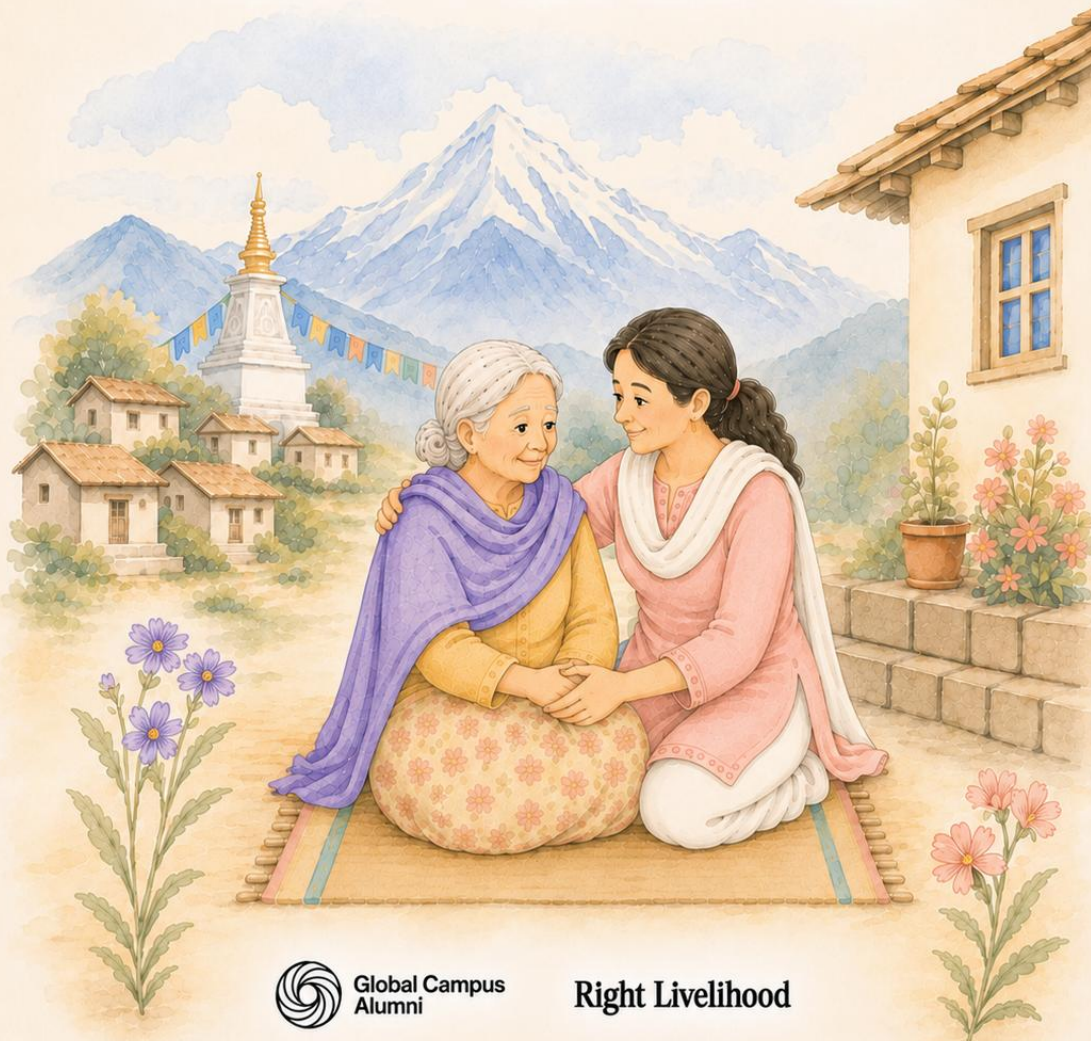




CARE WITH DIGNITY



A Simple Guide for Unpaid Dementia Caregivers



Global Campus
Alumni

Right Livelihood

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A Simple Guide for Unpaid Dementia Caregivers

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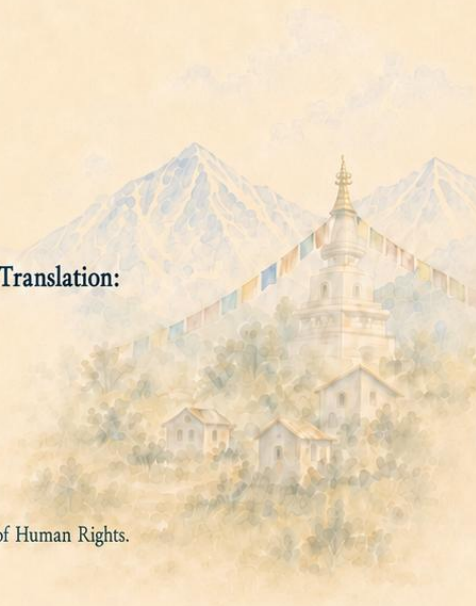
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Supporting Unpaid Dementia
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ACKNOWLEDGEMENT

This toolkit and advocacy brief were developed as part of the Global Campus Alumni Cross-Regional projects, in partnership with Right Livelihood.

