or a lack of understanding about why referrals have not been accepted.

It is important to ensure that workshop participants understand the following:

- Admission criteria
- Person has been diagnosed with a life-limiting illness and is not currently receiving curative treatment but may be receiving treatment for management of symptoms
- Person has needs which require the support of a specialist community palliative care service such as symptom management, end of life care, holistic care requirements and/or carer support
- Person and carer/family are aware of the palliative status and the referral to the palliative care agency
- Person lives in the catchment area of the palliative care agency they wish to be referred to
- Specialist palliative care - referral to a specialist palliative care agency for the management of complex needs and symptoms
- The palliative approach - care of the dying in their place of choice with generalist services involvement e.g., aged care facility with GP and nursing staff
 - If symptoms are stable and patient/client/family/carers are comfortable there may be no need for the involvement of specialist services

Session 3: Before the conversation

Aim: At the end of the session participants will have an

- Appreciation for the kinds of things that prevent or deter people from having conversations about palliative care.
- Understanding of the information they must know prior to initiating a palliative care conversation

Duration: Approximately 10 minutes

Slides: 14-22

This is the most difficult part of the workshop yet, arguably, the most important because of the discomfort people can experience when having the conversation about moving from a curative to a palliative approach. Sometimes the level of discomfort can induce avoidance of any discussions.

Process:

- Start at slide number 14 to introduce this session/topic and conduct the activity presented in the box on the following page.
- Upon completion of the activity, use slide 15 to summarise barriers to end-of-life conversations
- Use slides 16 & 17 to introduce the Clinical practice guidelines for communicating prognosis and end-of-life issues with adults in the advanced stages of a life-limiting illness, and their caregivers and explain the acronym PREPARED.
- Use slides introduce the information to assist in preparing for the conversation.
- Use slides 18 -21 to identify useful information in helping to prepare for a palliative care conversation.
- Use the cartoon on slide 22 to highlight that every individual is different and it's important to respect and respond to the different needs and wishes. At the end of this slide, summarise topics being presented in the next 3 sessions (as per presentation notes)

Supporting Information:

The following information is provided to support the slide presentation. Additional information is also included in the notes section of selected slides.

Preparing for the conversation (slide 20)

Health professionals need to:

- Know about the patient's medical and psycho-social history prior to initiating the conversation.
 - This instils confidence in both the health professional and the patient/family
- Negotiate who should be present.
- Know who their patient wants to have as support and ensure that they have a choice about who is present. Try to ensure they are not alone unless they want it that way.
- Assess how information is to be transmitted and how the patient would like this to be. E.g. do they want information to be given only to certain family members? How involved does the patient want to be in decision-making? How much autonomy would they like?
- Book an interpreter if necessary (make sure the interpreter is briefed prior to the meeting)
- Have available written material/phone numbers and resources for follow up
- Ensure privacy and uninterrupted time
 - If you are on a tight schedule advise the patient and schedule another time for further discussion. Do not give the impression of being rushed or the patient will not want to bother you with questions. Make sure you provide adequate time without interruption to conduct the conversation. If this is not possible delay discussion until you can devote the appropriate care. It may be another task on your list but if you are discussing options and end of life care it is critical that this is given due reverence.
- Ensure appropriate environment and timing
 - Make sure the environment is private, clean, safe, quiet and comfortable. This means they will listen to what you have to say without being distracted by such things as noise, cold, heat or be inhibited by lack of privacy. It also speaks volumes about how important you regard the interaction.

Barriers to end-of-life conversations activity

Read the cartoon on slide 14 and ask participants:

“What do you think are the main reasons people would be reluctant to have a conversation about palliative care?”

Expect answers such as:

- Lack of confidence
- Fear of upsetting the person
- Insufficient information about palliative care
- Don't want to be the bearer of bad news in case it impacts on the relationship
- Negative thinking about what palliative care is about

After answers have been provided move to the next slide in the presentation (slide 15) to summarise that there are several reasons why people may not want to initiate a palliative care conversation.

