Pastoral Visitor Program

(PVP)

HANDBOOK

...

REFERENCE SOURCE

Special Note: Please read the introduction pages before you become alarmed at the size of this document!

24 September, 2024

CONTENTS

PREFACE

Do not be anxious about anything, but in everything, by prayer and petition, with thanksgiving, present your requests to God. And the peace of God, which transcends all understanding, will guard your hearts and your minds in Christ Jesus. (Philippians 4:6-7)

Pastoral or Spiritual care is the work involved when a person assists in promoting the inner well-being of another through the provision of general and spiritual support and comfort, and assistance in times of need.

Every person of any age who cares can benefit by learning more about the skill of caring. Caring spiritually for others is an important element of a service in Christ. People of all ages (including children) become ill from time to time. Being able to help these people regain their peace of mind through appropriate emotional and spiritual assistance is an essential activity for Christ's servants.

It is recognised that the well-being of people who are elderly involves good spiritual and emotional as well as physical health. Skilled spiritual carers can assist these people in maintaining and developing the spiritual aspects of their lives.

This Handbook aims to help young or older adults who already show their care for others, to care more effectively for all people. This is a benefit for both the *carer* and the *cared for.* While there is a general focus on conversations with elderly people, the principles provided can be applied to all ages.

Of course, we also care for well people. Many of the considerations and skills in this can be equally applied in our caring for people in everyday life. This includes people, like us, who experience the ups and downs of life and frequently would benefit from a skilled and caring friend and listener.

It is hoped that you will find the material in this Handbook and the associated workshops useful and stimulating, and that you will benefit from considering it.

This document is both a resource book and a 'training' activity. It is intended for use by trained spiritual carers to refresh their skills and to reflect on what they are doing, and also to be used by trained spiritual carers as a basis for the training of volunteer spiritual visitors. The document arose initially from the development of a training program for spiritual carers used in Christadelphian Aged Care facilities in Brisbane and Sydney. It has been redesigned to provide recent developments in thinking about spiritual care, and detailed training for volunteer pastoral visitors and professional carers with a greater level of responsibility in spiritual care management.

I am grateful to the many people who have offered feedback during and after the training programs, and at other times. I hope the suggestions are reflected in the revised Handbook.

May God be with you in this aspect of His service.

Laurence Lepherd, Toowoomba, Queensland, September 2024

OVERVIEW AND INTRODUCTION

Workshop plan – Introduction

Why you? Discussing some issues.

Q1 What are your reasons for wanting to become involved in a Pastoral Visitor Program?

Q2 Is your prime reason to help others, or to fulfil your own needs?

Outline of the Program as per the Contents page of the Handbook.

Don't be put off by the size of the Handbook! Apart from being an outline of the Program, it should be a useful reference source for you for some of the basic aspects of pastoral visiting.

Discussion will be the essential feature of this Program. Pastoral care discussion leaders have found that discussion by participants in workshops have greater value than a 'talking head' presentation! Reading and digesting information is important but it is the subsequent discussion follow up that is the icing on the cake.

Please be aware: It is **vital** that you read carefully the designated pages provided at the top of each workshop plan **before the workshop**. We will not be going through these notes word by word, it will be assumed by the workshop leader that you have read the notes and that you are prepared to discuss your thoughts on the questions and any material related to the topic.

Please also look at the videos associated with the workshop. As you will see, we will be discussing them in the workshop.

Supplementary readings are available under the Resources heading in the PVP index page of the Adelphicare website:

https://www.adelphicare.org/visitor/index.html

Participant questions.

Spirituality

A start!

Our spirituality – the transcendent or uplifted nature of our 'inner-self', is central to our well-being. Everyone has spirituality. Everyone has an 'inner-self' that can be lifted above the ordinary. It is acknowledged that spirituality can attain even greater importance in individuals as they approach older age and the end of life where a peaceful life is sought. As one spiritual carer put it, "Our spirituality is what makes us tick!"

This Handbook is designed to provide information about spirituality in a person's well-being, especially elderly people, and how pastoral visitors can be trained to encourage spiritual development to help them achieve a greater peace of mind. The Handbook provides

information about spirituality, the ageing process and how people, men and women, can become trained to be pastoral visitors.

The Handbook provides:

- ✓ A context for a contemporary approach to pastoral conversations;
- ✓ A reference source for all pastoral visitors;
- ✓ Training for visitors that includes a basis for minimum competency in pastoral visiting.

The Program is based unequivocally on Christian principles. It emphatically endorses the Christian ethos as fundamental to all its activities. The Handbook liberally cites relevant Biblical statements.

The Handbook, and training

The Pastoral Visiting Program is underpinned by an ethos of Spiritual Reflection. It is important that spiritual carers reflect on their own spirituality and the spirituality of others, and, especially with the latter, place spirituality in a wider context. It is also important to recognise the distinction between spirituality and religion where the former refers to an individual's inner-self and the latter refers to spirituality associated with a specific organisation or church. In this context, this Program is more concerned with the development of individuals.

Spiritual Reflection and Infinite Respect

The Program, as well as being underpinned by Spiritual Reflection, is also founded on the principle of Infinite Respect where carers respect all people in all aspects of their life, including their spiritual ethos – Christian, other faith traditions, agnostics, atheists and others. Infinite Respect does not mean that visitors endorse the beliefs or life-style of the people they care for, but acknowledge the human right for them to hold such beliefs. Confidentiality of carer and resident discussions and relationships is also fundamental to the Handbook.

Care context

The Christadelphian aged care homes have a firm commitment to providing spiritual care for all residents. The Christadelphian emphasis on recognition of God and His Son Jesus as central to an individual's life is reflected in the provision of permanent spiritual carers in all locations and a further commitment to enlisting the assistance of volunteer pastoral and spiritual visitors to add to the work of the appointed coordinators.

Fundamental to all spiritual care is the recognition that all people have spirituality, and this can have many dimensions. We should respect the spirituality of individuals and endeavour to support each person in the way that is most appropriate for them.

To this end, spiritual carers should accept the statement by Patricia Egan in the Foreword of the *National Guidelines for Spiritual Care in Aged Care.*[1]

> In Australia, we have a rich diversity of faiths, cultures, beliefs and traditions and it is important we uphold the rights of older people to express their spirituality in a way that is meaningful for them. These Guidelines recognise that the spiritual dimension is an important aspect of holistic care in the context of individuality and diversity.

National Guidelines

The *National Guidelines* are available in the resources associated with this Handbook and on the website: https://www.adelphicare.org/visitor/index.html . Click on Resources Index.

Spirituality is universal, deeply personal and individual. It goes beyond formal notions of ritual or religious practice to encompass the unique capacity of each individual. It is at the core and essence of who we are, that spark which permeates the entire fabric of the person and demands that we are all worthy of dignity and respect. It transcends intellectual capability, elevating the status of all of humanity to that of the sacred. (McSherry & Smith, 2012)

The *Guidelines* mention the difference between spirituality and religion where spirituality refers to the dimension of life referenced in the above statements whilst religion usually refers to the organisation of spiritual beliefs by a community. An important distinguishing statement is:

> Spiritual care is not necessarily religious. Religious care should always be spiritual. (*Guidelines*, p.8)

Core values

The values embraced in the *Guidelines* are

- Respect and dignity
- Compassion and empathy
- Inclusion and diversity
- Dignity
- In addition, it is accepted that spiritual care and other concepts are not mutually exclusive; they are complementary.

Concluding observations

The *Guidelines* support the concept that the essence of spirituality is "that which gives meaning, purpose, connectedness and hope" to people. They observe that there is no standard model for the way spiritual care is provided but that the core of spiritual care is assisting in the development of meaningful connectedness with people.

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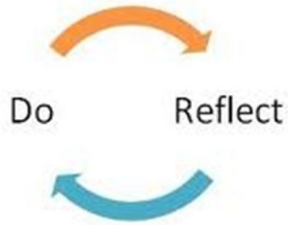
[1] Meaningful Ageing Australia (2016) *National Guidelines for Spiritual Care in Aged Care,* Meaningful Ageing Australia, Melbourne. The document is available in the resource section associated with this Program – https://www.adelphicare.org/visitor/index.html

Reflective practice – a basis for this Program

The main pedagogical foundation of this Program relates to Reflective Practice. This involves spiritual carers in reflecting on their own spirituality in a personal, emotional way, reflecting on their spirituality in a broader Biblical context, and also in a broader secular context. These three types of reflection can help carers be more understanding of themselves in a living context. They need to understand more about themselves before they can assist others more effectively.

At the same time, one of the purposes of pastoral carers is to assist other people, especially those who are ageing, to reflect on their own spirituality. Spirituality is very personal. In order for people to be able to achieve a greater peace of mind during their ageing, spiritual carers need to develop skills to lead people into personal reflection for themselves and in their broader context.

Every opportunity will be taken during the implementation of this Program to encourage participants in this reflection.



What can you do as a Pastoral Visitor in an aged care home?

1. Foster the development of spiritual care in aged care facilities for the benefit of residents and staff;
2. Work with staff and residents in the development of their spirituality and the way it can lead to their greater peace of mind;
3. Help people to understand more of their own spirituality as part of their learning of the spirituality of others;
4. Effectively develop caring relationships;
5. Become more aware of diverse peoples in aged care facilities;
6. Care with Infinite Respect and within Scriptural, legal and ethical parameters;

MODULE 1 – WHAT IS SPIRITUALITY AND PASTORAL VISITING?

Workshop plan

- ✓ We will consider the Handbook pages 11-19 in this workshop.
- ✓ Please prepare four specific points that struck you as you were going through the reading.
- ✓ Look at the video *Spirituality and Connection* (Laurence Lepherd) What is a key word in understanding spirituality?
- ✓ Look at the video *Know Yourself* (Louise Buttsworth) and make a note of three things that you found important in the content of the video.
- ✓ Using the quotations and diagram on page 14 of this Handbook, and any other sources to which you would like to refer, develop your own definition of spirituality and then discuss it in the workshop.
- ✓ How might you engage in personal Reflective Practice?
- ✓ What is your personal, emotional reaction to caring for a person who a) has a leg amputated; or, b) is in severe abdominal pain as the result of surgery; or, c) is having chemotherapy for cancer? or, d) is despondent because they are 'old' and 'useless'.

Participant questions.

What's in this Module?

1. What is the meaning of spirituality?
2. What are the functions of pastoral visiting?
3. What is the role of prayer in our pastoral visiting?

Spiritual care

Whoever loves God must also love his brother. 1 John 4:21

At the start

Christian rationale. The premise of this Handbook is that we carry out spiritual care within a Christian context. This means that we have a personal commitment to Christianity and will use our own faith to facilitate our capabilities to be more effective visitors. In our caring, we

may not always be dealing with people who have a Christian commitment. We may meet people[2] who have no religious commitment whatever. We may see others who have a significantly different faith or Christian belief to ourselves. We will find that everyone we visit has some 'spirituality', especially when they are sick, but it may not be in a form with which we are most familiar. A fundamental position for a visitor is to respect the individual for whom we are caring. Our primary aim is to help the individual notwithstanding their gender, faith, religious commitment or cultural background. Our Lord Jesus Christ set this example.

Limitations. We ought to consider the specific context for 'care' referred to in the module. We will only deal with care associated with visits to an aged care home or the domestic home, or discussions with friends over a relatively finite period.

Another aspect of these modules is that we will not be covering the more practical elements of caring such as providing meals, helping with housework, taking children to school etc. This does not mean that these contributions are not useful or important. They are very helpful. However, in the limited time of the workshops, we will focus only on the communicative elements of caring.

Focus. Lastly, before we get down to specifics, there is one other fundamental element that we must always bear in mind. The key person in any caring is the person, not ourselves. In any communication with an elderly person, it is that person's 'agenda' that is important, not ours. Generally, an ageing person becomes more self-centred – and that is not said unkindly. It is the nature of older age. We show incredible insensitivity if, when we visit, we do not spend time making ourselves aware of the person's circumstances and letting them determine where the 'content' of the visit goes.

Why you?

Why do you want to care for the those in need? This may seem an obvious and unnecessary question, but it is important that you are clear about your motives in your own mind right from the start. Think of a couple of reasons why.

Something to discuss

Is your prime reason to help others, or to fulfil your own needs? Your answer probably involves a balance of the two.

[2] It is recognised that people, our friends, patients and the elderly are either male or female. To avoid the tedium of writing and reading '(s)he' throughout the Handbook, please accept that It is recognised that people, our friends, patients and the elderly are either male or female.

What is spirituality?

This is a vexed question. Not too many people have developed an all embracing, universally accepted definition. It has been variously described as a puzzle, nebulous and fuzzy. Provided below are three definitions that are quoted in the *National Guidelines*.