The development of this toolkit benefited from the guidance, expertise, encouragement, and generous support of many individuals and organizations. Conceived with the aim of creating a resource for caregivers that is simple, visual, practical, and culturally meaningful, this publication would not have been possible without their valuable contributions.

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Most importantly, deepest gratitude is extended to the unpaid dementia caregivers who generously shared their stories and experiences. The conversations included moments that were overwhelming and emotional, yet participants spoke openly about their challenges, laughter, and hope. Thank you for trusting us with the parts of your lives that were not always easy to share. This toolkit was not simply made for you—it was made with you. It is hoped that this publication will contribute to ensuring that caregivers' voices continue to be heard.

Bidya Maharjan
Project Lead
Global Campus of Human Rights Alumni



Right Livelihood



ABOUT THIS TOOLKIT

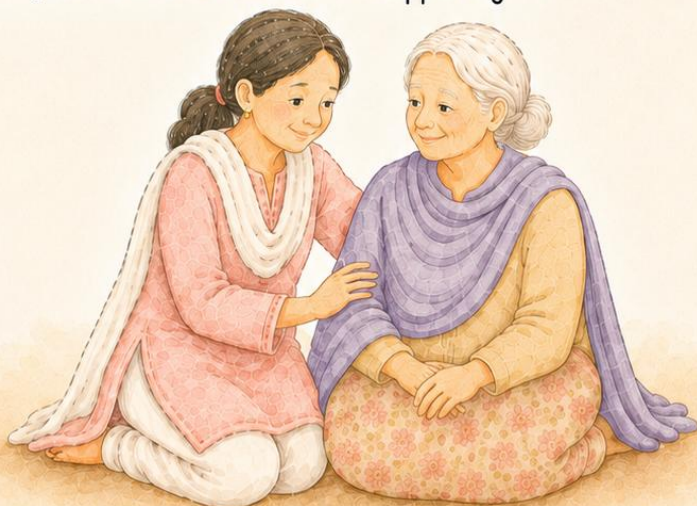
Care with Dignity is a practical toolkit developed to support unpaid dementia caregivers in Nepal.

It was co-created with caregivers, drawing on their lived experiences, ideas, and everyday realities of caring for someone with dementia.

The toolkit shares simple information, practical tips, and encouragement to help caregivers better understand dementia, provide care with confidence, and look after their own wellbeing.



Whether you are caring for a parent, spouse, relative, or friend, this toolkit is here to support you.



PURPOSE OF THIS TOOLKIT

Why this guide was created

This toolkit helps to:



Increase understanding of dementia



Strengthen caregivers' confidence



Provide practical everyday caregiving guidance



Promote dignity, inclusion, and shared responsibility for dementia care

WHO IS THIS TOOLKIT FOR?



Family caregivers



Friends caring for someone with dementia



Community volunteers



Community health workers



Anyone supporting a person living with dementia

HOW TO USE THIS TOOLKIT

Read it in the way that works best for you.



You do not need to read this toolkit all at once.



Each section focuses on a different part of dementia care and can be read on its own.



You can return to any section whenever you need practical guidance or support.