Session 4: Engaging with the patient/family/carer

Aim: At the end of the session the participant will understand how to:

- Elicit patient/family/carer preferences
- Demonstrate the key principles of effective communication
- Communicate to create rapport and maximise positive outcomes
- Address cultural issues

Duration: Approximately 15 minutes

Slides: 23-28

Process:

- Use slides 23 - 28 to present the principles of good communication and information on how to conduct a patient-centred conversation that ensures understanding of the patient's point of view and goals.
- Emphasis should be placed on the importance of seeking information about the patient/ family/carer and their cultural background and confirming their understanding of the diagnosis/prognosis and options to ensure positive outcomes.
- Of particular importance is having current knowledge about the patient's condition and the knowledge the patient and family/carer has of the patient's condition.
- Any cultural or language issues must be addressed and any family dynamics that may impact upon the conversation should be addressed prior to the commencement of the conversation - especially if there is a need for an interpreter.

Supporting Information:

The following information is provided to support the slide presentation. Additional information is also included in the notes section of selected slides.

Create Rapport (slide 24)

This slide includes principles and skills to ensure positive, effective communication.

- Make sure you have sufficient skill

Just because you are asked a question does not mean you are the best person to answer it. If you have limited time or you do not have the time/skill/information, then acknowledge that you have heard the question and validate its importance. Then ask if you could organise for someone more appropriate to visit and answer their question(s).

If it is urgent, use whatever resources are available e.g., perhaps calling a colleague/other agency as appropriate. If there are no other options do the best you can while making known your limitations. Sometimes it is necessary to say, *“I don't know but I will find out and get back to you”* and state a time/date.

Be clear about your role and where possible involve the most appropriate member of the team. Trust yourself. The patient has confided in you because they trust you and find it easy to talk to you or they need help urgently and you are handy. Use the team to meet the needs of the patient but remember we all have preferences about who we prefer to relate to. Being honest and sincere is what really matters.

- Provide attentive interaction and skilled communication

Positive relationships are developed through taking time and having appropriate, warm, attentive interactions.

- Practice good interpersonal skills
 - Introduce yourself; explain your role and where you are from.
 - State what you have come to discuss.
 - Is this a good time?
 - Be warm and approachable.
 - Make eye contact if culturally appropriate.
 - Speak clearly and do not use jargon.
 - Validate emotion if it arises.
 - Practice active listening techniques and check understanding frequently.
 - Allow time and space to 'digest' the conversation from time to time.
- Treat people as unique individuals
 - Make sure you know who the patient is
 - What they value
 - What their culture requires
 - Get to know how their relationships function, and where their support comes from.

Do not make any assumptions based on what has been written or obtained from other sources. Check with the patient and get to know their personal wishes and concerns and details of their life past and present.

Elicit Patient and caregiver preferences (slide 26)

What are the patient/carer/family needs and what is their current understanding?

- What do they understand about their current situation?
- Find out what they know about their prognosis and disease
- Do they know why they are talking to you?
- What are their expectations and what do they need at the moment?
- What do they see as important right now in terms of priorities and what is most difficult for them?

This defines their agenda as opposed to yours. If you are at different places – start with theirs.

They may choose NOT to know about their prognosis or be involved in decision-making.

Please note: Slide outline instruction covers the common question of what to do when the patient doesn't speak English and the family does not want them to know the prognosis.

Session 5: Managing the conversation

Aim: After this session the participant will be able to:

- Provide appropriate responses to intense emotion from the patient/carer/family
- Manage the pace and duration of the conversation in a helpful and appropriate way
- Communicate skilfully and in a way which maximises positive outcomes for the patient/family/carer
- How it feels to have a conversation about palliative care via a role play

Duration: Approximately 20 minutes

Slides: 29-37

Process:

- Use the PowerPoint presentation (slides 29 – 36) to present information on best practice for communicating and the pitfalls of communication that can have a negative impact on the patient/family/carer.
- Use slide 37 when conducting the role play as it provides a summary of the information about Mrs J.
- Upon completion of the presentation, engage participants in a role play to practice the skills of good communication around a referral to palliative care.
- Details of how to conduct the role play are provided in the box at the end of this session information.
- Upon completion of the role play, return to the presentation (slide 38) and deliver the next session (communication after the conversation).