> *Spirituality is a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions and practices (Puchalski et al, 2014).*
>
> *The definition of spirituality is: that which lies at the core of each person's being, an essential dimension which brings meaning to life. Constituted not only by religious practices, but understood more broadly, as relationship with God. However God or ultimate meaning is perceived by the person and in relationship with other people (MacKinlay (2001).*
>
> *Spirituality is universal, deeply personal and individual. It goes beyond formal notions of ritual or religious practice to encompass the unique capacity of each individual. It is at the core and essence of who we are, that spark which permeates the entire fabric of the person and demands that we are all worthy of dignity and respect. It transcends intellectual capability, elevating the status of all of humanity to that of the sacred (McSherry & Smith 2012).*

The Apostle Paul succinctly describes spirituality through the Greek word 'pneuma', often translated as 'spirit', and hence spirituality, as being a person's 'inner being' (Ephesians 3:16 New International Version).

It is accepted by many scholars that Spirituality is multidimensional, that it is part of a person's inner being, and can be kept internally or expressed externally, and can then lead to inner peace, alleviation of suffering and purpose in life. The diagram below is a synthesis of the literature relating to spirituality.

The idea of spirituality leading to peace of mind is essential in spiritual care work. A word of caution, though. A person 's spirituality may not lead them to peace of mind if they are disturbed or feeling guilty about something. In this case, their spirituality may work against them.

The diagram on the next page provides a model for exploring spirituality in older people.[3]

An essential aspect of considering spirituality is to recognise its distinction from religion. *Religion* or *religious* generally refers to a person's involvement in a formal organisation that concerns spiritual matters. It is important to realise that a person can be spiritual without

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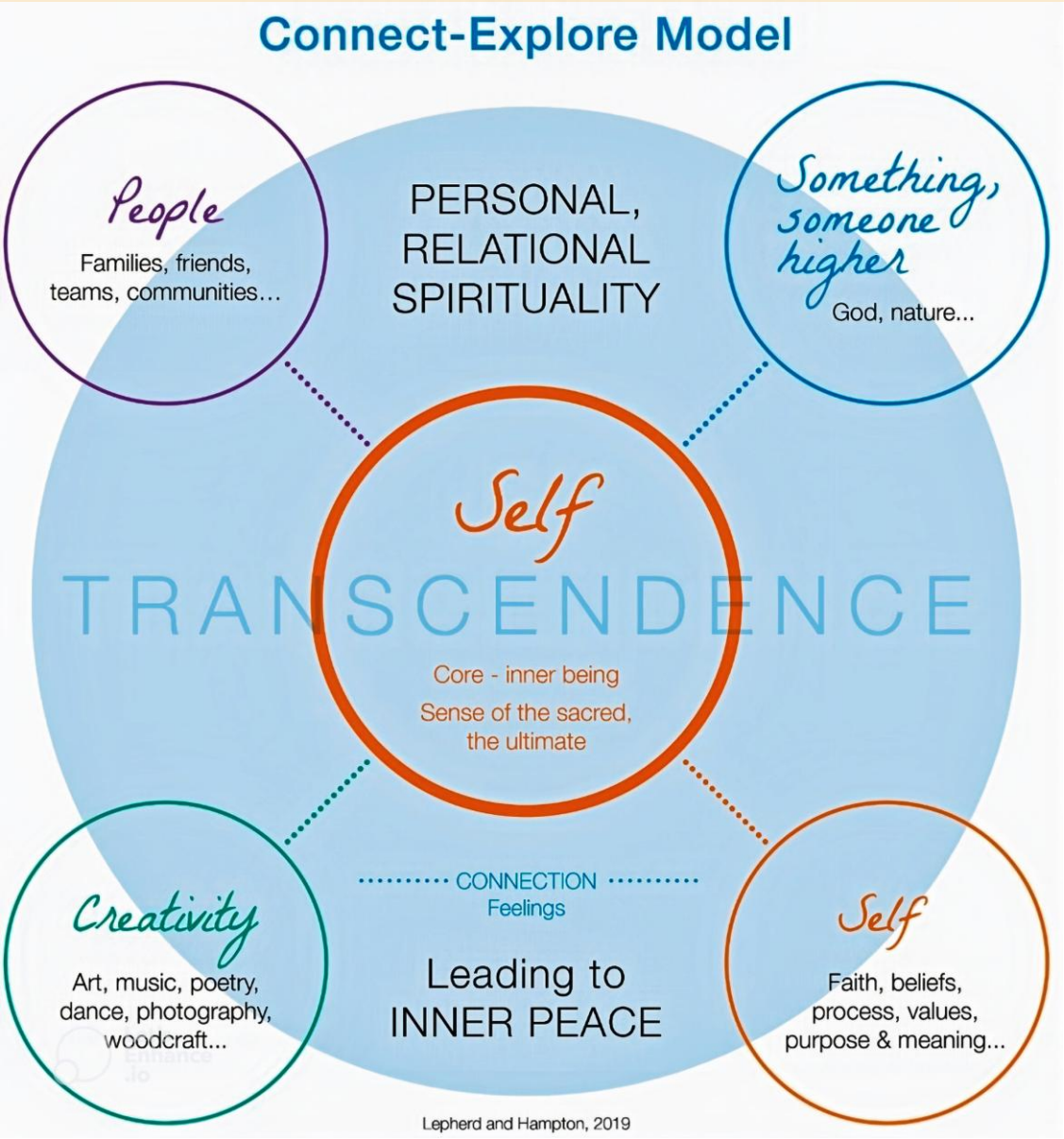
[3] Lepherd, L., Rogers, C., Egan, R., Towler, H., Graham, C., Nagle, A., & Hampton, I. (2019). Exploring spirituality with older people: (1) rich experiences. *Journal of Religion, Spirituality & Aging*, 1-35. https://doi.org/10.1080/15528030.2019.1651239

being religious. And, of course, a person can be religious (go to church every Sunday) without being spiritual, i.e. they go for the social company.

Something to do and discuss

Using the above quotations and diagram below, and any other sources to which you would like to refer, develop your own definition of spirituality and then discuss it with others.



Spiritual distress

We spend a lot of time thinking about a person's spirituality, something which helps them, if it is in a healthy state, to achieve comfort and peace of mind. Often healthy spirituality can be tempered by an experience of spiritual distress. This happens when a person finds that circumstances change, and they become very distressed in their spirituality.

We always have to keep in mind what spirituality is. We have emphasised in this Handbook that spirituality includes a number of elements. To reiterate, it involves our connectedness,

(in varying degrees) with our individual self, to others, to something higher or bigger than ourselves (which may include religion), nature, and creative expression. Distress may occur when there is a breakdown in the connectedness between any or all of these elements - depending on the severity.

Some examples

We can become distressed within ourselves if we become unhappy with the way that we are performing in whatever activity we want to be successful in. As a result of a number of things in which we do not perform to the best we can, we might lose our self-esteem which could create in us some despondency. Another example might be our relationship with God if we regard God as something bigger than ourselves. In this situation, we might be distressed because we find that God does not seem to help us in the way we would like. Another example might be a way a person is connected to nature. Many people who have a strong commitment to the land and spend their life in a way that relies on the closeness of themselves to nature, may find that when there is, for example, a natural calamity, their spirituality is become distressed because they are unable to connect in the way they have in the past. In this situation it might seem that nature has let them down.

In older people, spiritual distress may show itself through such things as a loss of hope in the future, a lack of purpose and meaning in life, and a breakdown in family, or other relationships. It may come about also during the period of prolonged chronic illness or acute illness. The person may question the value of their beliefs when there does not appear to be any way out of their current predicament.

What can a pastoral visitor do about this?

If we have a clear understanding of what we believe spirituality is in terms of the elements we have already discussed, then when we are talking to an older person (any person for that matter) we can listen for the element in which they may seem to be having difficulty, say for example family relationships, and explore that element with the person so that by exploring their feelings about their situations, we may be able to help them reconnect with the family or the person with whom they are having difficulties. The aim of this would be to restore the connectedness and reduce their spiritual distress. The same approach could also be used to identify for example, the lack of connection a person has with God. Helping them to understand the relationship and talking through their breakdown, can help them understand their position in the scheme of things and their distress might be reduced. The same can occur with their own self esteem.

Exploring with them the reason for their lack of self-esteem and trying to encourage their greater self-belief, may help them to reduce that spiritual distress which has become evident.

Seeking further assistance

We need to remember, though, that if a spiritual distress situation becomes beyond our ability to help, we need to discuss the situation with our supervisor or someone more

qualified on the possibility of seeking further assistance through counselling to help the resident restore their spirituality and thus their peace.

Something to discuss

Rod is 83, is a widower, and has just moved into an aged care home. He had lived 'on the land' for all his life. He is now despondent. How could you help him?

Spirituality and the role of prayer

Pray without ceasing. 1 Thessalonians 5:17

We cannot emphasise enough that a person's mental approach to becoming well is very closely linked to their physical progress. A person who has a developed Christian faith can have a mental attitude to illness that is positive and can thus play an important part in healing. At the same time, some may have a 'fearfulness' at being found unworthy. This can mean their understanding of forgiveness is not developed and that the appearance of a strong faith may be superficial. This can result in an unhelpful spirituality.

Leaving Christian spirituality aside, an ageing person who has a positive and practical view of life can also influence the degree of their recovery. Whatever the spiritual view of the person is, it is a responsibility of a carer to respect this, without necessarily agreeing with it.

Prayer is a vital element in the function of the visitor. We recognise that we need God's help in our work.

Self-reflection – Knowing yourself (Louise Buttsworth)

This might seem an issue more in keeping with a course in psychology than in an introduction to caring for ill and/or ageing people. However, there is no doubt that caring can be a very distressing time for the carer as well as the cared-for. A sensitive carer will be moved emotionally by the predicament of the sick person. It is important that in preparation for your role as a visitor you think about your own emotions with regard to a very sick or grieving person. You should also try to talk to someone who knows how to listen and who understands the role you are embracing as a carer. The video in this section should help you understand a little more about this concept.

Something to discuss

What is your personal, emotional reaction, for example, to caring for a person who a) has a leg amputated; or, b) is in severe abdominal pain as the result of surgery; or, c) is having chemotherapy for cancer? or, d) is despondent because they feel 'old' and 'useless'.

Defining spiritual care[4]

Encourage each other with these words. 1Thessalonians 4:18

There are many definitions of spiritual care. We ventured one in the Introduction. Here it is again:

> Spiritual care is the work involved when a person assists in promoting the well-being of another through the provision of spiritual support and comfort, and assistance in times of need.

Other definitions include concepts of:

- the mutual concern of people for one another
- helping acts to troubled persons
- mutual healing and growth
- growth as full human beings

You will notice that the original definition and the additional concepts embrace a wide variety of life's circumstances. They can include people of different:

- gender
- cultures
- ages
- socio economic status
- spirituality.

Self-disclosure

Self-disclosure is the practice of discussing your own circumstances with a person. This might be a similar illness or similar circumstances. Read through the following conversation and make some observations on it.

> *Person*. I had a nasty fall – I just slipped on the wet path for some reason and went straight down. There was no one around at the time and I had to wait half an hour before someone came by. I was in dreadful pain! They took me to the hospital and I had to wait two hours before a doctor saw me and gave me some attention.
>
> *Carer*. Oh, I know exactly how you feel! The same thing happened to me. It was awful. I was calling out and no one heard. I was panicking and in such dreadful pain! And when I got to the hospital they didn't care how I felt. They took ages and ages to give me attention and even then I had to wait in the queue for x-rays and it was still hurting so badly. Oh, it took me such a long time to get over it and I'm still …

[4] Information in this section is adapted from Bachler, Kevin F, 2003, 'Health, Illness and Hospitalisation' in *Hospital Ministry and Spiritual Care Course*, Trinity College, Brisbane.

The carer is trying to show sympathy (pity) with the person by 'sharing' a similar experience. What has happened, though, during the carer's response?

There is a place, however, for self-disclosure. The key is to help the person to feel better after the discussion – not worse, as would most likely happen in the above example. This can be done in two ways:

- ✓ keep the focus of conversation on the person, not yourself;
- ✓ help the person to realise that it is possible to live through such an experience – in other words, try to help the person to be positive in overcoming their difficulty.

And finally…

A spiritual carer is usually part of a team. It is important that you realise you are not alone in your caring work. Try to discuss caring issues with other carers you know when you feel the need to cope with something you are not sure about. Even to talk about an issue (confidentially) can enable you to clarify your own thinking.

Confidentiality

Spiritual care can involve discussing matters of a personal nature with those for whom we are caring. It is imperative that a carer treats matters discussed confidentially unless there is a need to seek assistance from fellow carers, in which case the anonymity of the cared-for person must be maintained. A commitment to complete the project associated with this Handbook acknowledges a commitment to confidentiality. While it is important for us to learn spiritual visiting skills, and discussing a visit to a person provides this opportunity, we must always ensure that issues are discussed only when the anonymity of the visited person can be retained.

Practical guidelines

Below are some things to do.