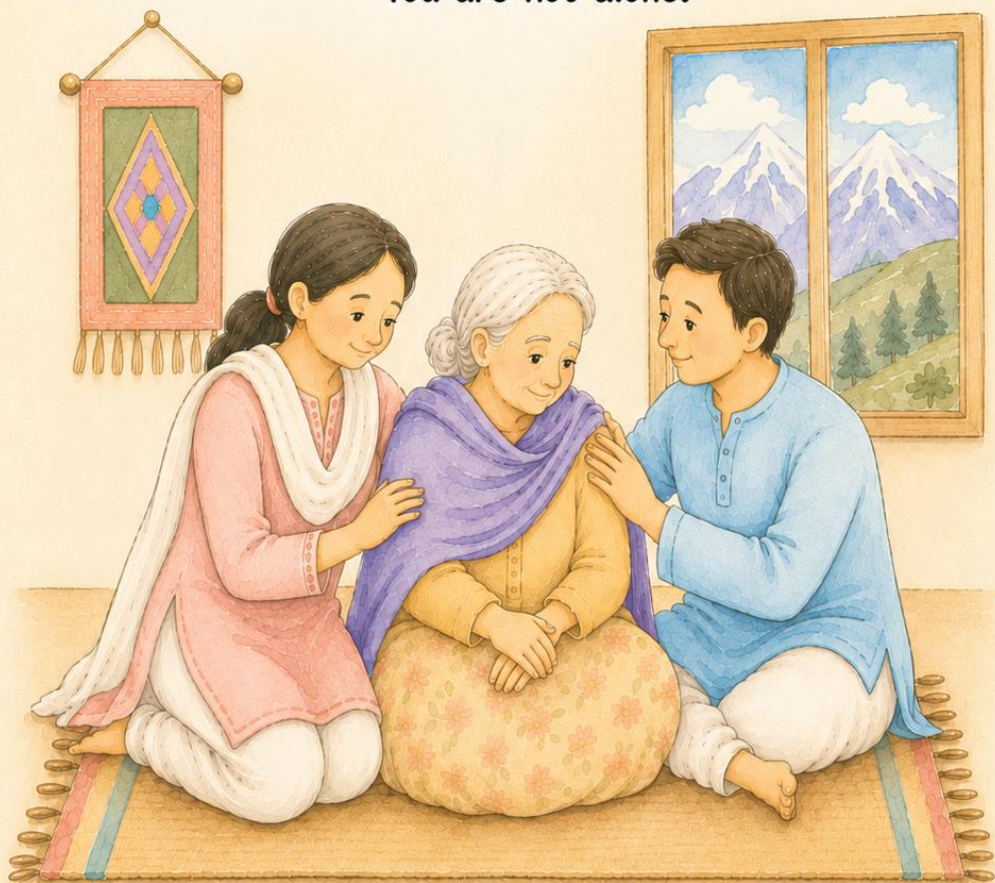


Take what is most helpful for you and your family.

1. You Are Not Alone

Caring for a person living with dementia can be exhausting, confusing, and lonely. Many dementia caregivers feel tired, stressed, and overwhelmed.

You are not alone.



2. What Is Dementia?

Dementia is a condition that affects the brain.

It can change:



Memory



Behaviour



Thinking



Everyday activities

Dementia is **NOT**



Normal ageing



Madness



A punishment



Something to be ashamed of



A person's fault

3. Understanding the Journey of Dementia

Dementia changes over time.
Each person's journey is different.



Early Stage

Minimal support needed

- Small memory slips
- Misplacing things
- Repeating questions
- Mild confusion



Middle Stage

More support needed

- Increased confusion
- Difficulty with daily tasks
- Needs reminders
- May wander



Later Stage

Full support needed

- Difficulty eating
- Difficulty walking
- Difficulty speaking
- Needs help with most activities

4. Behaviour Is Communication

Behaviour is often a way of communicating an unmet need.

What we see



Shouting



Wandering



Anger



Repeating

What may be behind it



Fear



Confusion



Pain



Hunger or thirst



Loneliness



Frustration



Feeling unsafe

5. How to Communicate

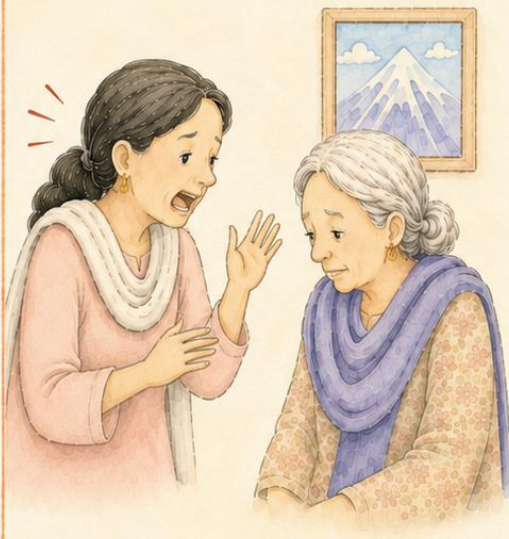
Small changes can make a big difference.

