

SPIRITUAL CARE & DEMENTIA

A Guide Presented By:
Prelude Ministries



“Be completely humble and gentle;
be patient, bearing with one
another in love. Make every
effort to keep the unity of the Spirit
through the bond of peace.”

EPHESIANS 4:2-3

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CHANGING PERSPECTIVE

THE SPIRITUAL CARE NEEDS OF SENIORS WITH DEMENTIA

When caring for others we must see things as they are, not as we are. We must learn to see things from the eyes of a senior citizen with dementia. What do they see? What do they hear? What do they feel? What do they fear? What questions do they have? How can we help them in their spiritual journey during this season of life?

We must also see seniors with dementia as God sees them, not as the world sees them. Most of the world sees seniors with dementia as scary and useless. The world tends to isolate dementia persons and “warehouse” them. God sees them differently. God loves them and wants to see them thrive; living out their time on Earth engaged and active, knowing God and feeling His love and care.

Dementia is loss: The world understands dementia as the loss of memory, but it is much more than that. It is certainly the loss of memory and cognitive ability, but more importantly, dementia is the loss of autonomy and independence.

It is also the loss of their dreams and aspirations for this stage in their life. No one dreams of living in a care facility for their senior years. We may dream of playing golf in Palm Springs or lying in the sand on Laguna Beach or weekends with family. Dementia is more than memory loss. It is the loss of dreams and hopes for this season of life. With loss comes grief.

This loss impacts individuals with dementia, but also their families as each deals with their grief differently. Spouses, children, grandchildren and friends all process their grief in different ways and at different paces. Processing grief is not a linear path. Much of our ministry is helping family and friends process their grief as they see their loved one decline in physical and cognitive health.

We start with a changed perspective. An open slate looking expectantly to God to fill in the details and equip us to move forward. This journey with a changed perspective starts today!

10 SPIRITUAL NEEDS

FOR YOUR LOVED ONE WITH MEMORY LOSS

I Need to Know that God Knows Me

He knows every detail of me and of my life.

(Ps 139:1-4, Jer 1:5, John 10:27, Rom 8:27, Heb 4:13)

I Need to Know that God Loves Me

(Ps 86:15, Ps 136:26, Jer 31:3, John 3:16, Rom 5:8, 1 Cor 13:3)

I Need to Know that God is with Me and He Cares for Me

God is with me in the good days and in the tough days. He is beside me every step of the way.

(Deut 7:9, 31:8, 33:27, Zeph 3:17, Jer 29:11, Josh 1:9, Ps 146:1-3, Isa 41:10, 1 Pet 5:10, Heb 4:16)

I Need to Know that Nothing Can Separate Me from God's Love

Not even dementia. Even as my memory and intellectual ability fades with time, God has not forgotten me. In God's memory are everything that I have done and said. God forgets nothing yet He forgives. My relationship with God remains intact even when my intellectual ability to understand Him (and the Bible) fades.

(Rom 8:35-39, Gal 2:20, Heb 13:5, 2 Tim 4:17)

I Need to Know that My Salvation is by Faith, Not by Works

Not by baptism; not by confirmation, not by rituals but by relationship. My salvation is by faith in Jesus Christ as the Son of God and the substitute sacrifice on the cross for my sin. A new covenant. By faith and grace alone in Christ alone.

(John 3:16, Rom 3:22-30, Rom 4:16, Rom 5:1, Rom 10:4,9-10, Rom 11:6, Gal 2:16,21, Gal 3:22,24, Eph 2:8-9, Phil 3:9, 1 Tim 1:16)

I Need to Know My Purpose at this Time in My Life

What is the meaning of life? Why am I here? God has a purpose for my life, now and into eternity. If we are not dead, we are not done. God is continuing to work in me and through me to impact the world around me.

(Isaiah 44:2, Isaiah 49:4, Jer 29:11, Acts 10:35, Col 1:16, Prov 16:4, Eph 1:4, 11-12)

I Need to Know I Still Have Value

I have value in my family, in my world, in my God.