Supporting Information:

It is important to emphasise that there is no 'little book of answers' that will make palliative care conversation easy and that those working in this area must ensure honesty with themselves and those around them to be effective.

Highlight the need to remain present and respond appropriately and respectfully even when intense emotions are being expressed.

Dealing with intense emotion & acknowledge emotions and concerns (slides 30 - 32)

Advise participants that when conducting palliative care conversations the following strategies and behaviours should be used to ensure effective management of intense emotions.

- Permit the expression of intense emotions without judgment
- Sit near the person without touching them
- If the patient and/or caregiver is very angry make sure you are safe and have access to the exit prior to having the conversation. Do not take the anger personally unless it is very clear it is directed at you. If this is the case, tell the person you will return to discuss the issues when they feel less agitated. If anger has been an issue consistently and safety a concern, then provision should already have been made to support difficult conversations with this patient by having someone with you and someone to support them.
- If the patient is very distressed allow them to express this. It is a rare person who can put aside the discomfort of their own feelings in witnessing distress and remain present. However, if you can, it sends an important message of the value of that person and how much you mean to be with them no matter what happens. It also shows you cannot be 'frightened' away, nor will you judge or abandon them.
- Feelings do not need to be fixed; however, they do require processing and sometimes the issue(s) creating the feelings require intervention
 - Some people are very private and do not externalise their feelings however this does not mean they are not experiencing intense emotions
- Do not talk during this time just remain in the silence and allow the distressed person to gather themselves. Do not use clichés to manage your feelings or theirs.
- When the distressed person speaks ask if there is anything they need. People can be afraid that if they are a burden physically or emotionally that others will get sick of looking after them. Being non-judgmental and present sends a strong message of care and comfort.

Managing the flow of conversation (slides 33)

Open questions:

- Conversation with patients, families and carers can be encouraged with open questions
- This means beginning your sentences with How, What, When, Where. (Why is not used as this can have an accusatory or judgmental note)
- Sentences beginning this way require responses with details provided by the person
- They open up a dialogue. "How are you feeling?" "What do you need most at the moment?"

Closed questions:

- Closed questions are not able to be answered with details as they entail a yes/no response. e.g., "Do you feel angry?"; "Are you OK?"

Using both strategies can help to control the flow of communication. If you are short of time, then asking open questions will potentially open up dialogue requiring time and attention. Using open questions at the beginning of the conversation and closed questions towards the end should help to ensure the conversation/appointment runs to schedule.

Group Activity - Role Play

In preparation for the activity, divide the group into subgroups of three participants per group.

Acknowledge that you (the facilitator) do not know the personal situations of the participants and that this exercise may raise some emotion or issues for some of them. Offer to discuss this after the session is finished.

Hand out the activity sheet and provide participants with the following information (which is included on the participant handout):

Mrs J. is a woman with breast cancer with bony metastases. She has been aware of this for some time. She has a husband and adult children. There has been a family meeting to discuss the findings of the latest tests and the prognosis has been given to the family. You are asked to go and talk to Mrs J. about her options for care – in particular a referral to palliative care.

Elect one person to observe and record, one person to be Mrs J. and one to be the health professional.

Give participants a few minutes to read through the questions and goals listed on the handout.

Have the groups conduct the role play for approximately 5 minutes.

At the conclusion of the role play ask the groups to provide some feedback to one another. It is expected that the observer will give feedback to the 'health professional' about what went well and what needed improvement. The 'patient' is free to comment on how it felt to have the conversation and what was helpful or otherwise.

