

*Module Two:*

**YOUR ROLE AS A DEMENTIA CAREGIVER**

# THE COMPASS GUIDE



**An education, support & coaching platform  
for dementia caregivers**

# *Being a dementia caregiver*

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- Caregiver Statistics
- Common Caregiver Experiences
- Risk of stress & burnout
- Self-care Strategies
- Mindset Matters
- Caregiver Grief Cycle
- Identify your Dementia Care "Village"
- Local Support Resources



"Alzheimer's takes a devastating toll on caregivers. Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial and physical difficulties."

(Alzheimer's Association, 2022)

3000

**Estimated number  
of Bermudians  
currently living  
with Dementia**

80%

**80% of dementia  
care is currently  
provided by  
unpaid family  
members**

1/3

**1/3 of dementia  
caregivers are  
aged 65+ many  
of which have  
their own health  
concerns**

2/3

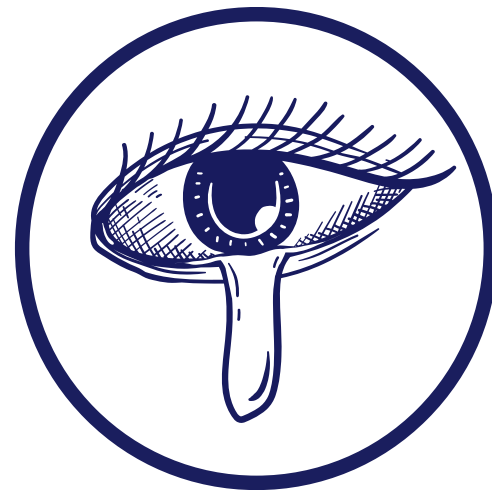
**2/3 of dementia  
caregivers are  
women who  
reside with  
their loved one  
with dementia**

25%

**25% of caregivers  
identify as "sandwich  
generation" meaning  
they support ageing  
parents as well as  
their own  
children/families**

# Common Caregiver Emotions

It is normal to experience a range of emotions as a care provider for someone living with Dementia. It is okay to mourn the loss of the relationship and future you imagined



- Denial
- Anger/frustration
- Jealousy of others
- Guilt
- Sadness
- Exhaustion
- Social Isolation
- Financial Strain
- Stress
- Burnout
- Growth mindset
- Acceptance



## HOW CARING FOR SOMEONE WITH DEMENTIA MAY BE DIFFERENT....

- Dementia caregivers typically provide care for longer periods of time than those caring for individuals with other health conditions (>60% will provide care for more than 4 years).
- Compared with caregivers of people without dementia, twice as many dementia caregivers report significant emotional, financial and physical difficulties.
- 59% of dementia caregivers report high-very high levels of stress
- 40% of dementia caregivers report symptoms of depression & anxiety as a result of their caregiving role.
- Dementia caregivers typically are required to provide more "hands-on" care assistance with intimate daily tasks such as bathing, dressing, feeding & toileting
- There are higher rates of behavioural outbursts and resistance to care secondary to cognitive decline and communication challenges
- Loved ones with advancing dementia may not have the insight into their need for assistance, may be resistant to care and appear ungrateful for care provided
- Dementia caregivers often feel like they are the only ones who know their loved ones well enough to provide good quality care
- Lack of dementia specific care and support resources in Bermuda