- ✓ Be spiritually aware through meditation and prayer.
- ✓ Check on the background of the person and of their current circumstances.
- ✓ Observe hygiene routines – washing hands before and after a visit.
- ✓ Once you have been aware of the background, have a plan for your visit, and be prepared to adapt.
- ✓ Sit or stand where you and the visited person can communicate comfortably.
- ✓ Allow the ill person to set the mood for your visit so you can observe their state of mind from the outset.
- ✓ Be empathetic, warm and accepting of the ill person's attitudes and expressions, giving emotional support and encouragement.
- ✓ Give your undivided attention.
- ✓ Look for non-verbal communication.

- ✓ Look for opportunities to explore the ill person's feelings and their spirituality.

Here are some things to **avoid:**

- ✓ Prying
- ✓ anecdotes
- ✓ being judgemental. It is not for the carer to determine whether a person's action is right or wrong, but rather to help a person explore their own perceptions for themselves.
- ✓ arguments, even if the visited person's language is provocative
- ✓ preaching – but be prepared to talk about spiritual issues
- ✓ manipulating the patient
- ✓ being manipulated by the patient
- ✓ chiding a patient for the feelings they might express
- ✓ encouraging unrealistic expectations of the person.

A closing thought

Ill and elderly people can be very vulnerable. Some may tend to want others to (i) make decisions for them. While others will simply (ii) not care and allow themselves to be manipulated by other people. As visitors we need to ensure that we do not take advantage of their vulnerability by pressing our own agenda, especially if it is in the sharing of our spiritual hope. What position should we take on the two issues raised above?

MODULE 2 – BASIC CARING: COMMUNICATION

Workshop plan

- ✓ We will consider the Handbook pages 20-26 in this workshop.
- ✓ Look at the video *Communication* (Laurence Lepherd) and note three points of particular interest.
- ✓ Listening – **LACE**. This will be a challenge: The leader will make a statement to which you will be invited (collectively) to respond according to the LACE model.
- ✓ Prepare an example of each of the following kinds of questions: i) open, ii) closed, iii) shopping list, iv) focused.
- ✓ The leader will make a number of statements and each participant will be asked to respond to each as a feeling statement.
- ✓ Make up your own feeling statement and each participant will be invited to respond.
- ✓ The leader will make some statements, and you will be invited to paraphrase one (each).

Participant questions.

What's in this Module?

1. Continuing to develop communications skills;
2. Understanding the importance of active, and LACE listening;
3. Understanding more about the complexities of feelings.

Communication skills: Listening

Be quick to listen, slow to speak. James 1:19

The art of caring is also the art of communicating. An important aim in caring is to learn about the circumstances of the sick or older person. It is often referred to as being part of the person's 'journey'. People just do not become sick and then well again. They exist in a context. They have come from somewhere before their illness, they are in a particular 'place' during their illness and are going somewhere after the illness - hence the concept of a journey. Helping to learn about the ill person's journey is one of the aims of the carer.

Attending

To learn about a sick or older person's journey we need to 'attend' to him or her – or visit them. There are three important initial elements of attending: observing, positioning and listening.

Observing – This comes first because it is what we should do as soon as we see the person we are visiting. What do you think are some of the things we should look for?

Positioning - Once we have made a quick but thorough 'look around' (without appearing to be prying), we should place ourselves in a good position to carry out a conversation. What do you think is important in positioning?

Active listening and further observation - Now our visit starts getting complicated because we are going to gain as much information as we can from the person so that we can help them appropriately. We emphasise active listening because we should be concentrating on learning as much as we can from them about their situation. This means that we use our eyes and ears to learn more. The ears will help us understand what the person is saying and the eyes will convey to us the person's body language. Carers generally refer to this as the verbal and non-verbal aspects of communication.

Verbal – we listen for the content: feelings, experiences, actions and thoughts.

What is one statement that a person might make in each of the above verbal categories?

Non-verbal – posture, facial expressions, focus, movement, reactions.

What is one example of each of the non-verbal categories that you might observe in a person?

'Listening is the skill of perceiving what people mean by the words they use and the way they speak them. The delivery of the words provides primary clues for understanding the person's meanings, and non-verbal espressions are especially helpful in highlighting emotionally relevant information.'

What kind of listening

There are quite a few models that describe good listening practices. We have used *Active Listening* above. This implies that listening involves us in 'doing' something. We all know about the 'inactive listener' – the person who sits in front of us with a glazed, far away look ('I wish I wasn't here!') Active listening implies that we are being attentive and trying to understand.

A more explicit model is known as LACE:

1. **L**ISTEN to what is being said
2. **A**CKNOWLEDGE by replaying the message
3. **C**HECK for understanding
4. **E**XPLORE the person's idea / statement

This is very practical and reflects the active listening proposed in this Handbook. Firstly, we listen attentively. We then acknowledge what has been said by

paraphrasing (included in the next topic). At the same time this helps us to determine that we have heard the person correctly (check), and we can go further from there with additional paraphrase and questions to explore the additional facts and feelings conveyed by the person speaking.

Other models frequently used are *reflective listening* – where, as visitors, we reflect on – think about – what has been said, and *compassionate listening* – where we try to identify and understand the feelings of the person.

Of course, they are all correct and useful. The advantage of LACE is that it spells out the process in a little more detail.

Understanding feelings

When talking with a person we try as much as we can to understand how they are feeling, or, in other words, what their emotions are. This can help us to determine how we approach our conversation.

Sometimes we (and the persons for whom we are caring) are uncomfortable with our feelings and emotions. This can happen because:

- We think they are not important;
- Emotions can be erratic;
- They can be painful;
- They can reveal how we are travelling with others and with God;
- They have to do with intimacy;
- We can think they are a sign of weakness;
- They can make us feel guilty; and,
- They are powerful and can frighten us.

How to do it …

A formula

(The dominant feeling is often the one that is mentioned last in a person's story.)

'You feel … (feeling noun) … because … (paraphrase/ summarise reason).'

Always add a check out e.g. 'Is that right?'

e.g. 'You feel happy/excited/surprised because you have made some new friends here, and you weren't expecting to do so. Is that right?'

e.g. 'I am hearing that you feel distressed/disempowered/sad because you no longer have control over your finance. Is that how it is for you?'

More about feelings

Identifying and reflecting feelings[5]

A powerful way to show the person that we have been listening to their story is to reflect the feeling(s) they express.

Feelings are neither 'good or bad'; they just happen.	It is what we DO with emotions that can cause problems. They are the source of many thoughts and actions.
Identifying and reflecting feelings validate them.	People often need assistance to recognise and accept their own feelings.
Especially when grieving, a person may find emotions and their intensity frightening and difficult to identify and express.	We can support and assist them by giving them permission to talk about their feelings, accepting them and normalising them.
An accurate reflection of feelings shows the person we are genuinely hearing them.	Even an **inaccurate** reflection may help the person to explore and identify what is happening to them.
Reflecting present-tense feelings is often the most useful.	This helps to ground the client in the present. They may identify past feelings, but how they experience them *now* can assist in normalising them.

Communication skills - responding

He who answers before listening – that is his folly and shame. Proverbs 18:13

Paraphrase

The art of paraphrase is one of the most fundamental means of gaining responses from people. It involves listening to what a person says, identifying keywords and then saying what the person said in different words. This has two important functions. Firstly, it shows that you *understand* what the person has said. Secondly, it provides the person with the opportunity to amplify his or her earlier statement and thus give you more information about their circumstances. You should aim to make the paraphrase shorter than the original statement. Thirdly, it can also provide the opportunity for correcting any incorrect perceptions you may have made. It largely corresponds to the 'Acknowledge' part of LACE.

[5] Roberts, Colleen, 2006, Orientation notes for volunteers at Bethsalem Care, Adelaide.

Try to paraphrase the following statement.

> Jill: 'It happened when I was cleaning the leaves out of the gutters on the garage roof. My husband was too lazy to do it! The ladder I was using gave way. I gripped the gutters, but they broke, and I fell awkwardly into the garden and landed with my leg underneath me. It's fractured in two places.' (Hint: 'How awful' is neither good nor enough!)

Questions

Where possible we try to avoid asking too many questions when we visit because the person may see this as prying – invading their privacy. This is one reason why paraphrasing is very useful. An ill person will often respond to the paraphrase by expanding more on their earlier description. This often saves the asking of more questions.

However, asking questions can often be the first way of helping the person to start their story. What kind of questions do we ask?

Open-ended – These questions are usually more appropriate because they provide the person with the opportunity to give a couple of sentences in response that will then enable you to follow up with paraphrase. They also give the person control over the conversation.

> Example: How did you feel about your accident?
>
> Give an example of your own.

Closed – These are not generally useful because they make it too easy for the person to say 'yes' or 'no'. However, they can be useful for clarifying something, but provide little new information.

> Example: Did you become ill yesterday?
>
> Give an example of your own.

Focused questions – These are usually in response to a person's direct statement. For example: Person – I just knew this was going to happen? Carer – How did you know? What gave you this feeling? Give an example of your own.

Shopping list – When it is difficult for a patient to explain what is bothering him, it is helpful to provide some possibilities. Person: I don't know why I'm not really feeling very well today. Visitor: Are you worried about your operation tomorrow, or is it that you wonder how your husband is coping with the children? Give an example of your own.

Questions to avoid

Loaded:	How are you finding treatment, terrible? A lot of people find treatment exhausting. Is that how you are finding it?
Double barrelled:	Have you told your husband or doctor? Do you want me to call the nurse or leave you alone?

A few other things …

- Keep your questions brief.
- Ask only one question at a time.
- Avoid loaded questions – these can sometimes be judgemental: 'You mean you haven't prayed for some time?'
- Avoid interrogations – what *you* want to know and not what the person wants to tell you.
- Be careful of 'why' questions – these can sometimes be accusatory.

Incidentally – 'must' is a good word to avoid in conversations with a sick or elderly person.

Some ways of checking your perception

- I get the impression that …
- It appears to me that …
- It seems to me that …
- I'm wondering if …
- It sounds to me as if …
- Is it possible that …
- I have a hunch that …
- I sense that …
- I perceive that …
- I get the feeling that …

These might be followed by:

- Am I correct? Right? Is that right? Is that correct?

Use a neutral caring tone of voice!

Here are some other possible blockages

Physical: Noise, distraction, location
Emotional: Anxiety, anger, distress, overwhelmed
Personal: Attitudes, communication style
Cultural: Language, customs, values, beliefs

Personal communications styles

Avoiding the real issue

Changing the topic
Ignoring feelings

Invalidating emotion

Discounting	"That's nothing"
Contradicting	"You don't feel like that"
Reassuring	"Don't worry about it"

Providing solutions

Ordering	"You have to…"
Threatening	"You'd better … or else"
Moralising	"You should …"
Suggesting	"Why don't you..."
Closed questions	"Did you … "

It is probably better to ask a question like**: "Have you thought of… ?"** This enables the person to think for him/herself about the issue.

Responses to a person's observations

While we try to paraphrase to tease out a person's story, we do need to respond to help the person become more at peace. Communicators have categorised the kinds of responses we can make – some of them are desirable and some undesirable. Here are a few:

Generalising – response is so general it can take the focus off a person's feelings.

Moralising – rejects the person's feelings and suggests how they ought to feel.

Dogmatic – often a religious response implying how a person should feel.

Probing – questions that explore feelings or attitudes. (However, avoid *inquisitorial* responses as these can become offensive.)

Empathic – responds to emotional content

Prompts

Sometimes it is necessary to prompt a person to continue with their story. Here are some phrases you can use:

Please continue …	That's interesting…	Really …
I see …	Tell me more …	Yes …
OK…	So …	Go on …
		Indeed …

Don't be afraid of silence

Silence can be uncomfortable to the visitor but may not bother the person being visited who may be:

- lost in a memory or deep thought;
- experiencing a deep emotion;
- gathering their thoughts together;
- tired or fallen asleep;
- affected by medication.

MODULE 3 – LOSS AND GRIEF; SUFFERING AND DEATH

Workshop plan

- ✓ We will consider the Handbook pages 27-40 in this workshop.
- ✓ Think of three different kinds of losses you have experienced. Describe each loss and the general impact each had on your life.
- ✓ How would you approach a) a committed Christian, and b) an atheist, to help them cope with their suffering?
- ✓ Think of your own experience when you have suffered loss and grief. See if you can determine into what 'categories' their grief seemed to fit.
- ✓ Think of a person in your own experience who has suffered loss and grief. Without identifying the person, see if you can determine into what 'categories' their grief seemed to fit.

Participant questions.

Please note that this is a big Module. Please read through it carefully and be prepared to **raise issues you would like to discuss**. We will not be able to cover all parts of the Module in a workshop, but it is important you are aware of the issues.

What's in this Module?

1. Understanding more about loss and grief;
2. Considering the issue of death;
3. Understanding important Scriptural principles about suffering and death;
4. Learning more about how we can assist people express their emotions at times of loss, grief, suffering and death.

Loss, grief and suffering: what are they?

Jesus: A man of sorrows and familiar with suffering. Isaiah 53:3

Let us then approach the throne of grace with confidence, so that we may receive mercy and find grace to help us in our time of need. Hebrews 4:16

We will give a lot of thought in this module because it is so important and has such a wide scope. As we are dealing with a variety of life's circumstances, we will be casting the net widely at the beginning and focussing more later on.