What helps



- Speak slowly
- One question at a time
- Smile and be patient
- Use simple words

What doesn't help



- Argue or rush
- Too many questions
- Use negative body language
- Correct constantly

Try this



Instead of: "What do you want to do today?"

Try: "Would you like tea or water?"



6. Daily Care Tips

Small actions can support dignity and safety.

Eating



- Small meals
- Familiar foods
- Sit together calmly

Bathing & Dressing



- Be gentle and patient
- Keep them comfortable
- Respect privacy

Medication



- Give on time
- Follow doctor's advice
- Keep a simple list

Sleep



- Keep a routine
- Daytime light
- Calm evening

Safety



- Remove hazards
- Keep paths clear
- Label rooms if helpful

Movement & Exercise



- Short daily walks
- Gentle stretching
- Simple household activities
- Activities they enjoy

Memory and Comfort Bag

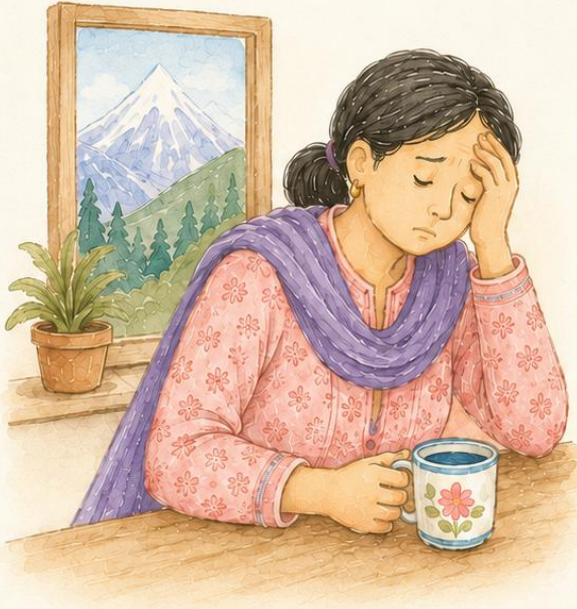
Keep a small bag of familiar things that can help the person feel safe, calm and connected.

Familiar items bring comfort and happy memories.



7. Understanding Stress

Caregiving stress can build up.
It is okay to feel overwhelmed.



Signs of stress



- Feeling angry often
- Constant worry
- Poor sleep
- Feeling exhausted
- Feeling alone

Stress Triggers



Lack of sleep



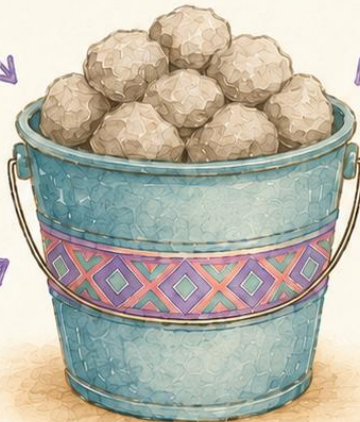
Financial pressure



Caregiving alone



Lack of support



8. Looking After Yourself

A tired caregiver also needs care and support.