(Isaiah 49:15, Jer 29:11, Jer 31:3, Rom 5:8, Peter 1:18-19, 1 John 3:11, Eph 2:4-7)

I Need to Know What Comes Next

Is this all there is? Working, living and dying?

(Psalm 39:4-7, John 3:16, Eph 2:8-10, Rev 3:8, Job 14:14-16, 1 John 5:13-14)

I Need to Know that God is Preparing a Place for Me

There is more to my life than this short time on Earth. It is but a Prelude to greater things. I will spend many more years in eternity.

(John 14:1-4, 1 Cor 2:19, Matt 25:34, Heb 11:16)

I Need to Know that God is Preparing Me for My Place in Eternity

As God prepares a place for me, He is preparing me for my place in His Kingdom. He has a role for me in eternity, a place for me to serve His Kingdom.

(John 14:1-4, 6, Heb 2:10, 1 John 2:16, John 14:7-11, 2 Cor 4:17-18)

“Grace, mercy, and peace from God the Father and from Jesus Christ, the Father’s Son, will be with us in truth and love.”

2 JOHN 1:3

GRIEF AND LOSS AS ALZHEIMER’S PROGRESSES

It is common for caregivers to have feelings of loss and grief as their life is changed by Alzheimer's. You are entitled to these emotions and may start to experience them as soon as you learn of the diagnosis. Share your feelings and seek support as you go through this process.

FEELINGS OF GRIEF

It’s normal to feel loss when you care about someone who has Alzheimer’s disease. It’s also normal to feel guilty, abandoned and angry.

Alzheimer’s gradually takes away the person you know and love. As this happens, you will mourn him or her and may experience the different phases of grieving: denial, anger, guilt, sadness and acceptance. The stages of grief don’t happen neatly in order. You may move in and out of different stages as time goes on.

Some common experiences in the grieving process include:

DENIAL

- Hoping that the person is not ill
- Expecting the person to get better
- Convincing yourself that the person has not changed
- Attempting to normalize problematic behaviors

ANGER

- Being frustrated with the person
- Resenting the demands of caregiving
- Resenting family members who cannot or will not help provide care
- Feeling abandoned

GUILT

Having unrealistic expectations with thoughts like: “I should have done ...” “I must do everything for him or her” or “I must visit him or her every day”

Feeling bad because you are still able to enjoy life

Feeling that you have failed if, for example, you cannot care for the person at home

Having negative thoughts about the person or wishing that he or she would go away or die

Regretting things about your relationship before the diagnosis

SADNESS

Feeling overwhelmed by loss

Crying frequently

Withdrawing from social activities or needing to connect more frequently with others

Withholding your emotions or displaying them more openly than usual

ACCEPTANCE

Learning to live in the moment

Finding personal meaning in caring for someone who is terminally ill

Understanding how the grieving process affects your life

Appreciating the personal growth that comes from surviving loss

Finding your sense of humor

Asking for and accepting help from others

WAYS TO COPE WITH GRIEF AND LOSS

FACE YOUR FEELINGS.

Think about all of your feelings — positive and negative. Let yourself be as sad as you want, and accept feelings of guilt because they are normal. Work through your anger and frustration. These are healthy emotions. Know that it is common to feel conflicting emotions. It is okay to feel love and anger at the same time.

PREPARE TO EXPERIENCE FEELINGS OF LOSS MORE THAN ONCE.

As dementia progresses, it is common to go through feelings of grief and loss again. Accept and acknowledge your feelings. They are a normal part of the grieving process.

CLAIM THE GRIEVING PROCESS AS YOUR OWN.

No two people experience grief the same way. Grief hits different people at different times; some people need more time to grieve than others. Your experience will depend on the severity and duration of the person’s illness, on your own history of loss and on the nature of your relationship with the person who has Alzheimer’s.

Everyone grieves differently and at their own pace. If your grief is so intense that your well-being is at risk, ask for help from your doctor or a professional counselor.

TALK WITH SOMEONE.

Talk with someone you trust about your grief, guilt and anger. If you decide to meet with a therapist who specializes in grief counseling, interview several so you can choose one you are comfortable with.