Some definitions

These are not academic definitions of the terms often used, but it is useful to distinguish between many of the words used in relation to grief and loss. We work widely initially because we are trying to recognise our role as carers in our social environment as a whole, as well as with specific individuals in specific circumstances.

Loss is being separated from someone or something of special value to a person.

Grief is an emotion that results from loss. It is a normal reaction to that loss. It can show itself in degrees of seriousness *Grieving* is a coping process that occurs through experiencing grief.

Bereavement is a condition we experience caused by loss through death.

Mourning is a process that occurs within us as we express our emotion towards our loss. It can occur with any form of loss but is more often associated with bereavement – loss through death.

Suffering is the condition of undergoing pain, distress or hardship. It can be physical, social or psychological, the latter including emotional or spiritual.

About loss

Loss occurs to us all at some stage in our life. In our environment we meet other people who have experienced loss in some form. Quite often we may be amazed how emotional a person can become about a particular loss. We need to avoid our own judgement on the degree to which the person's grief is being expressed about a particular loss and recognise that if a person is grieving about that loss it is their personal, emotional expression. The carer's task is to try to help them through that grieving, not to be judgemental on whether or not they are grieving 'too much'.

What are some of the things a person may 'lose'?

- a favourite toy
- a pet
- a parent
- a grandparent
- classmates and friends
- partner
- house and possessions
- control
- employment
- independence
- social status
- faith
- health
- trust
- funds
- health faculties
- companionship

You will notice that we have included loss 'items' that cover a range of ages – from children to the elderly. This list is by no means exhaustive. How many other items could you add? Sometimes losses can be seen as primary and secondary. For example, when a man's wife dies the loss to the man is directly primary. A secondary loss can occur to the man because

such a loss affects a general family relationship resulting in a change in some aspects of family life.

How grief can be seen

Below are some ways in which grief can be manifested.

Feelings and emotions

- Sadness
- Anger
- Guilt and self-reproach
- Anxiety
- Loneliness
- Fatigue
- Helplessness
- Shock
- Yearning
- Emancipation
- Relief
- Numbness
- Fear
- Shame
- Disbelief
- Depression

Cognitions

- Sense of confusion
- Sense of 'losing it'
- Sense of unreality
- Short attention span
- Loss of short term memory
- Hallucinations
- Pre-occupation
- Making decisions

Spiritual

- Blaming God
- Meaning system challenged
- Loss of faith
- Why me?

Physical sensations

- Hollowness in the stomach
- Tightness in the chest
- Tightness in the throat
- Oversensitivity to noise
- A sense of depersonalisation
- Breathlessness
- Weakness or ache in the muscles
- Lack of energy
- Dry mouth
- Headaches
- Nausea
- Tiredness
- Shaking

Behaviours

- Sleep disturbance
- Appetite disturbance
- Absent mindedness
- Social withdrawal
- Dreams of a deceased person
- Avoiding reminders
- Sighing
- Restless overactivity
- Crying
- Visiting places or carrying reminders of the loss
- Treasuring objects
- Erratic behaviour
- Mood changes

(After J. William Worden, 1982)

Important points about grief

- Grief arising from loss is normal and natural.

- It is a unique experience because people are individuals.
- Coping with grief is also a unique experience.

Something to discuss

Think of three different kinds of losses you have experienced. Describe each loss and the general impact each had on your life.

About suffering

Suffering can be physical or psychological. Many older people suffer in either or both of these dimensions. As the body ages, people experience more physical pain and suffering as the result. This can then lead to psychological suffering. For example, Madeleine is 85 and suffers from arthritis. She is in constant pain and is frustrated that she cannot do what she used to do so well – get out into her garden, planting and weeding. She puts up with the pain until one day she just breaks down when she claims vehemently "I'm so sick of this pain and uselessness!". Her physical pain has become psychological and emotional. And then if she exclaims that she does not know why God has let her get into this situation, her suffering becomes spiritual.

Many people regard suffering as being positive. While this is generally true in hindsight, it is very difficult, (and most inadvisable) to say to a person who is suffering physically and psychologically, "In the long run, you will really benefit from this problem you are encountering." Many of us who have experienced suffering can say retrospectively that we benefited from our experience, but this is not the answer when we are sitting opposite a person who is in excruciating pain.

What can we do? One approach is to say, "I am so sorry you are in such pain. Can I do anything to help?" The person could possibly say, "Nothing", or, they may say, "Could you ask a nurse to come to me, please?" The person may accept your offer to pray with them. Ultimately, your presence with them during their suffering could be of great benefit for them. They can appreciate your offer to help, even if you cannot, and they can appreciate your being with them during their suffering. Remember, you do not always have to speak, and, in some cases, it would be better if you did not because the person may be too exhausted to think of conversation yet would like your silent company.

A perspective on suffering

If we place our trust in God, He will guide us during times of suffering. He has never indicated that life would be without its problems; there are times when we have them. We all have them to a greater or lesser degree. How can we cope with them?

Much suffering in the world occurs because of man's increasing descent into greater and greater sin. Many men are evil and cause immense suffering for others. But there is a solution. God's love is not that He allows suffering but that He has provided the way out – the hope of eternal life! This is so positive.

Sometimes we are asked, or we ask ourselves, “Why me?” Why has this suffering happened in this way? The only real answer is, “We do not know”. If some suffering happens to us today, it is not because of something wrong we might have done yesterday. In simple Biblical terms, we suffer because we are part of a creation of humanity that were disobedient to God, they sinned, and suffering has continued since then. (The is an article ‘Why?’ accessible from the Resource index page.)

God exists. He has provided a framework within which we can cope with suffering. He will help us. He has demonstrated His willingness to help those who trust Him. This does not necessarily mean that He will relieve us from absolute suffering, but He will help in our ability to cope with it. We must develop that relationship with Him that enables us to have absolute faith and confidence that He will be with us.

Probably the last word on this is in Hebrews 2:9-10. “But we see Jesus, who was made a little lower than the angels, for the suffering of death crowned with glory and honour, that He, by the grace of God, might taste death for everyone.” Jesus’ suffering and death has resulted in humankind’s ability to overcome suffering and look forward to a life without it in God’s Kingdom.

Something to think about and discuss

How would you approach a) a committed Christian, and b) an atheist, to help them cope with their suffering?

Loss and grief: focus on death and bereavement

These have come so that your faith-- of greater worth than gold, which perishes even though refined by fire-- may be proved genuine and may result in praise, glory and honour when Jesus Christ is revealed. 1 Peter 1:7

Focus on death and dying

Having looked at broader issues of loss, we start to focus now on the issue of grief arising out of death. It is important to try to understand the factors that help determine grief. In a long-respected study in 1972, J. William Worden arrived at the conclusion that there are six main factors that determine the degree of grief a person experiences. In the following table, Worden’s ‘determinants’ are listed in the left-hand column and possible different circumstances are listed in the right-hand column.

1. Who was the person? — Spouse, parent, baby, son/daughter, sibling, relative, friend, work colleague; what was their age?

2. What is the nature of the attachment?

Strength of attachment	Close bond; acquaintance

Security of the attachment	Extent of emotional and/or financial security
Ambivalence in the relationship	'Hot and cold' – closeness but distance
3. Mode of death	Sudden death or long illness?
4. Historical antecedents	What have been the previous grief experiences of the person currently grieving?
5. Personality variables	Is the person grieving emotionally stable or volatile?
6. Social variables	What gender? What is their spirituality?
	What is the grieving person's socio-economic status?
	What culture? What support does (s)he have – ecclesial/work/club etc

Harvard Bereavement Study (Parkes, 1972)

Something to discuss

Try to see how these determinants may apply to one person in your experience. (If you feel comfortable, you may like to reflect on your own experience in a grieving situation.)

Common phases of grief

People have been writing about grief for a long time. The Bible has many examples of the way men and women have grieved. It has already been stressed that people grieve in different ways. Observers of grief patterns have tried to describe the ways in which people grieve. In the last fifty or sixty years, one observer, Elisabeth Kubler-Ross, described what she saw as seven stages of grief. The implications in her writings, at least initially, were that there was a kind of schedule of stages that grieving people went through. More recent observers have suggested that rather than stages, people go through phases. The implications for this are that there are certain elements of grief that people have in common, but they do not necessarily follow a schedule. They do not necessarily occur in the same order for every individual, and the phases can be longer or shorter from individual to individual. The phases can also differ in intensity, depending on the degree of the loss and consequent grief, and they can overlap.

Some phases of grief are:

1. Initial shock
2. Expression of emotion

3. Denial that the loss has occurred
4. Anger at the loss
5. Sadness
6. A feeling of guilt
7. Acceptance and hope

It is stressed that these may not be evident in every grieving person. They are phases or elements that many people go through. You will notice that some of the manifestations of grief listed in the tables above can be evident in many of the phases listed above.

It is also important to recognise that stereotypes associated with males and females may affect the way a person feels able to grieve. Another factor is culture – some cultures are more (or less) outwardly emotional in grief than others.

Some forms (or categories) of grief

There is no such thing as 'normal' grief. However, there are some categories of grieving that are more pronounced than others. As carers we need to be aware of these.

Acute sorrow

Probably the closest to 'normal' grief is acute sorrow. In this, a person experiences a loss but is able to cope with the loss and arrives at resolution and closure. While the loss may be remembered throughout life, the degree of acceptance has enabled the grieving person to handle the grief and generally overcome it.

Chronic sorrow

In distinction from acute sorrow, Susan Roos has described chronic sorrow as 'a set of pervasive, profound, continuing and recurring grief responses … The loss is a living loss.'[6] As carers we can sometimes meet people who have such a loss. They might be behaving 'normally' but become very upset when reflecting on a specific loss occurring some years previously.

Anticipatory grief

This can be quite common. It refers to the emotion expressed by a person in anticipation of a loss. It might be a dying person who recognises they are going to lose their life. It is also common to those who are awaiting the death of another person. In this last case, these factors may be evident:

- despondence and depression
- increased concern for the dying person
- efforts to adjust to the consequences of the death.

There are some positive elements of anticipatory grief. It allows a family, for example, to adjust to the reality of the impending death over a period of time. It also allows in some instances for unfinished 'business' to be conducted between the family and the dying person

[6] Roos, Susan, 2002, *Chronic Sorrow – A living loss*, Brunner-Routledge, New York.

and enables the family to make some plans for the future.

Disenfranchised grief

This is a difficult term but a simple concept. Sometimes, people find themselves in a situation where they are not 'allowed' to grieve. There may be a number of reasons for this.

- The grieving person was in a relationship with the dead person that was not accepted by his/her family.
- The loss is not deemed by some others to be significant – a miscarriage, for example; or 'your mother was very old and lived a good life'.
- The griever is not recognised – 'the little boy hardly knew his grandfather anyway'.
- The mode of death is dismissed – an 'at fault' teenager killed in a high-speed road accident or a suicide.
- In a religious setting there is pressure put on the griever to recognise that the dead person is 'now in a better place and we should be happy!'.

Sometimes the carer needs to be able to lead the grieving person to realise they are allowed to grieve – it is not only 'not wrong' but it is important that grieving takes place.

Something to discuss

Think of a person in your own experience who has suffered loss and grief. Without identifying the person, see if you can determine into what 'categories' their grief seemed to fit. (Perhaps you might refer to an example of your own loss and grief.)

Where to from here?

We've looked briefly at the descriptive elements of loss and grief. We need to harness this knowledge now to be effective visitors of those who may benefit from our help.

Loss and grief: Helping people who are mourning

> All Scripture is God-breathed and is useful for teaching, rebuking, correcting and training in righteousness, so that the man of God may be thoroughly equipped for every good work. 2 Timothy 3:17

The first two Parts have tried to help us understand basic factors associated with loss and grief. From this understanding, we can build a foundation for trying to help a person who is grieving. This can come through the person's spirituality – the condition that helps the person gain peace of mind.

Spirituality in loss and grief

It was mentioned earlier that, for caring purposes, there is a distinction between spirituality and religious spirituality. In caring for someone who is grieving we should note that there might be many ways in which we help in their spirituality to help them towards 'peace'. Think about these two examples:

John was dying of cancer. He was only young and had two young children. In discussions, it was evident that he did not have a significant religious faith. He spoke of a well-known sportsman who had a similar illness, and John saw this person as a model for himself. The sportsman was not an atheist but he didn't seek strength through God. He gained personal strength through his own success in overcoming his illness. John looked to the sportsman as a model for his own peace and encouragement.

Carley was grieving because her husband, Floyd, had died suddenly four weeks previously. They had no children and Carley, after initially being distraught, was settling back to work with renewed energy, determined to overcome her grief through concentrating on the work she enjoyed so much. She was surrounded at work by good colleagues and friends who supported her with understanding and practical assistance.

In both cases there was no overt religious spirituality. John found his peace through the example of someone else, and Carley found hers through her work ethic and friends.