Ways to Cope



Take breaks



Ask for help



Join Care Circles



Rest when possible



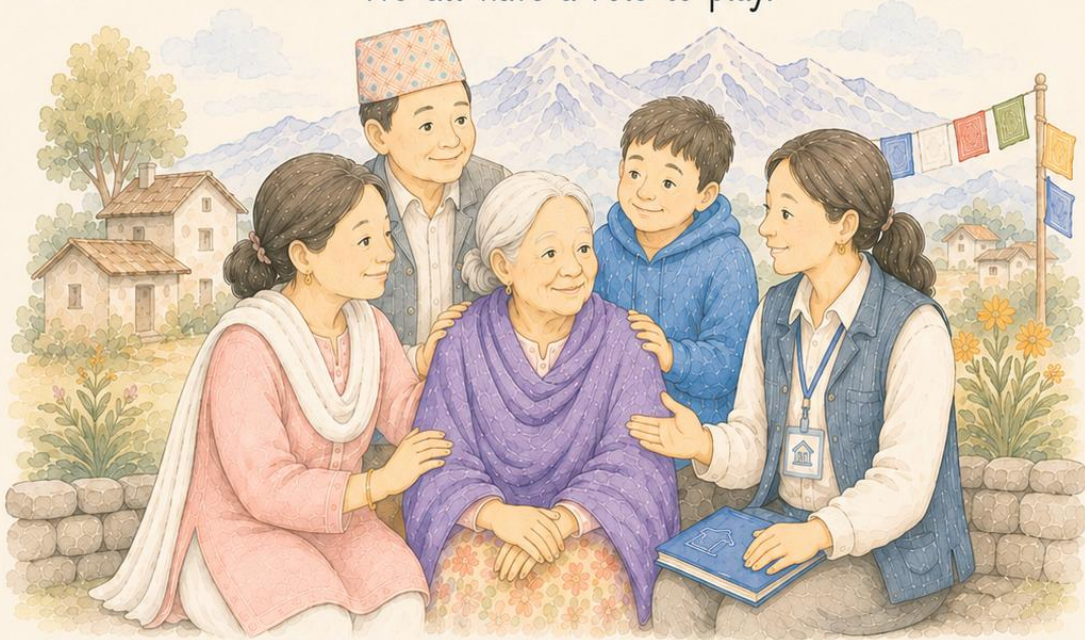
Talk to someone
you trust



Continue activities
you enjoy

9. Care Is a Community Responsibility

We all have a role to play.



Family — Support each other



Neighbours — Check in and help



Community Groups — Create support and understanding



Youth — Be Aware, Be Understanding



Government — Provide services and support



Together, we can build dementia-friendly communities where caregivers and loved ones are respected and supported.



Dementia Caregivers Have Rights Too

You have the right to:



Respect and dignity



Information and support



Health and rest



Be heard



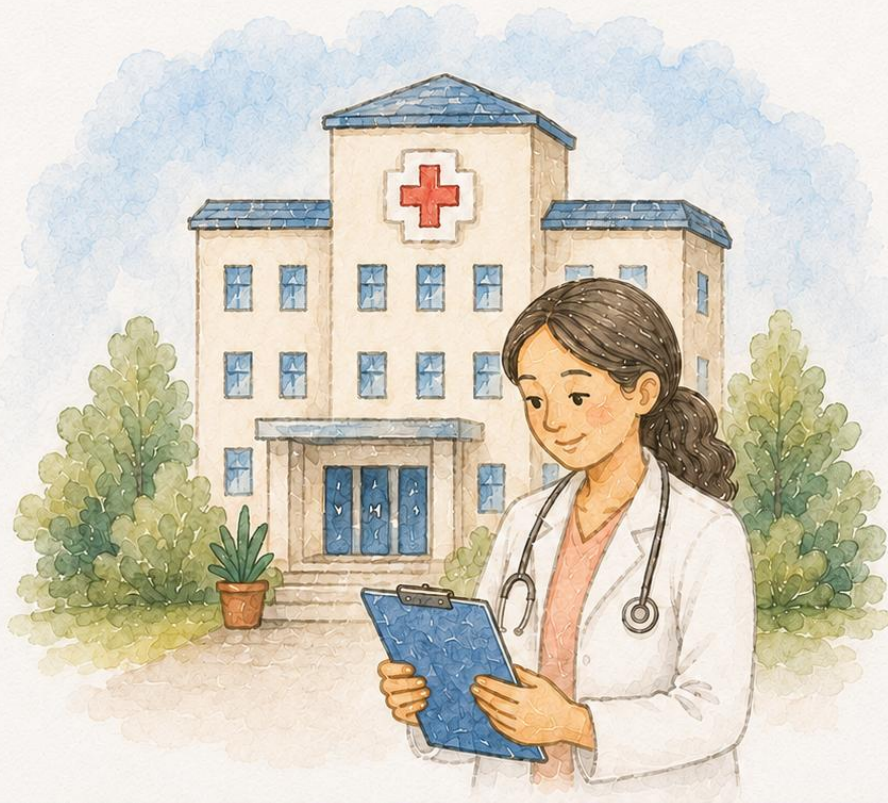
Safe and fair treatment



Taking care of yourself is not selfish —
it is your right.

WHEN SHOULD I SEEK HELP?

Seek help if you notice



Sudden
changes



Health
problems



Safety
concerns



You feel
unable to cope

ADVOCACY BRIEF

Supporting Unpaid Dementia Caregivers in Nepal

1. Why This Matters

Unpaid caregivers provide most of the daily care for people living with dementia, yet many receive little information, recognition, or support.

“This is the first time we attended a Care Circle focused on us as caregivers.”

— Unpaid caregiver

2. What We Learned

Through focus group discussions and numerous conversations with caregivers, we learned that caregivers need:

- Simple, practical information
- Someone to listen to them
- Opportunities to meet and support each other
- Recognition and a voice in shaping support

“We are glad that we could co-create this toolkit together and help other caregivers too.”