Have the groups reconvene into one large group and discuss the activity. Some of the questions could be:

- What was it like to be the patient? What did you need? What was helpful? How did it feel?
- What was it like to be the health professional? What were the difficulties? How did it feel?
- What were the observations given from the observer?
- Have they had to have similar conversations before?
- Do they feel better equipped to carry out the conversations now?
- Do they have any concerns about having these conversations?

The facilitator should be prepared to spend some time after the session debriefing with some of the participants who have had experiences that resonate with this exercise.

Session 6: After the conversation

Aim: After this session the participant will gain an understanding of the following:

- How to monitor the quality and outcomes of conversations
- The importance of communicating information so that the patient does not have to repeat their stories unnecessarily
- The importance of team work, documentation and communication within the team

Duration: Approximately 20 minutes

Slides: 38-41

Process:

- Use the PowerPoint presentation (slides 38 - 41) to deliver the first part of this session.
- Upon completion of the presentation, refer participants to the handouts which provide links to references and additional training program.

Supporting information:

Practice is one of the key forms of improving skills. Practice, accompanied by formal professional development programs will assist participants in becoming more comfortable with and skilled at palliative care conversations.

The following information is provided to support the delivery of information presented on the slides. Additional information is also included in the notes section of selected slides.

Monitor the quality and outcomes of communication *(slide 39)*

- The patient, family and carers are partners in the delivery of their health care. It is important that the person coordinating the palliative care referral reviews conversations and addresses concerns, questions and feelings before pushing ahead with other topics of conversation.
- The creation of a respectful relationship underpins excellence in care and quality outcomes. This is a constantly changing process as each adjustment or crisis occurs.

Summary

Aim: To highlight the key points from the program, thank participants for attending and invite them to complete the evaluation survey.

Duration: 5 mins.

Slide: 42

Process:

- Use slide 42 to review the key points of the session, which include:
 - Defining palliative care and the setting in which it takes place
 - Explaining the process and criteria for referral to palliative care service
 - Information about communication skills and techniques for ensuring effective palliative care conversations
 - Providing information about further training and skill development opportunities
 - Thank participants for attending and to invite participants to complete the other side (side 2 – post session) of their evaluation form.
 - Collect evaluation forms or direct participants where they should leave them.
 - If appropriate, provide your contact details to participants should they wish to contact you with any additional questions.
-

Suggested hand-outs and resources

Type of resource	Description	Where to find it
Comprehensive workshops on a variety of relevant topics	Cancer Council	www.cancervic.org.au/for-health-professionals/training-education
Information about your local palliative care service	Service brochures, contact details, etc. Or if the service doesn't have a brochure, a business card.	Ask your local palliative care service.
Palliative Care Victoria brochures and fact sheets	For example, "About Palliative Care" and many others.	www.pallcarevic.asn.au
SMRPCC website	SMRPCC's website address.	www.smrpcc.org.au
Grief and Bereavement Services	Australian Centre for Grief and Bereavement Griefline Telephone Counselling Service.	www.grief.org http://griefline.org.au/
Examples of videos about talking to patients about prognosis and dying.	PBS (United States) Irish hospice Frontline Communication (bad news over the phone)	www.youtube.com/watch?v=jaB9M8B_Tuw www.youtube.com/watch?v=juKAMBh9J54 www.youtube.com/watch?v=wIUrfzLDrlg
Advance care planning/legal information and strategies	Advance Care Planning Australia	www.advancecareplanning.org.au www.publicadvocate.vic.gov.au
Clinical practice guidelines for communicating prognosis and end of life issues with adults in the advanced stages of a life-limiting illness, and their caregivers	The Medical Journal of Australia Comprehensive booklet outlining issues in relation to communication including 'scripting' and examples of conversations.	www.mja.com.au/journal/2007/186/12/clinical-practice-guidelines-communicating-prognosis-and-end-life-issues-adults
Palliative Care information for everyone	Caresearch	www.caresearch.com.au

Example evaluation

Pre- program evaluation

Please complete this evaluation survey and return it to the facilitator at the end of the program.