While, as carers, we may have a Christian approach to loss and grieving, it is important that while we ourselves care in this framework, we respect the need for others to cope with their loss and grief in their own way. Our role is to help the suffering person to cope in the way determined by them, even though we may not accept their way, or if we believe there is a better way.

A Scriptural framework

Much of the following is a Scriptural perspective embraced generally by Christians. It is useful both for ourselves as carers ('know yourself'), helping those who are ill or facing death, and those who are in bereavement.

The essence of coping with any stressful situation is having faith in God that we will be helped through that stress. It is a living belief that what happens to us takes place in a God-caring environment. This does not mean that we will not have the stresses, illness and loss during our lives. What it does mean is that we have a firm foundation for coping with those difficulties. Remember, grieving is often an expression of love.

Central to faith is hope. In the case of Christians, it includes the hope and reassurance of

- The possibility of happiness/peace/growth as the person returns to a more normal life;
- God's saving grace;
- God's forgiveness;
- Eternal life

Part of the coping process is to recognise that God is ever with us and He has a plan for us. Learning to accept what happens to us because we are being guided by God is central to coping. Stresses are not punishment for sin; they are a part of life.

The Apostle Paul had some very sound advice …

I have learned to be content whatever the circumstances.
Philippians 4:11

… and this from a man who had been stoned, imprisoned, shipwrecked, had a long-term physical impediment and was generally persecuted. Paul regarded everything as loss that he might win Christ. He always kept before him the hope of the kingdom. He said, 'for the hope of Israel I am bound with this chain.' (Acts 28:20) (He was in house arrest in Rome at the time he spoke this, waiting for his appeal to Caesar to be heard.)

It is important to keep to the forefront of our mind Scriptures that are helpful.

Old Testament

- Your rod and your staff, they comfort me. Psalm 23:4
- The Lord is close to the broken-hearted and saves those who are crushed in spirit. Psalm 34:18
- God is our refuge and strength, an ever-present help in trouble. Psalm 46:1
- … and call upon me in the day of trouble; I will deliver you, and you will honour me. Psalm 50:15
- But I call to God, and the Lord saves me. Psalm 55:16
- He heals the broken-hearted and binds up their wounds. Psalm 147:3
- So do not fear, for I am with you; do not be dismayed, for I am your God. I will strengthen you and help you; I will uphold you with my righteous right hand. Isaiah 41:10
- The poor and needy search for water, but there is none; their tongues are parched with thirst. But I the Lord will answer them; I, the God of Israel, will not forsake them. Isaiah 41:17

New Testament

- Blessed are those who mourn, for they will be comforted. Matthew 5:4
- Humble yourselves, therefore, under God's mighty hand, that he may lift you up in due time. Cast all your anxiety on him because he cares for you. 1 Peter 5:6-7
- Is any one of you in trouble? He should pray. Is anyone happy? Let him sing songs of praise. James 5:13
- Therefore we do not lose heart. Though outwardly we are wasting away, yet inwardly we are being renewed day by day. 2 Corinthians 4:16
- Praise be to the God and Father of our Lord Jesus Christ, the Father of compassion and the God of all comfort, who comforts us in all our troubles, so that we can comfort those in any trouble with the comfort we ourselves have received from God. 2 Corinthians 1:3,4
- For everything that was written in the past was written to teach us, so that

through endurance and the encouragement of the Scriptures we might have hope. Romans 15:4

- For God did not appoint us to suffer wrath but to receive salvation through our Lord Jesus Christ. He died for us so that, whether we are awake or asleep, we may live together with him. 1Thessalonians 5:9-10
- But God, who comforts the downcast, comforted us by the coming of Titus, and not only by his coming but also by the comfort you had given him. He told us about your longing for me, your deep sorrow, your ardent concern for me, so that my joy was greater than ever. 2 Corinthians 7:6,7

Prayer

We cannot stress enough the importance of prayer in our personal lives and also in our caring activities. 'Know yourself' means placing ourselves in a God-centred context. We seek His guidance and help for ourselves and for the people we care for. 'Pray continually' said the Apostle Paul (1 Thessalonians 5:7). There is no doubt that prayer was central to Paul's life in all circumstances.

Applying principles

While the above religious spirituality is central to our personal life and can be extremely helpful in our caring activities, we should also realise that personal outworking of those Scriptures by us is essential when helping the sick or bereaved. This involves us in working through caring in a practical way.

What can happen and help?

1 *Help a person accept the reality of the loss.*

What can happen

- Death of a close person can lead to a sense of unreality. When the reality is accepted the person can deal with the emotional impact of the loss.
- Unreality can also lead to denial – the loss did not occur 'He hasn't really left me; he'll come back'.
- A form of denial (not accepting reality) is denying the meaning of the loss: 'He wasn't really a good father; We weren't close at all; I don't miss him.'

What can help

- Help the person talk about the loss – perhaps the person needs to talk about the situation many times to help realise the reality.
- Suggest visiting the graveside.

2 Help the person to identify and express feelings – to fully experience the pain and grief

What can happen

- The person may have difficulty in expressing their emotions; their feelings

become 'bottled up' inside them.

- Help the person to identify and express feelings – to fully experience the pain and grief.
- The person may have difficulty in expressing their emotions; their feelings become 'bottled up' inside them.
- Lack of emotional expression can prolong the period of mourning.
- A person tries the geographic cure – relocating themselves to avoid the memories that bring a reminder of loss.
- People can be insensitive:
  - 'Boys don't cry.'
  - 'Pull yourself together.'
  - 'Christians shouldn't feel sad; dying is glorious.'
  - 'But she was *very* old.'

What can help

- Use sensitivity in your comments.
- Encourage tears where the person has this emotional nature.
- Sit quietly where the person is so distressed (s)he doesn't want to talk.
- Use touch where you know this would be welcomed.

3 Assist the person to live without the deceased – adjust to an environment where the deceased is missing

What can happen

- A person is 'lost' without the person on whom they were so dependent.
- Decision making can be erratic.
- The reality of raising children alone, facing an empty house and bed and managing finance, is daunting.

What can help

- Discourage the person from making a life-changing decision.
- Be careful not to promote a sense of helplessness.
- Avoid doing too much for the griever.
- Listen and facilitate their thinking suggesting they get professional help with decisions that need to be made.
- Help them to realise they can make the necessary decisions.
- Help them to adjust to the environment that is different.

4 Assist the person facilitate emotional reaction – Help a person withdraw emotional energy and reinvest it in another relationship

What can happen

- This can be a complex situation. The possibilities range from someone who wants to form a new relationship quickly, to another who fears to form a relationship because of dishonouring the first.

- Too quick a 'replacement' may lead to an inadequate feeling of loss for the first association that may hinder the sustenance of the second relationship.

What can help

- The building of trust between the carer and the grieving person that can enable the carer to lead the griever to a rational decision.
- Encourage the griever to realise that a new relationship may not dishonour the first and would not be, in fact, a replacement. (All people are different.)
- Assist in the relocation of emotional energy from the loss of one relationship into other channels – that may not necessarily be other relationships.

5 *Provide time for grieving*

What can happen

- People mourn at different rates and over varying lengths.
- Special days – Christmas, wedding anniversaries, birthdays can be triggers for revisited emotions.
- Simple events can trigger emotional 'throwbacks' to the realisation of loss.

What can help

- Recognise that there is no timetable for grieving.
- It takes time to accommodate the ramifications of a loss.
- Realise that the griever may need emotional support for a long time after the initial loss.

Some others

- Grieving people sometimes think they are 'going crazy' because they are not their 'normal self'. They may be distracted, despondent or preoccupied – unable to focus. Try to reassure them that this is not an unusual reaction at a time of grief.
- People grieve differently. Allow for these differences.
- Drugs, pills and alcohol can impair the bereavement process by intensifying the emotions. If a consistent pattern develops to the extent that it is evident to the carer that the process is not healthy, a sensitive suggestion that the griever may need additional help or counselling could be appropriate.

Platitudes to avoid

- 'I know how you must feel' (We don't; everyone is different.)
- 'This will soon end.'
- 'You're standing up well.'
- 'You'll be fine.'
- 'I'm sorry' (with no opportunity for further discussion) may close off discussion.
- 'Make new friends and you'll soon forget the one who has died.'

Helping a person express themselves

It is often difficult to help a person talk about their grief (or, their illness). It can be useful to ask quietly such questions as 'Why do you think this is happening to you?', or, 'What have

you been thinking?'. There are some dangers in asking these questions. The person may confide in you some deeply emotional feelings. As carers we encourage a person to express themselves by being attentive listeners. It is not necessary for us to try to find answers. Often the fact that the person has expressed themselves provides them with some relief. They don't always expect an answer. They are comforted by the carer's presence and their willingness to listen.

To close

Part of a paragraph from *Coping with Loss*[7]

> We have a Saviour who knows our sorrows and the Lord God, our Father, is aware of the fall of a sparrow, and continually reaches out to us, his children, in mercy and love. 'Let us then, with confidence, draw near to the throne of grace that we may receive mercy and find grace to help in time of need.' (Hebrews 4:16.)

This is so relevant to ourselves ('know yourself') and to the people we care for.

Love each other as I have loved you. John 15:12

[7] Pearce, Rosemary, *Coping with Loss*, Christadelphian Support Service NSW. The complete leaflet is available in the PVP resource page on the Adelphicare.org website..

MODULE 4 – AGEING and AGED CARE

Workshop plan

- ✓ We will consider the Handbook pages 41-52 in this workshop.
- ✓ The ageing process in the later years is generally associated with loss and therefore grief. What do we lose as we age?
- ✓ Suggest a number of ways you might be able to help stimulate an elderly person during a conversation with them. Now suggest some 'don'ts' that will only send them to sleep!
- ✓ How might you approach them to assist in their spirituality?
- ✓ What are three points that struck you as important as you watched the video *Order and Chaos* (Carmel Hayden)?

Participant questions.

What is Active Ageing?

Over recent years or so there has been a significant shift from regarding the ageing process as something that involves people becoming more and more useless to recognition that older people can have a lot to offer and can benefit from being very active in their lives.

While this might be seen as an excellent quantum shift, the recognition needs to be tempered with the realities of people who are ageing physically, psychologically and socially. There needs to be a balance between understanding the realities of gradual degeneration but making the most of what for many is increased time and more healthy living. This module seeks to try to address this balance.

One of the important things about interaction with older people is that they enjoy narrative – telling stories. One special aspect of this for us is that we learn to use this aspect of their life to explore their spirituality.

What's in this module?

Understanding more about a number of aspects of Active Ageing, viz.

1. The process of ageing
2. Physical, psychological and social aspects of changes in ageing
3. Memory
4. Spiritual aspects of ageing

The process of ageing

> Those who do what is right will grow like a palm tree. They will grow strong like a cedar tree in Lebanon. Their roots will be firm in the house of the Lord. They will grow strong and healthy in the courtyards of our God. When they get old, they will still bear fruit. Like young trees they will stay fresh and strong. Psalm 92:12-14

This Module focuses on use of those skills and understandings specifically relating to the elderly.

While much of this module relates to the elderly in aged-care facilities, it should be remembered that older people are not necessarily only found in such places. There are elderly members of our ecclesias that we meet frequently. We might also visit the elderly in their homes and also in hospital when they are ill. The basic principles of spiritual care are the same.

It is important to remember that spiritual care is something we do all the time; it's not just something we do in hospital or in an aged-care home. The principles of spirituality, and effective communication, are just as important no matter where we have an opportunity to care.

This module commences with the broad principles of the ageing process. We move then to the more specific aged care home situation and cover some of the issues associated with such an organisation.

Something to discuss

The ageing process in the later years is generally associated with loss and therefore grief. What do we lose as we age?

What is ageing?[8]

Ageing is normal. In the process, the body's cells gradually become depleted because those that deteriorate are not replaced. There are distinct physical changes which occur as we get older. These changes, on their own, do not lead to ill health. The extent and effect of the changes will vary greatly between individuals.

An elderly person can expect some or all the following:

- to need less sleep
- to need less food (but will still need nutritious food)
- to have difficulties with digestion (can be improved significantly by correct diet)

[8] Material in this section is quoted and adapted from *Ageing*, n.d., Carer Support – an Australian Government initiative (Australia).

- to be more susceptible to infections (depending on how healthy the person is)
- to be less strong (can be negligible in a fit and healthy person)
- to be more forgetful of recent events (not to be confused with Dementia)
- to take longer to work out complex problems
- to have difficulties with sight or hearing
- to want less fluid and/or to have difficulty excreting fluid.

At the same time, a normally ageing person does not necessarily:

- become incontinent
- become senile or demented or stop functioning sexually
- get sick a lot or be ill all the time
- feel depressed, useless or lonely.

Although some loss of memory is normal in an ageing person, it does not indicate dementia. There are different conditions which cause dementia, the most common being Alzheimer's Disease, which affects 5% of people at age 65, and 20% of people over 80.