Alzheimer's Association, Facts & Figures, 2022

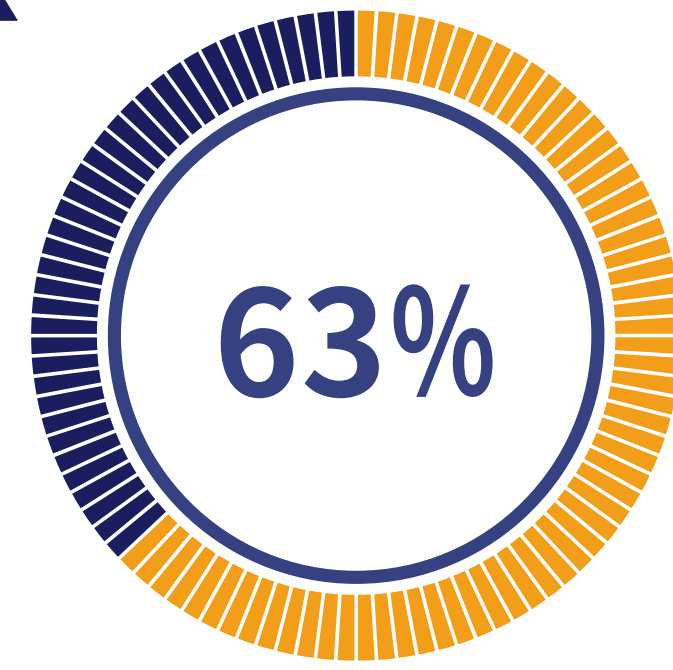


# Caregiver Stress & Burnout

- Chronic stress leading to physical health concerns
- Poor mental health
- Social isolation
- Lack of self care
- Inability to balance other roles & responsibilities
- Increased mortality rate

*Higher*

**MORTALITY  
RATE THAN  
NON  
CAREGIVER**



*Healthy*

**SPOUSES WILL  
DIE BEFORE  
THEIR PARTNER  
WITH DEMENTIA**

# 12 Signs of Caregiver Burnout



Anxiety, depression,  
irritability and  
impatience



Constantly feeling  
exhausted



Neglecting your  
responsibilities and needs



Falling sick  
more often



Loss of interest in  
activities you  
once enjoyed



Changes in  
sleep patterns



Changes in appetite  
or weight



Feeling overwhelmed,  
helpless or hopeless



Withdrawal from  
family and friends



Feel like your life revolves  
around caregiving



Constantly worrying even  
when help is available



Wishing to hurt yourself  
or the person you are caring for



# Common Caregiving Mistakes

- Trying to manage it alone
- Not asking for help
- Feeling that people should offer help without being asked
- Not planning ahead
- Not educating yourself on dementia
- Avoiding important conversations with your loved one
- Not pacing yourself
- Neglecting self-care

# *Taking Care* **OF YOURSELF**

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**IS AN ESSENTIAL PART  
OF TAKING CARE OF  
OTHERS.**

**THE HEALTHIER THE  
TREE, THE BETTER THE  
FRUIT IT CAN OFFER.**



# What is Self-care?



**"SELF CARE" LOOKS  
DIFFERENT FOR  
EVERYONE, BUT HERE  
ARE SOME BASICS TO  
CONSIDER...**

- Get dementia educated- the more you know about your loved ones condition, the more realistic your expectations will be
- Know and accept your limits
- Take care of your health- eat well, hydrate, move daily, prioritise sleep, attend medical appointments
- Forgive yourself- you are only human
- Join a support group
- Ask for and accept help when offered
- Train your brain to focus on the positives/strengths that remain
- Retain a sense of humour
- Use positive affirmations
- Schedule regular respite time each week to participate in activities you enjoy
- Spend time with people who bring you joy
- Seek professional help if needed
- Build your dementia village
- Participate in "5 minute fixes" as needed daily

**TAKE A  
SHOWER**

**HAVE A HOT  
or COLD  
DRINK**

**GO FOR A  
WALK  
AROUND  
THE BLOCK**

**STRETCH**

**CALL A  
FRIEND**

**5**  
**MINUTE  
FIXES**

**LISTEN TO  
YOUR  
FAVOURITE  
SONG**

**SIT  
OUTDOORS**

**WATCH A  
FUNNY  
YOUTUBE  
VIDEO**

**CRY**

**MEDITATE**

**EAT A  
HEALTHY  
MEAL/SNACK**



# Mindset

“ You either get bitter or you get better. It's that simple. you either take what has been dealt to you and allow it to make you a better person, or you allow it to tear you down. the choice does not belong to fate, it belongs to you.