Please complete this side of the survey **BEFORE** the program starts. You will be asked to complete the other side of this form at the end of the session.

Thank you for your support and we look forward to your feedback

THE LEARNING OBJECTIVES for today’s program are for participants to:

- Understand what palliative care is
- Understand how to make an appropriate palliative care referral
- Understand the settings in which palliative care takes place
- Understand how to have difficult conversations using basic communication skills
- Identify where to get additional training and skill development

PLEASE RATE THE FOLLOWING STATEMENTS (please tick the appropriate response):

statement	Compl etely agree				Don't agree
I know what palliative care is					
I know how to refer to palliative care					
I can identify 3 settings where palliative care takes place					
I feel confident about facilitating a conversation with a patient regarding a referral to palliative care					
I know where to find further training to ensure effective communication skills for difficult conversations					

Tell us a little about yourself

Professions _____ Workplace _____

Thank you & please remember to complete the other side at the end of the program

Post- program evaluation

PLEASE RATE THE FOLLOWING STATEMENTS (please tick the appropriate response):

statement	Compl etely agree				Don't agree
I know what palliative care is					
I know how to refer to palliative care					
I can identify 3 settings where palliative care takes place					
I feel confident about facilitating a conversation with a patient regarding a referral to palliative care					
I know where to find further training to ensure effective communication skills for difficult conversations					

2. Please rate the degree to which this program met your learning needs

Fully met

Partially met

Not met

3. Please rate the degree to which this program was relevant to your work

Fully relevant

Partially relevant

Not relevant

4. As a result of today's program, what changes to your work practices are you now considering?

5. What is your key take-home message from today's program?

6. Any other comments ?

Slides print out for participants

Difficult conversations

- Diagnosis of a life limiting illness
- The move from curative to palliative
- Referral to specialist palliative care or palliative approach
- Options for end of life care- funeral planning, advance care planning, legal issues

The verb *'to palliate'* means ...

relieve without curing

to ease or comfort

to reduce the severity of

What can be palliated?

- uncertainty
- the search for knowledge and understanding
- emotional distress
- financial uncertainty
- family function and need for support
- the desire to understand options
- spiritual needs
- symptoms

What is palliative care?

Palliative Approach	Specialist Palliative Care
<ul style="list-style-type: none"> ... care of the dying through generalist services (e.g. aged care facility/GP) 	<ul style="list-style-type: none"> ... referral to a specialist palliative care agency for management of complex needs and symptoms

Where is palliative care?

- Community Palliative Care
- Palliative Care Inpatient Unit (Hospice)
- Hospital consultancy

What is *community* palliative care?

Provides assistance to patients, families and carers in their home

Different agencies have different service models

Staff work in conjunction with local services and the GP

Provides access to specialist palliative care and expertise

What is *in-patient* palliative care?

SHORT TERM

- symptom control/pain management
- stabilisation of condition
- respite-relief for family/carer

LONG TERM

- ongoing care till death



Referral

- referral to specialist PC when there is a specialist need
- early referral is beneficial and palliative care services will respond according to their resources and the urgency of the referral
- level of involvement can change as required



Who can make a referral?

- hospital palliative care consultants
- self-refer, family/carer
- GP or specialist doctor, health professionals
- ring the local palliative care provider and discuss the situation

Ensure patient is in the service's catchment

To find the local one, check www.pallcarevic.asn.au/



What is an appropriate referral?