Ageing is a normal part of the life cycle. It is not a disease and most aged people live full independent lives. However, many diseases and debilitating conditions occur more frequently in older people. These conditions should be recognised and treated, not accepted as 'just part of growing old'.

Ageing and disability

Around 90% of Australians over the age of 60 are free of any significant disability for which they need help with personal care or getting about. About 60% are free of any disability which handicaps them or prevents them looking after themselves.

Often illnesses which are not life-threatening cause the most handicap. In older people conditions which reduce mobility are a major problem. Major causes of handicap in older people are:

- problems with bones and muscles (e.g. arthritis)
- incontinence
- heart disease
- dementia
- foot problems
- sight problems
- hearing problems
- dental problems

Social activities

All humans need connections with others in order to be healthy and happy. The more involved an ageing person is with their community, family and friends, the healthier and happier they will be. Social contacts may be more difficult to arrange than in the past, but *they* are no less important.

Often there are alternative ways for ageing people to take part in activities. Encourage the person you care for to keep up social contacts.

Physical, psychological and social aspects of ageing

As visitors, it is important that we recognise the reduced capability of older people in relation to their stamina/endurance. They become tired more easily. When we talk with them we must remember that they may not have the enthusiasm for conversation that we have. They may become frustrated when they cannot think of something simple. They may not remember an event of a couple of weeks previously. We need to make allowances for this very natural ageing process.

Something to discuss

Think of some specific conversations you have had with elderly people. In what ways have they shown their older age physically?

What are some of the ways you can support a person (whether at home or in a home) in coping with their physical changes?

Some physical aspects of ageing

Symptoms of ageing

Kirkwood[9] states that symptoms of ageing include:

- weakened immune system, with a greater tendency to contract seasonal infections, viruses and other illnesses;
- greater likelihood of developing heart disease and cancer;
- adverse changes in body mass and muscle tone;
- failing memory, learning and ability to change and manage new situations; and,
- changes in sensory organs: touch, hearing, sight, taste and smell are less acute, slower and weaker to respond and function.

Age brings a natural deterioration of the body. The signs that accompany it often reflect the kind of lifestyle lived in earlier years:

- too much sun and sand earlier can lead to skin cancer
- inadequate exercise and poor diet can lead to overweight and potential heart failure, dangerously high cholesterol levels (and consequent stroke), and also diabetes and possible amputations
- sports injuries can lead to bone and muscular deterioration and poor mobility

[9] Kirkwood, Neville A. 2005, *Pastoral Care to the Aged*, Morehouse Publishing, Harrisburg, PA, p.3.

- back and other injuries through work or unguarded activity (e.g. lifting a heavy weight incorrectly) can lead to arthritis in the joints
- insufficient calcium (diet) and also inadequate care after menopause can lead to osteoporosis. This in turn can lead to an increased likelihood of hip and limb fractures.

There are many other signs of ageing that are simply the result of the inability of the body to replace weary or dead cells.

- The simple weakening of the immune system can lead to increased incidence of cancer. One of the most common kinds of cancer in men is prostate. Some 10,000 men are diagnosed with prostate cancer every year in Australia.
- Older people become physically smaller.
- Older people are slower to move, to bend, to get up.
- They may have impaired sight – they need more light when they try to read the card you brought.
- They may have impaired hearing – they may ask you to repeat what you have just said.

Another physical deterioration that has mental implications is the decrease in the size of the brain. The implications of this, among other things, is increased forgetfulness – remembering a person's name, forgetting what we were going to put on the shopping list, and then forgetting to take the list to the shops anyway!

Some psychological aspects of ageing

Psychology refers to the mind, emotions and personality. In this Part we cover a number of psychological aspects of ageing, including emotions, personality and some mental health issues. Immediately below are some general 'mind' issues that may relate to an ageing person. There may be:

- anxiety about possible or actual illness
- a sense of shame and disgrace when some things that have been part and parcel of their life - neatness, cleanliness – become 'tatty'
- a fear of memory loss (and embarrassment)
- loss of excitement experienced in their active, younger life. Perhaps he/she was a good administrator, social leader. Now, there is no opportunity for a leadership role or to continue with accepting responsibility.

Moving into aged care - emotions

When an older person needs to move to an aged care home there may be considerable emotional upheaval. It is helpful for the carer to be aware of both the positive and negatives aspects of such a move. (Have a look at Carmel Hayden's video *Order and Chaos* that focuses on some of the issues older people face when they move into aged care.)

Positive

Entry to an aged care home or retirement village leads to lifting of a heavy burden because:

- difficulty of maintaining a tidy home, having to depend on others to help with shopping and other household chores has now gone
- no obligation to feel bad about charity because now he/she pays for services
- lonely hours of boredom have gone because there is now company
- routine of home is now varied
- if previously living with a relative, the instructions associated with the relative's absence ('use the hot water in the thermos, don't boil the jug') are now no longer necessary
- they forgot their medicine when living alone and suffered because of it. The aged-care home takes care of this
- they don't need to worry if they die in their sleep because 'no one would find out'.

Negative

Entry to an aged care home or retirement village may lead to a loss because:

- the move means abandoning their home with all its independence and memories, and perhaps, their pet
- there may be anger that they are unable to look after themselves as they once did
- there may be despondency as they think that the aged-care home is the last place before the grave. They become fearful of the potential for dementia or disability
- while the aged-care home may result in social contacts they may not be the same as their family and friends they used to have
- some fears can be justified. Not all aged-care homes have staff who give absolute individual attention, and maybe the staff talk down to them: 'Have *we* taken our medicine today?'
- some personal privacy that they had at home may be lacking where some staff or visitors may not knock before entering, or private conversations (medical, family or financial issues) may be overheard by other residents. (Sometimes other residents have nothing else to do but listen to someone else's conversation because they do not have the frequency of visits that others do.)
- maybe the food is not 'as I used to cook it'.

Personality

Personality is regarded as the dominant characteristic of behaviour, thought and emotional patterns of an individual. Personality is generally demonstrated through an individual's 'traits' or 'characteristics'. A person might be 'labelled' as 'shy' or 'aggressive' or 'assertive'. But these labels are not always consistently applicable. A person may be shy in a broadly social context, for example, but may be assertive in

their work situation.

Studies have shown that personality does not really change of its own accord as a person becomes older and is, in fact, remarkably stable. For example, the gregarious person can still be gregarious as they become older. However, circumstances – illness, grieving – can lead to change.

Despite a perception of little change, some studies have shown that there may be small changes.

- Older people tend to become more mellow.
- Men seem to become a little more feminine and women a little more masculine.
- People in later life slow their pace of activities.
- Some adults become more excited or perplexed about the occurrences of everyday life.

It should be remembered that while these are general observations, there are many instances where the general 'rules' are not applicable to all older people.

Something to discuss

Think of two older people you know and have known for some time. Has their personality changed? If there have been any changes, in what ways have they taken place? Have there been any circumstances that might have caused the changes?

Some social aspects of ageing

Rise in the presence of the aged, show respect for the elderly. Leviticus 19:34

It has become increasingly recognised that social experience is an important part of ageing. There have been two ideas about social aspects of ageing. One suggested that as people become older they want to have less and less to do with other people. They withdraw from the sort of contacts they had earlier in their life. Some aspects of this idea are:

- as people get older they have less to do with others as others have less to do with them
- they have fewer and weaker emotional ties with others
- they show a decreasing interest in world affairs
- they become more self centred and self occupied.

The other suggestion is that the more active older people are, the more they will gain life satisfaction. One aspect of this is that it is important to either encourage older people to continue the activities they once had, or find replacement activities.

It is an advantage to combine functional ability and social participation in the description of quality of life in old age, as 1) a high social participation may compensate for a poor functional ability, and vice versa, 2) the combined measure is meaningful for both sexes, and 3) it gives more information than the two concepts used as separate

outcome measures.

The quality and density of a person's social network is more important than the number of people in the network.

What are the implications of all this?

The spiritual care visitor needs to be aware of all these issues during a visit to an older person. It is for this reason that visits to people in aged-care can, of themselves, offer considerable stimulation.

Something to discuss

Suggest a number of ways you might be able to help stimulate an elderly person during a conversation with them. Now suggest some 'don'ts' that will only send them to sleep!

Grey hair is a crown of splendour; it is attained by a righteous life. Proverbs 16:31

Memory[10]

The issue in the ageing process is that our ability to know, think and judge starts to deteriorate because the senses used in the processing of the information that helps us to know, think and judge deteriorate. Not only this, but it was mentioned above that the information we receive is stored – in our memory – and our memory deteriorates. If there is a decline in our memory, it is more difficult to process the information we have received (even if we have received it all) because it isn't there long enough to process and make a response! Even if we are able to recall something from our memory, it may be that we have deteriorating abilities to speak the response because there is a possibility that our motor abilities do not enable us to implement a physical response very quickly.

Of course, the rate and degree of cognitive deterioration varies from one individual to another. For example:

> *Jocelyn* is 99. We visit her and unwittingly interrupt as she is completing the daily newspaper's crossword. 'I cannot think of the word for this clue. Can you help me?'
> *Jeremy* is 69. He reminisces a lot but frequently has trouble remembering the names of the places he visited and the people he met.

And then there is the all too familiar, for some of us, "seniors' moments" that can strike

[10] Some of the following is based on information in Rybash, John W., Roodin, Paul A. and John W. Santrock, 1991, *Adult Development and Aging*, Wm. C. Brown Publishers, Dubuque, IA. p. 1991.

some people very quickly!

Attention

Memory plays a vital part in cognition. One of the elements in receiving and processing information is *attention*. This is often viewed in two parts – *selective* attention and *divided* attention.

Selective attention is the need and ability to select relevant information for the task in hand. Often we try to store all information that reaches us. A consequence of this is that we try to process too much and end up not processing vital information that will help us in our thinking and awareness. An everyday example of this is when we are writing a letter and we try to keep one eye on the clock because of an appointment, one ear on the radio to find the latest cricket score, and answer questions from someone else in the room. Our main goal – writing the letter – suffers from our inability to select what is necessary for us to focus on the letter.

In *divided* attention we have difficulty in processing all of the information that is vital to a goal we have set. For example, when driving a car we need to use a number of skills to enable us to reach our destination. Apart from the skills of watching the speed, watching for traffic, steering correctly and using the brakes at the correct time, we need to be able to see the street signs so that we not only drive correctly but we end up at in the correct place.

Another aspect of attention is referred to as *limited attentional capacity* – the capacity for people of varying ages to pay and maintain attention to a task. This is more complex as it is obvious that people of all ages have varying degrees of attentional capacity. It is generally recognised, however, that older people have a more limited attention span.

Something to discuss

How do you share a conversation with a person who is having difficulty remembering something while talking with you? How do you help them?

Spiritual aspects of ageing

Even to your old age and grey hairs I am he, I am he who will sustain you. I have made you and I will carry you; I will sustain you and I will rescue you. Isaiah 46:4

Elements of religious or spiritual belief and practice

It is generally recognised that there are three broad elements in a person's spiritual

life:

1. Participate in organised religious ritual practices and activities
2. Engage in private religious devotion, meditation or reflection
3. Engage in a daily life that exhibits a continuing religious or spiritual experience.

These are not mutually exclusive. In fact, many Christadelphians (and other religious people) would try to have each of the elements in their lives. The fact remains, however, that some people will 'go to church on Sunday', or not go to church but be independently 'worshipful', or live a good 'Christian' life without engaging in the other two activities.

And, of course, you will meet people who are not religious but have their own spirituality. If we use some gentle exploring questions we will find out a little of their spirituality. It may well be, for example, that they receive their comfort from a non-religious source. If that is the case, the spiritual carer to pass judgement on that person. Remember, it is the person's agenda that is important. We should be willing to help a person find peace and comfort through the Scriptures if we are asked but, if we are not, we respect the person's own wishes.

An older person unable to attend religious meetings may rely on the spiritual carer to provide spiritual help. Older Christadelphians will generally like to 'do the readings'. They will often ask questions and expect good answers. They will often like to talk about current world events that will help them to be encouraged by the imminent return of Christ. This gives them comfort in their older age.

If their partner in life has died, they will often simply look forward to being reunited in the Kingdom after the resurrection (even though they know that marriage in its current form, will not exist in the Kingdom.)

- They will often like to pray.
- They will often like to reminisce about ecclesial activities or family activities.

You might consider that your presence can often be the only spiritual association they have during a week, especially if they are isolated.

- They look forward to your visit.
- Despite their isolation they continue to grow spiritually.
- They can become excited at the prospect of the realisation of their Christian hope of eternal life.

It is the constant stimulus of things that give them peace and comfort that help them towards the latter end of their life.

About spiritual life of the elderly

- The ageing process has a way of facilitating spiritual growth because of loss, pain and suffering.
- C.S Lewis said that 'pain is God's megaphone to a deaf world'.
- Such events may be a catalyst that leads to a renewed faith.

- In a crisis, people tend to move towards rather than away from God.
- Listen to their story.