**JOSH SHIPP**

**THE COMPASS | 2023**



## **THE CASE FOR AGING IN PLACE AT HOME**

# *Current System Limitations*

- No specialised dementia facilities on island
- Hospital is equipped to provide acute care services not long term care for PWD
- Role of first responders
- Limited residential care beds/waiting lists for placement
- Inappropriate use of physical and chemical restraints
- Limited respite care options



# Importance of Mindset

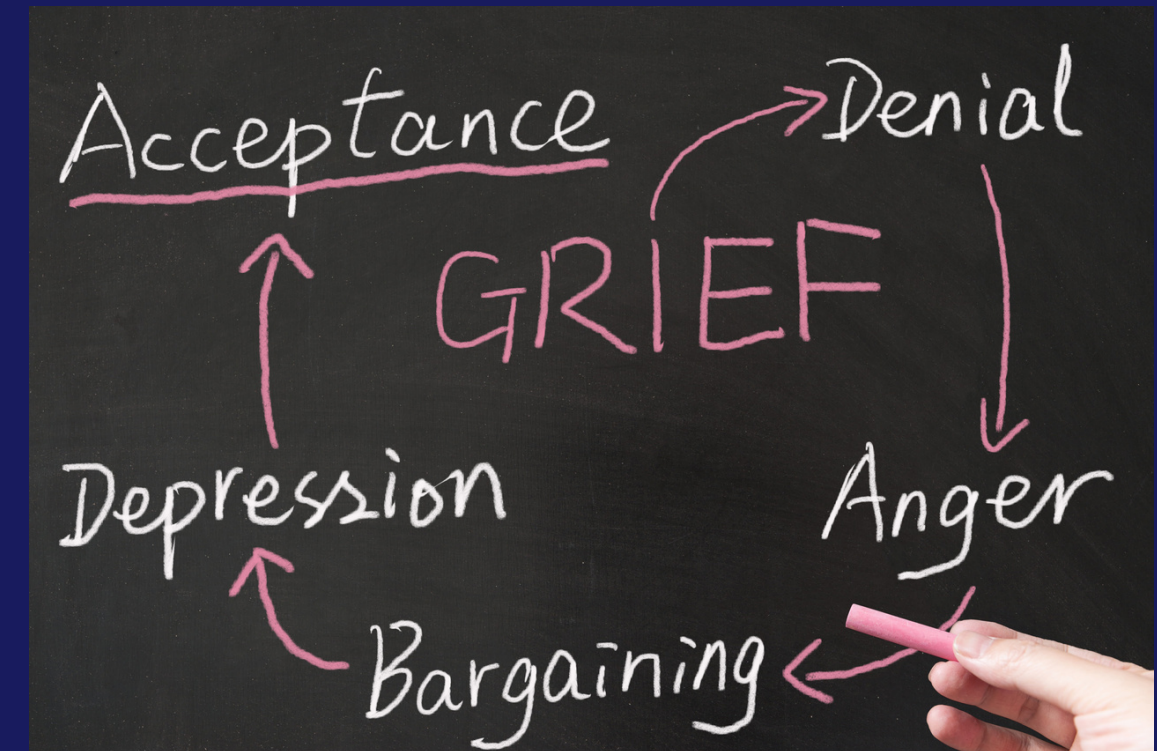
- This is a process that takes time and experience
- Moving towards acceptance of current situation
- Think-feel-act cycle: The way we think about an issue, impacts the way we feel about the issue, which in turns guides our actions in the moment
- The good news is that we can consciously adjust our thoughts to foster more positive outcomes in future



# Caregiver Grief Cycle

Anticipatory Grief = grieving those that are still with us, grieving the future we planned, grieving the relationship we had.