COMBAT FEELINGS OF ISOLATION AND LONELINESS.

Caregivers often give up enjoyable activities and companionship. Make a lunch or movie date with friends. Taking a break may help you relieve stress and grief, and strengthen your support network. Stay involved in activities that you enjoy.

JOIN A SUPPORT GROUP.

When you talk with other caregivers, share your emotions. Cry and laugh together. Do not limit conversations to caregiving tips. Alzheimer’s Association support groups take place all across the country. Find one near you. If you prefer online support, join ALZConnected, our online caregiver community with message boards.

KNOW THAT SOME PEOPLE MAY NOT UNDERSTAND YOUR GRIEF.

Most people think grief happens when someone dies. They may not know that it is possible to grieve deeply for someone who has a progressive cognitive illness.

ACCEPT YOURSELF.

Think about what you expect from yourself. Is it realistic? Learn to accept the things that are beyond your control. Make responsible decisions about the things you can control.

TAKE CARE OF YOURSELF.

The best thing you can do for the person you are caring for is to stay healthy. This includes taking care of your physical, mental and emotional well-being. Create balance in your life. Do things that bring joy and comfort, and give yourself time to rest. Ask for help when you need it, and accept the help that is offered.

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END OF LIFE

Only God knows the day and time your loved one may pass away. For most, Prelude is a resident's final earthly home before entering into eternity.

Prelude Ministries will do everything in our power to support and minister to the family and resident at the end of life. As end of life approaches, Prelude's team will be deliberate in our interactions with the resident, building on the relationships we have established. Prelude has a **Family Care Basket** which is equipped for your use with items intended to provide comfort and support.

When the resident passes, the family may want to exit the room as the Prelude staff makes the resident presentable to the family. Once completed, we engage in a **Resident Bedside Memorial Service**. This follows the medical staff's pronouncement of death and is held with the permission and approval of the family.

The Pastor leads this short service for family who are present and often Prelude staff will join. We also invite family members, friends and staff to share a meaningful memory, family experience or value. Once finished, the funeral home will take the body from Prelude in an honor walk procession to the funeral car.

Prelude Pastors are available to assist with navigating the end of life process and often have conducted the celebration of life services at the request of families.

No one travels through life without, at some point, experiencing the loss of someone or something dear. The loss of a loved one through death is one of life's most intense challenges, and the pain can be overwhelming.

But God doesn't leave you to suffer alone.

Cling to the Lord and He will comfort you through the process of grieving and, in the future, will replace your sorrow with great, unending joy.

PLANNING ACTIVITIES FOR YOUR LOVED ONE

BEST PRACTICES FOR SELECTING ACTIVITIES

- Involve the person in activity decisions.
- Don't spend a lot of money unnecessarily.
- Look around the house for material for DIY activities.
- Remember that what works today may not work tomorrow.
- Tailor activities to the person's work life and interests.
- Include children as much as possible in interactions and activities.
- Include the person in holiday celebrations to the extent they are comfortable.
- Choose activities with a "sweet balance" skill level.
- Have a variety of activity options available in anticipation of changing stages.
- Avoid providing too much stimulation at one time.

BEST PRACTICES FOR SUPERVISING ACTIVITIES

- Consider the time of day before starting an activity.
- Help get the activity started.
- Break the instructions down into easy-to-follow steps.
- Don't criticize or correct.
- Concentrate on the process and not the result.

ACTIVITIES TO TRY WITH YOUR LOVED ONE

- Read a story
- Use the life legacy
- Talk to them
- Listen to music/dance/sing
- Fold clothes/towels
- Lead them in stretching
- Tell jokes
- Look at magazines
- Go for a walk around the room or outside
- Play with cards
- Color a picture
- Naming games
- Ask questions- "Do you like coffee or tea better?"
- Finish the line activity sheet- "The early bird gets the ____" (worm)
- Play catch or kickball
- Dominos
- Bean bag toss
- Paint nails
- Give a backrub
- Offer a snack such as a banana
- Puzzles
- Do some reminiscing- "Tell me about a time you ____"
- Use balloons for play
- Visit gardens



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