Talking about spiritual well-being - more ideas

If you visit officially in an aged care home, it may be that a spiritual interview was conducted on admission or by the care coordinator. If you are a recognised, 'official' part of the healthcare team, it would be useful to try to discuss this with the coordinator. It could help you to understand a resident you may be visiting. It is important, however, to use this as background information and that no reference is made to it in your conversations. The essential element, as always, is confidentiality.

Here are some more questions you might find useful in exploring for yourself the spiritual state of an elderly person (or any ill person, for that matter). **Warning: Please be careful** that the use of such questions doesn't appear to be intrusive to the person. You might also restrict yourself to just one or two of these questions, depending on how they respond.

- How are you feeling about this within yourself?
- When you want to feel strength, where do you go, who do you see?
- When you want to feel strength and comfort, what do you think of?
- Who would you like to see more of? What is it that they bring to you? How would seeing them be good for you?
- What sustains you (or, keeps you going) most at the moment?
- When have you felt loved, guided and supported in a most wholesome way?
- When do you feel connection and compassion for other lives?
- Is forgiveness a part of your life, forgiveness of both yourself and others?

Other things to consider

Each elderly person approaches mortality and spirituality in a different way.

- Anger – 'You are not fair, God. I lived a good life. Why this?'
- Acceptance – Considerable physical disability but smiles gently at a visitor.
- Avoidance – a bad prognosis. The person sits in a chair all day and pretends to be asleep if someone comes near.
- Transformation – after a vigorous life, and despite extreme difficulty, the person has changed, of necessity, to a more sedentary life.

Each person in the above categories needs to be thought of differently.

Final words…

A person's spirituality is a deeply personal issue. Considerable sensitivity and gentleness needs to be exercised when a carer is exploring this issue with a person.

When having a conversation with an older person you should be aware that they often love to tell a story – sometimes called a narrative approach to aged care. This has been described as “empowering older people to present their own life story, recognizing their uniqueness and showing a genuine interest in their narrative”. This helps the older person and can be fascinating for the pastoral visitor.

MODULE 5 HEALTH ISSUES IN AGED CARE

Workshop plan

- ✓ We will consider the Handbook pages 53-65 in this workshop.
- ✓ Please prepare four specific points that struck you as you were going through the reading.
- ✓ What are three points that struck you as important as you watched the video: *Depression and Anxiety* (Kylee Mingham)
- ✓ What are three points that struck you as important as you watched the video: *Palliative care*(Cathy Strachan).
- ✓ What are three points that struck you as important as you watched the video: *Dementia* (Cathy Strachan).
- ✓ How can you distinguish between when a person is despondent or depressed? What would you do if there is any doubt?
- ✓ Introduction to the Project associated with Module 6.

Participant questions.

What's in this module?

Understanding more about health issues in ageing. These include:

1. Palliative care
2. Dementia
3. Anxiety and depression

Palliative care

I have upheld since you were conceived, and have carried since your birth. Even to your old age and grey hairs I am he, I am he who will sustain you. I have made you and I will carry you. Isaiah 46:3-4

We looked briefly at palliative care earlier, and we look at grief and loss in another Module. We are now going to focus more on the probability that an ageing person who is in decline is facing the end of life. He or she may be very unwell and has been given little hope of recovery.

There is a variety of circumstances in which an ill person may be designated as needing palliative care. The person may wish to be at home. In this case, there are specific palliative care teams who visit the home to carry out their specific roles. The team will most likely include the medical person who is looking after for example, the pain level of the ill person. There may be a carer who looks after the day-to-day functions of the

ill person – helping with medications, providing hygiene care, assisting with diet and nutrition. You, as a spiritual carer, may be invited to become part of that team.

A person may be admitted to a hospice where there is 24 hour care for the dying person. An elderly person may be in aged care, again, where 24 hour assistance is available. In each case you may be able to provide specialist emotional and spiritual support while the other members of the team carry out their specific functions. Not always will other members of the team have the expertise (or the time) to sit and listen with the dying person and 'live' their journey with them.

Peter Hudson[11] provides a list of things that you may be able to do with a person in palliative care that will help provide emotional care. (Some of the items have been adapted from Hudson's initial list.)

- Provide some time alone with the ill person whenever you can to help them to share their inner thoughts with you. (This may not always be possible as close relatives will often want to spend all the time with their family. On the other hand, it is useful to suggest to the relative that perhaps they need a break and you will be happy to spend the time with the person. Sometimes, a dying person will not want to talk about some things with family.)
- Ask if there is anything you can do to make things easier.
- Suggest some relaxing and enjoyable things to do together.
- Ask if there is anything they have a desire for. (You may not be able to help provide for their wishes, but, if the request is simple, you may be able to help.)
- Remember that it is normal for your friend to feel downhearted from time-to-time.
- Encourage involvement in day-to-day things such as news and social activities.
- Remind your friend of the skills and different roles of the palliative care team.
- Tell your friend how much you care for him or her and want to help.

The needs of the dying

- I need help reflecting on my life, so I can make sense of it.
- I need to know that you will not judge me.
- I need to talk about my thoughts, fears and feelings.
- I need to know that you are willing to 'stay with me' on this journey.
- I need you to be honest with me.
- I need you to see me as a whole person.
- I need you to be reliable.
- I need to have my pain controlled.
- I need to be believed.

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[11] Adapted from Hudson, Peter, 2004, *Supporting a Person Who Needs Palliative Care*, Palliative Care, Victoria.

- I need you to be my advocate.
- I need your love and reassurance.
- I need you to help me relieve my fears and loneliness.
- I need you to help me discover my own philosophy, my own inner resources, confidence and spirituality.
- I need to find images of death that inspire me rather than frighten me.
- I need you to guide me to understand/support my family's emotions.
- I need you to allow me to be myself.
- I need to have some control over my life – my treatment; my future; where I would like to die.
- I need you to speak directly to me and not over my head.

Some does and don'ts for spiritual/palliative care

- Know and accept your feelings about death.
- Recognise and respect the individuality of each person's response to life and death.
- Be available and 'present' to listen.
- Allow the ill person to express as much or as little as he or she wishes.
- Be able to accept silence.
- Don't be shocked at anything you hear, even religious disbelief.
- Don't let your feelings of helplessness stop you from reaching out – presence may speak louder than words.
- Allow the expression of negative feelings, like anger.
- Don't tell the person that you understand how he or she must feel.
- When appropriate, pray with the ill person in your own words.
- Don't change the subject when the person starts talking about death.
- Don't tell the person how he or she should be feeling or behaving.
- Always be honest but sensitive.
- Draw strength from your own spirituality.

Practical spiritual care

It may well be that the dying person would like you, as the spiritual carer, to have a conversation with them about their hope. A Christadelphian will normally like this. They will normally want to talk about their hope and spiritual strength, even though they may feel unwell. It is not uncommon for a dying Christadelphian to want to 'do the readings' at any opportunity. They may not have the strength or 'wellness' to read for themselves but may be more than happy for you to read for them. Depending on their state of health at the time, they may like a reading. It is their choice.

Sometimes they won't feel like making a decision. In this case it is practical for you to suggest 'Why don't we read …', or, 'Do you have a favourite Scripture you would like to read?'

It may well be that the person with whom you are reading will want to discuss the readings. It is this intimacy with the Scriptures that will often provide strength for those who do not have much further hope of life at this stage. Always, it is what the person would like. It may just be that you will need to make suggestions first.

If you were asked to select some Scripture to read, what passages might you select? Some broad categories are – praise of God; comfort and assurance that God guides; the hope of the Kingdom and resurrection.

Here are some passages:

- Praise – Psalm 8; Psalm 9; Psalm 54; Psalm 103; Psalm 150
- Comfort and assurance that God helps – Psalm 31; Psalm 55:16-23, Psalm 46; Psalm 23, James 1:1-7
- The hope of the Kingdom and resurrection – Jeremiah 31:10-14; John 11:24; 1 Thessalonians 4:16-18; Philippians 3:10

What might you include in a prayer?

- Praise of God, and thanks, because of the hope of salvation.
- Thanks for the many blessings of life.
- Prayer for personal help for the ill person in their specific circumstances.
- Prayer for the help of those who care for the ill person.
- Prayer for the comfort of family members who are concerned.
- Prayer for continued guidance.
- Prayer for God's kingdom to be established.

And a few more things …

- Avoid being overzealous. Older people don't like being rushed and will 'tune out' if you 'move' your conversation too quickly.
- Listen to the ailing person's story with genuine interest – but avoid anecdotal stories of your own.
- Avoid providing your own medical opinions about a particular situation or illness. Leave this to those with medical expertise.

Something to discuss

One day, a person you have been visiting for some months tells you that he has just been informed he has only two or three months to live. How would you deal with this news both within yourself, and as a carer for the dying person?

Dementia

Do not cast me away when I am old; do not forsake me when my strength is gone. Psalm 71:9

What is dementia?[12]

If you or someone you care for has a diagnosis of dementia, you will probably have questions about what it means, what to do and who can help – both in the short term and in planning for the future.

The most important thing to understand is that help is available. Whether you're living in your own home or in an aged care home, there are aged care services that specialise in helping people with dementia.

You will find some basic information below to direct you towards resources that may help answer your questions.

There are a number of different types of dementia. Dementia is a condition (a group of related symptoms) that is associated with an ongoing decline of the brain and its abilities, including:

- memory
- thinking
- language
- understanding
- judgement

People with dementia may also become uninterested, have problems controlling their emotions or behave inappropriately in social situations. Aspects of their personality may change or they may see or hear things that other people do not.

Usually, dementia occurs in people who are aged 65 or over. The older you get, the more likely you are to develop this condition. Around one in four people living in Australia over 85 years have dementia.

What are the most common types of dementia?

The most common type of dementia is Alzheimer's disease. It accounts for between 50% and 70% of all types of dementia. Alzheimer's disease is a degenerative condition that affects the brain. As brain cells die, the substance of the brain shrinks causing certain information to no longer be recalled or understood.

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[12] Quoted and adapted https://www.myagedcare.gov.au/getting-started/health-conditions/dementia accessed 2 October, 2017.

Vascular dementia is the second most common form of dementia. The condition is related to problems with the circulation of blood to the brain.

When is memory loss more likely to be associated with dementia?

Many people worry that forgetting things might indicate dementia. It is normal to occasionally forget appointments or a friend's phone number, but memory loss associated with dementia will most likely be persistent and progressive, not just occasional.

The Alzheimer's Australia website provides more information about memory loss, including advice that may help you to distinguish between normal memory loss and memory loss associated with dementia, as well as tips for keeping your memory sharp.

Communicating with people with dementia

You may notice changes in the way that you communicate with the person you care for. For example, they may find it hard to find a word, speak fluently, understand, write, read or express emotions. They may also lose normal social conventions of conversation, for example ignoring what you're saying or interrupting you.

When communicating with someone with dementia it's important to:

- check their hearing and eyesight to make sure that this isn't the source of the problem
- remember that people retain their feelings and emotions even though they may not understand what you're saying
- stay calm, allow time for them to understand, use short, simple sentences and help orientate them by describing what you're about to do, who is about to visit and their relationship with this person
- use positive body language and touch, as this forms a large part of communication, and
- try not to
    - argue
    - be condescending
    - order the person around
    - ask questions that rely on a good memory, or
    - talk about them in the presence of other people.

Footnote

There can be confusion (even amongst medical professionals) over the difference between dementia and Alzheimer's disease. The distinction between the two terms is often fuzzy. Simply, Alzheimer's is a form of dementia. Alzheimer's is regarded as a degenerative disease of the central nervous system that leads to dementia. It is characterized by lesions that gradually destroy cells in the brain. 'General' dementia is a deterioration of mental capacities due to physical changes in the brain. It is not necessarily a disease caused by a microorganism or deficiencies in the body's required nutrients.

Something to discuss

What are some of the main attributes you need personally to care for a person with dementia?

Anxiety and depression

You might like to look at Kylee Mingham's video *Depression and Anxiety*. It will serve as a practical introduction.

> Is not wisdom found among the aged? Does not long life bring understanding? Job 12:12

Anxiety[13]

Research on both the cause and treatment of anxiety in older adults, lags behind research in other mental conditions, such as depression and Alzheimer's. Until recently, anxiety disorders were believed to decline with age. But now experts are beginning to recognize that ageing and anxiety are not mutually exclusive: anxiety is as common in the old as in the young, although how and when it appears is distinctly different in older adults.

Anxiety disorders in the elderly population are real and treatable, just as they are in younger people. Another commonality between old and young is the high incidence of depression with anxiety. Depression and anxiety go together in the elderly, as they do in the young, with almost half of those with major depression also meeting the criteria for anxiety, and about one-quarter of those with anxiety meeting criteria for major depression. As with younger persons, being a woman and having less formal education are risk factors for anxiety in older adults.

Most older adults with an anxiety disorder had one when they were younger. What "brings out" the anxiety are the stresses and vulnerabilities unique to the ageing process: chronic physical problems, cognitive impairment and significant emotional losses.