- Person is diagnosed with a life-limiting illness and is not receiving curative treatment (but may be receiving treatment for symptom management)
- Person has needs which require the services of a specialist palliative care agency
- Person/family/carer are aware of the palliative status and the referral
- Person lives in the catchment area of the agency they wish to be referred to



Information to include

- relevant contact details of health care providers, referral source, and family/carers
- prognosis and whether or not the patient and family/carers knows and understands this
- current medical history and psycho-social situation
- reason for the referral to a specialist palliative care agency e.g., Psycho-social support, symptom management.
- the urgency of the referral



Barriers to end of life conversations

- lack of confidence
- fear of reactions
- not sure of support from the workplace
- religious /cultural knowledge
- ethical /legal boundaries



Recognition and Support

- palliative care conversations are difficult
- clinical practice guidelines developed to support communication of prognosis and end-of-life issues
- health professionals to consider the recommendations conveyed by the acronym PREPARED



- **P**repare for the discussion
- **R**elate to the person
- **E**licit patient and caregiver preferences
- **P**rovide information
- **A**cknowledge emotions and concerns
- (Foster) **R**ealistic hope
- **E**ncourage questions
- **D**ocument



Prepare for the conversation

- know everything possible about the medical and psychosocial history before the discussion
- ensure privacy and uninterrupted time
- negotiate who should be present
- ensure appropriate environment and timing



What does the patient know?

- Patient may choose **not to know** about their prognosis
- Patient may not accept their potential death
- Patient may delegate care decisions and discussions to someone else



Create rapport

- make sure you have sufficient skill
- allow time
- provide attentive interaction and skilled communication
- treat people as individuals and be culturally aware



Communicate effectively

- empathy
- active listening
- restatement /reflection
- revisit conversations
- document and update information



Elicit patient and caregiver preferences

- It is critical that preliminary discussion identifies the wishes of the patient
Interpreters may be necessary
- Clarify the patient's or caregiver's understanding of their situation
Establish how much detail and what they want to know
- Consider cultural and contextual factors influencing information preferences
- Consider the caregiver's distinct information needs, which may require a separate meeting (provided there is patient consent)



Barriers to effective communication

- Focus on health provider
"I had that problem..."
- Request /explanation
'Why' questions
- Clichés and false reassurance
"Everything will be ok"



Barriers to effective communication

Advising	You should
Devaluing	Don't be sad Everyone has times like that
Approval/Disapproval	You shouldn't have done that
Defending	Making excuses
Changing the subject	Is my blood pressure high? What did you have for lunch?



Dealing with intense emotion

- Permit the expression of intense emotions without judgement
- Sit near the person without touching them
- Do not interrupt or talk
- Allow them to gather themselves and respond when they indicate they are ready. Ask if there is anyone/anything they need
- Feelings do not need to be fixed-just expressed
- Manage your own emotions appropriately



Acknowledge emotions and concerns

- Explore and acknowledge (patient and/or caregiver) fears, feelings and concerns
- Respond to distress
- Be honest without being blunt or giving more detailed than is desired



Manage the flow of conversation

Open questions

- who, what, when, where
- opens up dialogue
- helps to explore issues

Closed questions

- require a yes/no response
- useful if you are short of time or wish to wind up a conversation



- Manage time
 - allocate sufficient time
- Check their understanding and update continually
- Ensure sufficient time to integrate new information



Ensure understanding

- Ask them to repeat the information in their own words so that you know they have understood the content of your conversation
- Provide written and verbal information if possible and in their language if appropriate



Provide information

Giving information/normalising experiences in jargon free language

- about medications
- resources and services (palliative care/welfare/legal)
- medical issues and treatment
- the dying process, when appropriate
- advance care planning
- grief and loss



Mrs J

- Has breast cancer with bony metastases
- Has been aware of this for some time.
- Has a husband and grown up children.
- Has had a family meeting to discuss the findings of the latest tests and the prognosis has been given to the family

You need to talk to Mrs J. about her options for care –in particular a referral to palliative care.



Monitor quality and outcome

- Monitor the quality and outcome of communications
- Document and communicate to the team
- Good outcomes are dependent on a respectful responsive relationship that allows the person to have a partnership with their health professionals



Further skills

- Identify strengths and challenges and find an appropriate education program
- Practise, practise, practice – experience counts
- Use supervision and mentoring to enhance knowledge and skill