- Denial
- Anger
- Bargaining
- Depression
- Acceptance



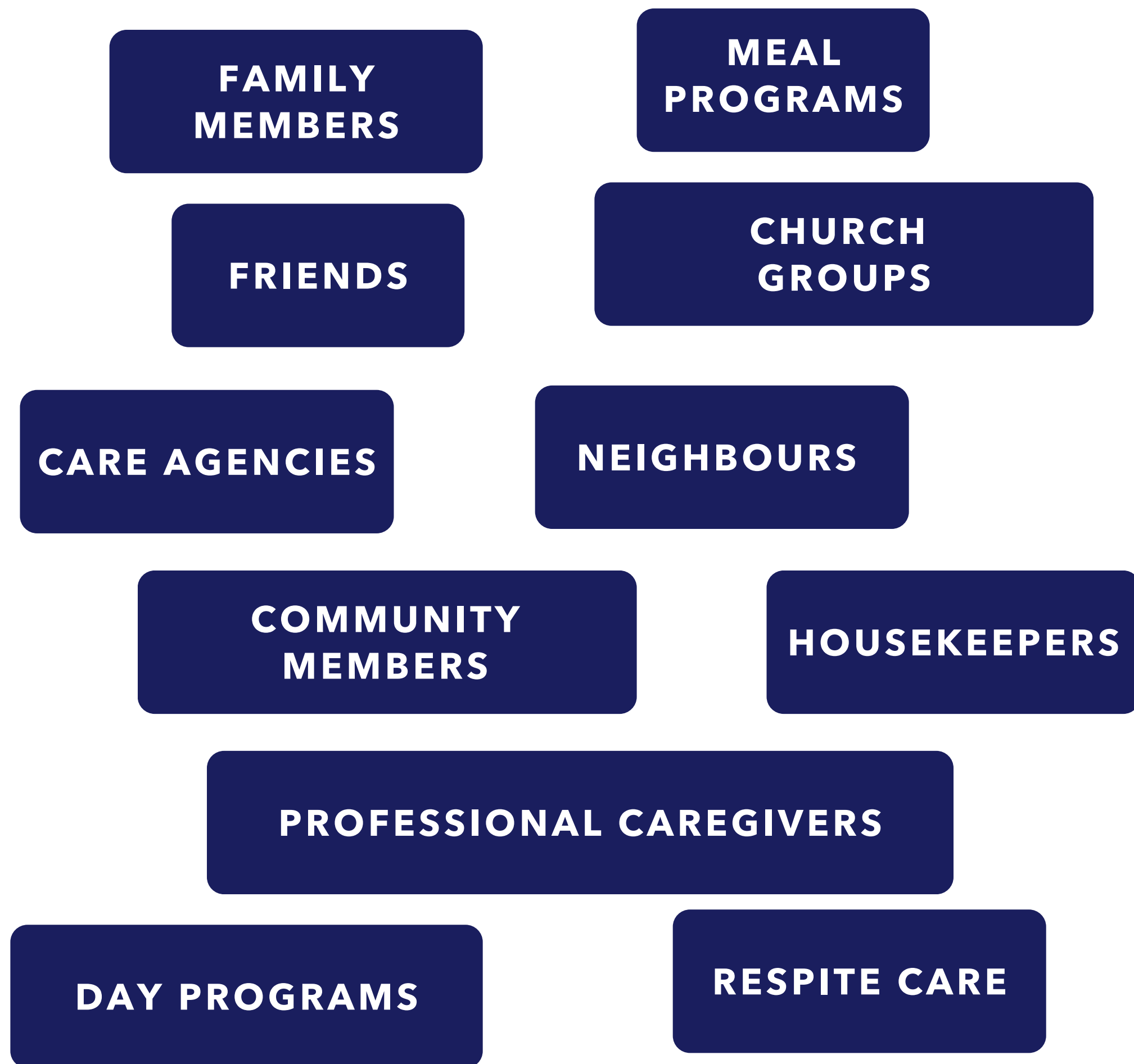
# THINGS YOU CAN CONTROL VS. THOSE YOU CANNOT

- Your understanding of Dementia
- Acceptance of the diagnosis
- Separating the condition from your loved one
- Tapping into local resources
- Asking for help
- Communicating your needs
- Focusing on the strengths/positives that remain
- The way you prepare and respond to challenges
- Your own behaviours
- Commitment to learning and doing better each day

- Your loved one's diagnosis
- The progression of the illness
- Lack of support resources
- Lack of understanding or support from family/friends



# RALLYING THE DEMENTIA CARE VILLAGE



# LOCAL CAREGIVER SUPPORT RESOURCES



## **NORTHSTAR DEMENTIA**

Care Consultation Services

Client-centered assessment, caregiver education & support services



## **ACTION ON ALZHEIMER'S & DEMENTIA CHARITY #929**

alzbermuda@yahoo.com

707-0600

Offering monthly virtual support group meetings for Dementia Caregivers



## **BERMUDA GOVERNMENT**

543-1111

24 hour Emotional Well-being Hotline  
Experienced Mental Health Practitioners  
available 9am-9pm 7 days per week

# Contact Information

**PHONE NUMBER:** (441) 704-0387

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**WEBSITE:**

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**Centennial**  
BERMUDA FOUNDATION

**“** NorthStar is pleased to have received the support of Centennial Bermuda Foundation’s Community Health & Fundamental Needs Committee through their grant for the development of this educational resource.”