Late-life anxiety disorders have been underestimated for several reasons, according to experts. For example, older patients are less likely to report psychiatric symptoms and more likely to emphasize their physical complaints, and some major epidemiological studies have excluded Generalized Anxiety Disorder, one of the most prevalent anxiety disorders in older adults.

Recognising anxiety in ageing

Recognizing an anxiety disorder in an older person poses several challenges. Ageing brings with it a higher prevalence of certain medical conditions, realistic concern about

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[13] Quoted and adapted from http://www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/ accessed 30 January, 2007, with contribution from Colleen Roberts.

physical problems, and a higher use of prescription medications. As a result, separating a medical condition from physical symptoms of an anxiety disorder is more complicated in the older adult. Diagnosing anxiety in individuals with dementia can be difficult, too: agitation typical of dementia may be difficult to separate from anxiety; impaired memory may be interpreted as a sign of anxiety or dementia, and fears may be excessive or realistic depending on the person's situation.

Many elderly people in aged care exhibit anxiety, some chronically so. It is very common with dementia, as people lose their sense of time, place and control generally over their life, and may feel victimized as a result. The anxiety may show itself by a resident demanding to know the exact time a visitor might come, or they may insist their medications arrive at exactly the same time each day. Trivial care concerns may become major issues for them, and are then passed on to any ready listening ear. A spiritual carer can provide the listening ear and the kindly reassurance that often help stabilise the emotion and relieve the anxiety expressed at a particular moment, but, in time, the anxiety seems to become worse.

Depression[14]

Depression is a serious disease – far more complex than simply feeling moody or blue. Older people experience similar symptoms to younger people – but these symptoms often go unrecognised, misdiagnosed or poorly treated. For example, symptoms such as loss of sleep, memory, or concentration are mistakenly regarded as being simply age-related.

Diagnosis is harder too, because older people often feel more comfortable talking about physical complaints than acknowledging depression as anything more than sadness. Also, when depression combines with dementia, there is an added complexity in diagnosis.

Depression and anxiety explained

The word *depression* is often used to describe the feelings of sadness which all of us experience at some stage of our lives. It also describes a form of mental illness called clinical depression.

Because depression is so common, it is important to understand the difference between unhappiness or sadness in daily life and the symptoms of clinical depression.

When we're faced with stress – caused by the loss of a loved one, or a relationship breakdown, or great disappointment or frustration, or anything at all – most of us feel unhappy or sad. But these emotions will usually last only a limited time. They are not regarded as clinical depression, but as a part of everyday life.

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[14] Quoted and adapted from Australian Government, *Depression*, http://www.agedcareaustralia.gov.au/internet/agedcare/publishing.nsf/ accessed 30 January, 2007

Clinical depression describes not just one illness but a group of illnesses. In all of them, the person affected has an excessive or long-term depressed mood, which affects their life. Clinical depression is often accompanied by feelings of anxiety. Whatever the symptoms and causes of depression, treatment can be very effective.

Depression is common

People of all ages, cultures and backgrounds can experience depression. The symptoms of depression vary in severity and from person to person. They can range from feeling irritable to feeling suicidal.

If you are caring for a person suffering from depression, the good news is that safe and effective treatments are available. But the first step to progress is in recognising the symptoms. Do any of the symptoms listed below seem familiar? If so, it's important to seek help for the person showing those symptoms as soon as possible. Symptoms are:

- increased moodiness
- memory and concentration problems
- feelings of sadness, anxiety or avoidance of certain situations
- unusual behaviour that is out of character
- lack of enthusiasm and energy
- feeling unworthy
- irritability and sensitivity
- social withdrawal
- feelings of hopelessness
- losing interest in the activities of others
- headaches, backaches or digestive complaints without a proper medical explanation
- loss of interest in food or exercise
- increased alcohol and drug use
- reckless behaviour
- difficulty in sleeping
- fatigue, pain, or
- suicidal thoughts.

Causes of depression

There is hardly ever just one specific cause of depression. Some people seem more likely to become depressed than others. Sometimes depression may happen without an apparent cause. At other times coping with stressful events may contribute to becoming depressed. Examples might include:

- the death of someone you love

- an accident or illness
- changing accommodation, or
- family crises.

Coping with ongoing stress can also result in depression. Examples of prolonged stress include:

- trying to make ends meet on a low income
- being unemployed
- being a long-term carer for a dependent person, or
- feeling lonely.

Sometimes more than one family member may experience depression. This is because the way we behave and react is partly shaped by our genes (the physical make-up we are born with). How we are brought up can increase the risk that we will experience depression.

Having unhappy experiences in childhood or in relationships can increase the risk of becoming depressed later in life. Equally, good experiences such as a close relationship with a parent or friend or a having a purpose in life can reduce the risk of depression.

The link between ageing and depression

Most surveys show that depression is not that common amongst older people living at home who remain in good health. But there does seem to be a link between disability and depression, as well as bereavement, loneliness, chronic pain, social isolation and the loss of independence.

However, none of these in themselves create depression. For example, it's normal to grieve for a loved one, but if this turns to depression it must be recognised and treated.

Depression is often not well recognised or detected in older people. Quite often symptoms of depression, such as problems with sleeping, are mistakenly dismissed in older people as just age-related. Doctors sometimes may assume that problems with memory or concentration are due to age-related changes in thinking, rather than being due to depression. Sometimes depression co-exists with dementia and this can make the specific diagnosis difficult. So it's important to have a thorough medical and psychological assessment.

There also seems to be a link between physical illnesses causing disability, and disability in turn causing depression. Bereavement, chronic pain and having to become more dependent upon others for care can lead to a sense of a loss of dignity and independence, which may cause someone to become depressed. Another risk factor for depression in older persons is that of becoming socially isolated.

These situations -- such as disability, loss and loneliness – may be more common in older people. But this doesn't mean that becoming clinically depressed as a reaction to them is normal. It is normal to grieve when faced with loss, but depression is a more severe and persistent sadness. Depression should always be investigated and treated

appropriately.

Treating depression and anxiety

The treatment received by older people will be the same as for any other age group. Treatment depends on symptoms, but will take one or more forms.

- Psychological interventions help people understand their thoughts, behaviour and interpersonal relationships.
- General supportive counselling assists in sorting out practical problems and conflicts and helps in the understanding of the reasons for depression.
- Anti-depressant medications relieve depressed feelings, restore normal sleep patterns and appetite and reduce anxiety. Unlike tranquillisers, anti-depressant medications are not addictive. They generally take 1–4 weeks to achieve their positive effects.

Talking with a health professional in a structured way can help relieve depression. This therapy involves a choice of one or more psychological therapies. The therapist aims to work on the way the person reacts to circumstances and relationships.

Other treatment

Whatever the severity of a person's depression, treatment should include learning new skills like problem solving and changes to lifestyle, cutting down on stress, increasing physical fitness and not using alcohol or non-prescribed drugs.

About getting professional help

Some people feel embarrassed about getting help for depression. In some cases, people might not even know they are experiencing it, but may be worried about bodily symptoms, such as headaches or chest pain. These are often how our body expresses tension and anxiety as part of a depressive illness.

Getting help for depression is not a sign of weakness. It is important to find ways of getting help to treat it as soon as possible. A doctor, nurse or mental health professional will be able to advise on the choices that can be made about the most suitable treatment.

What can a depressed person do to help their own treatment?

The greatest contribution to a positive outcome from treatment comes from:

- developing a trusting relationship with the health professional, working together to find a suitable treatment
- identifying and working on factors which appear to have contributed to the depression, and
- continuing with treatment for as long as is necessary to deal with the issues

causing the depression.

Other support during recovery from depression

Maintaining and making good friendships is also very important in recovery from depression. Make the most of family, friends and local community groups. Try to help the person avoid being isolated.

There are also groups run by people who have experienced a mental illness and who have had successful treatment. These include self-help and mutual support groups or associations, and mental health consumer organisations. Such organisations may offer mutual support by phone or in groups that meet face to face. Some offer web site chat rooms. Others provide formal information and referral services for personal support, postal or telephone information for the depressed person and their family or partner, and some may suggest clinics, after-hours crisis lines and information about the treatments available.

Although they are not direct treatment services, these organisations may be helpful when the person is trying to find the right treatment, and may make it easier to remain in treatment to get the best results.

What role can a pastoral visitor take in helping a person with depression?

Some of the answers can be found above. The essential one is providing support and understanding. The extent we can help may depend on the degree of depression. If the person lives at home it is important that a carer tries to determine the extent of depression by carefully finding out the degree of the symptoms indicated above. If the symptoms are mild and the depression doesn't seem to last very long, providing the companionship and support on a regular basis may be sufficient. If the symptoms are more pronounced, encouraging the depressed person to seek professional help is a good option. (While you may wish to make it easy for the person to seek help – finding the doctor's phone number, or a helpline phone number, it is important that the person him/herself makes the contact and appointment. You may offer to accompany them to the appointment.)

When caring for a depressed person, it is important to realise our limitations. We are not counsellors. We are listeners and observers. While in some instances listening to the story and providing spiritual support may be enough to help the person overcome 'mild' depression (despondency), we are not qualified to help with deeper depression over a longer period of time. This is where our skills in encouraging a referral become important.

In an aged care home, it is likely that the staff will be aware of a resident's depression and are taking appropriate action. In this case, a pastoral visitor can support the resident again, through listening and offering spiritual encouragement.

Research has demonstrated that using religious beliefs and activities can be very

effective in relieving depression in a religious person. These research findings also relate to older people. So, encouraging religious people to talk about their faith, offering to read appropriate Scripture with them, (not always the Psalms where David talks about his own depression), and encouraging them to articulate (and thus reinforce) their hope, can all help.

You should be aware, however, that depressed people may cry out for God's help but become further depressed when God does not appear to respond. They may feel deserted and angry. They may feel that they cannot read the Bible or pray. Try to encourage them to do a little but you should be aware that pushing them to read or pray if they do not wish to, may only heighten their feelings of guilt. A simple 'I will pray for you tonight' may be all that you can do immediately, but ultimately, you can probably do no better than offer your own faithful prayer.

Something to discuss

How can you distinguish between when a person is despondent or depressed? What would you do if there is any doubt?

MODULE 6 – CONVERSATION WITH AN OLDER PERSON

Workshop plan

- ✓ We will consider the Handbook pages 66 and 67 in this workshop.
- ✓ What are three points that struck you as important as you watched the video: *How can I talk with an older person* (Laurence Lepherd)
- ✓ The main part of this workshop is to discuss your Project – "Conversation with an older person"
- ✓ Each participant will be asked to talk about their conversation and reflect on their involvement in it, in other words, engage in self-reflection.

Participant questions.

What's in this module

Taking the opportunity to reflect on the possible circumstances of one older person, possibly in an aged care home, and to suggest possible responses to the issues raised. (Look at Laurence Lepherd's video on *How can I talk with an older person*?)

> May the words of my mouth and the meditation of my heart be pleasing in your sight, O LORD, my Rock and my Redeemer. Psalm 19:14

Project – Report on a conversation

We would like you to visit or speak with an elderly person, record the conversation in writing and to reflect on the visit using the headings below as your guide. The main aim of this project is to enable you to put into practice what you have developed.

It is emphasised that this project is a little 'self-centred' in that, while you are trying to show you care for the older person, you are also trying to develop and refine your own visiting and caring skills. The reflection, then, should be on yourself, not on the person.

The report should be strictly anonymous. Privacy is important when visiting people. It is important that other members of the workshop group should not be able to identify the person visited. Give the person a fictitious name so that at least (s)he appears to be human – much better than writing 'the person' in your report! The visit might be anywhere between 15 to 30 minutes. A short visit is quite acceptable. While you should try to recall the conversation verbatim, it is acceptable to write what you can remember. (Please do not audio record the visit or take notes during your conversation.

If you wish, you may like to 'create' a conversation for yourself. This can be challenging because you need to think of the other person's possible conversation's directions as well as your own responses. You may find it easier to recall a conversation you have already had with

some else. As you get closer to this project, you will be given an example of a conversation and an analysis to help you.

You should send your written conversation to the workshop leader two days before the workshop. You will be asked to discuss the conversation and present your analysis at the workshop itself.

Project – Personal reflection

1 Where did the conversation take place?
2 What were the surroundings?
3 How did the person look when you first saw him/her?
4 How did you commence the conversation?
5 What were the essential elements of the person's story?
6 What were the person's non-verbal expressions during your conversation?
7 What was the general direction of your conversation?
8 What were some of the person's keywords?
9 How were your paraphrasing and questions?
10 What were the spiritual issues you were able to discuss with the person?
11 What were your impressions of your conversation?
12 Future directions?

Please be frank and honest in your analysis! We all made mistakes once, and, unfortunately, can continue to make them. The emphasis in the project is not on how correct you are but how you reflect on your visit.

Completion of the Program (PVP)

That brings us to the end of the Program. We trust you feel that you have developed your personal spirituality and have also developed your caring skills and understanding further.

Always care in a God-centred framework and never underestimate the power of prayer.

God be with you

Laurence Lepherd