— Unpaid caregiver

3. Our Call to Action

We encourage governments, health services, and organisations to:

- Recognise unpaid dementia caregivers
- Provide practical information and support
- Create regular Care Circles and peer-support spaces
- Include caregivers when designing services and resources
- Build greater community understanding of dementia

4. Our Message

Unpaid dementia caregivers are a vital part of Nepal's care economy, yet their invaluable contributions remain largely unrecognised and unsupported.

Caregivers need more than responsibility.

They need recognition, information, support, and a voice.

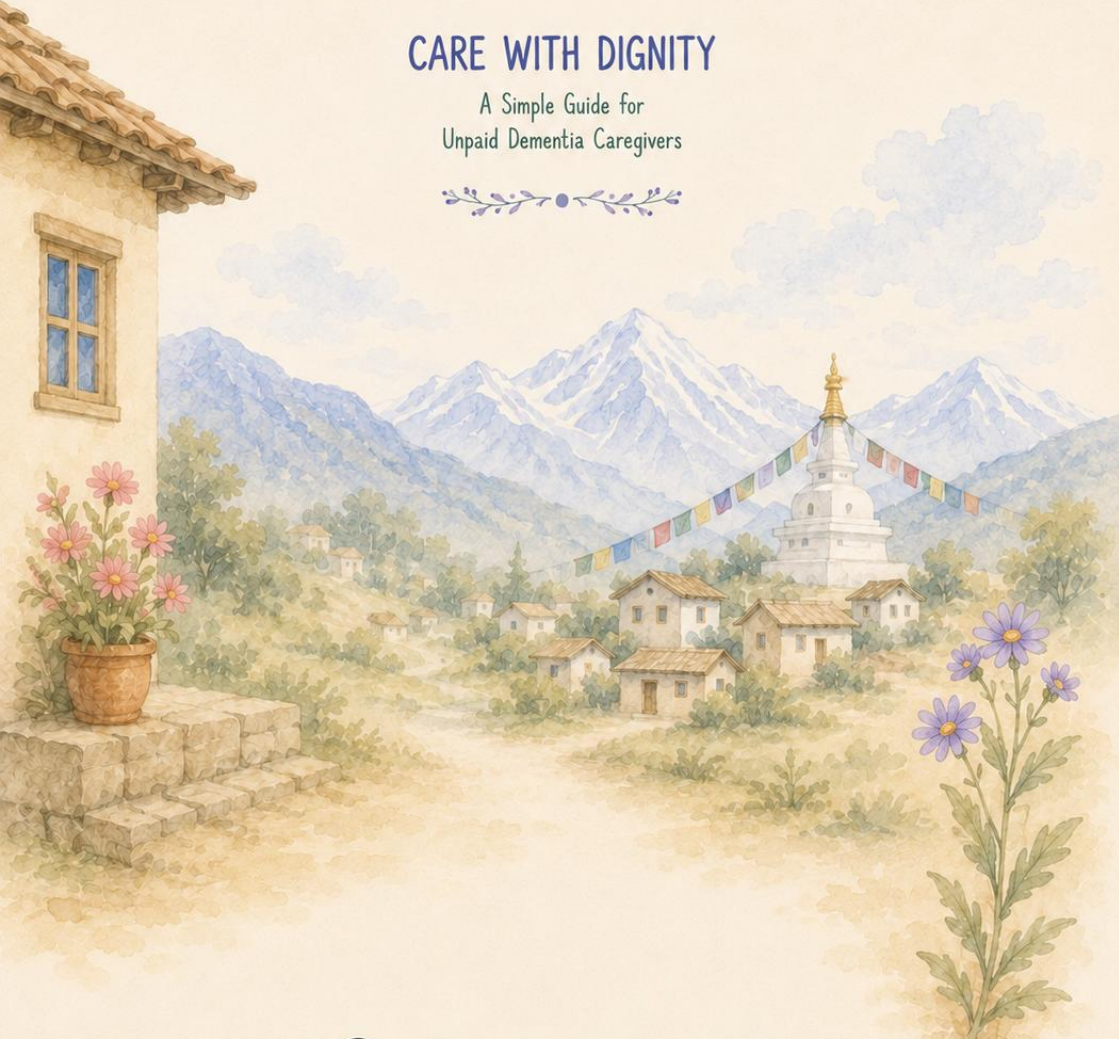
With Care, With Dignity





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