

FAMILY CAREGIVER ESSENTIALS™

Video Course

Study Guide



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General Introduction to Study Guide Materials

This study guide has been prepared to provide a reference for the information covered in the Family Caregiver Essentials™ Course. You can take notes on the pages, refer to the information from the video presentations and use the resources listed at the end of the guide.

It is a summary of the modules and the information. It is not designed as a copy of the presentation slides.

We hope you enjoy the course and find helpful information and tips to make your caregiving journey easier.

General Welcome and Instructor Introduction

Steven Bailey, Managing Director of Age Safe America, provides the general welcome to the Family Caregiver Essentials Course. He describes the purpose of the course and the general course outline.

The course instructors are:

Chris MacLellan, M.A., Founder of Whole Care Network, Inc.



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The caregiving journey can be a roller coaster.
You are not alone on the ride!

Module 1 – Suddenly You're A Caregiver

This module is the overview of the course and
review of the module contents.

Module 2 – Becoming a Care Partner Advocate

Key Points

1. Advocacy: Understanding Your Role As An Advocate
2. Verbal – Non-Verbal Communication: Why Our Verbal and Non-Verbal communication needs to be consistent.
3. Listening Skills: Important Tips for Active Listening
4. Responding to Emotions: The Difference Between Sympathy and Empathy.
5. Attending: Why Effective Attending Provides Comfort to Your Care Partner
6. Meet in the Middle: Choose Your Battles Carefully

Module 3 – Creating a Care Team

Key Points

1. Your role as CEO: You Are Now The Chief Everything Officer!
2. Creating Your Care Team: Why You Need A Variety of Skills And Talents On Your Team
3. Asking for Help: You're The Best Caregiver, But You Are Not The Only Caregiver
4. Key Players: Identify Your Key Players And Access Their Abilities.
5. Leaving Family Baggage Behind: Why This Is Not the Time To Settle Old Family Wounds.
6. Fly Like the Geese! To Be A Good CEO, You Have to Fly like the Geese

Module 4 – Importance of Self-Care

“Almost everything will work again if you unplug it for a few minutes, including YOU.”

-Anne Lamott

8 Keys to Caregiver Self-Care

1. Form a caregiving support team.
2. Make time for yourself every day.
3. Eat right.
4. Get regular exercise.
5. Prioritize sleep.
6. Turn to healthy emotional outlets.
7. Maintain your social life.
8. See your doctor.

Module 5 – Glossary of Caregiving

Health Care Professional Terms

Activities of Daily Living:

Personal care activities performed daily, such as feeding oneself, bathing, dressing, getting out of bed or a chair (also known as transferring), toileting and grooming.

Adaptive Equipment:

Devices used to assist in completing ADL.

Ambulation:

Ability to walk from place to place independently, with or without an assistive device.

Bilateral:

Term pertaining to the right and left sides, such as handrails on both sides of a hallway are bilateral rails.

Disability:

Limitation in activity and function due to a medical condition in physical, mental, emotional and/or sensory systems.

Durable Medical Equipment (DME):

Equipment that provides therapeutic benefits to a patient who has certain medical conditions and/or illnesses, such as bath chairs, reachers, walkers or wheelchairs.

Instrumental Activities of Daily Living (IADL):

Activities that relate to independent living, such as preparing meals, managing money, shopping for groceries and other items, completing household tasks and using the telephone.

Incontinence:

Loss of bladder control causing urine leakage.

Letter of Medical Necessity:

Written report from a health care professional that documents a specific diagnosis and necessary treatment, used with insurance to fund DME, home modifications and therapy.

Low Vision:

Level of vision loss, ranging from minor to severe. Common causes are glaucoma, complications from diabetes, macular degeneration. Specific symptoms are blurriness, black spots, extreme glare sensitivity.

Mobility:

Method used to move from place to place, such as a walker, manual or power wheelchair or scooter.

Progressive disease:

Disease that worsens and for which there is not cure, although it may be controlled with medication. Examples are ALS (Lou Gehrig's disease), muscular dystrophy (MD), multiple sclerosis (MS) and Parkinson's disease.

Range of Motion:

Degree of physical movement that is allowed at a joint.

Reimbursement:

Amount that a funding source will pay for services.

Transfers:

Act of moving from one surface to another, such as from bed to a chair or chair to the shower.

Traumatic Injury:

Injury that has a sudden onset, usually from an accident or act of violence, such as spinal cord injury (SCI), cerebrovascular accident (CVA or stroke) and traumatic brain injury (TBI).

Urinary Tract Infection (UTI):

Second most common infection with several common causes. Can lead to confusion, mental changes, tiredness, low fever and readily treated with antibiotics and increased fluid intake.

Visual field cut:

A complete or partial loss of vision often associated with a traumatic brain injury such as a CVA or TBI.

Visual neglect:

Passive, decreased awareness of the loss of the field of vision so the patient is unaware that part of the visual field is missing.

The following are words and phrases common to the evolving world of housing for seniors as we may be faced with these changes in our role as caregiver.

Housing Terms

Accreditation:

Senior housing and care providers receive accreditation when they meet industry standards set by nongovernmental agencies such as Joint Commission on Accreditation of Healthcare Organizations (JCAHCO).

Assisted living facilities:

Licensed in many states, the facilities offer varying levels of care. Residents can receive help scheduling medical and dental appointments, including transportation. Many facilities offer personal hygiene assistance, medication management, and more extensive care at an increased cost.

Board and care homes:

Often remodeled homes with varying staff ratios and typically 6 to 15 residents offering assisted living services. They are licensed in some states.

Congregant Housing:

A similar setting to assisted living with meals and transportation provided in a group setting.

Continuing Care Retirement Communities (CCRCs):

CCRCs offer a succession of care levels, beginning with independent living, assisted living, memory care and skilled nursing. Residents do not have to leave the community as their level of need increases but may have to move within the community.

Independent Living:

Ranging from modest to fancy, independent living complexes cater to active and generally healthy seniors. Dining room meals, social outings, activities and transportation are usually offered.

Memory care:

Specifically for people with Alzheimer's disease and/or dementia, these facilities emphasize safety and security. Staff members help residents with daily activities and medication management.

Residential Care Facilities for the Elderly (RCFEs):

This is a general term for remodeled homes (board and care) or more formal assisted living facilities.

Retirement Communities:

Another name for independent living communities or 55+ communities.

Senior Living Apartments:

Age-restricted complexes without formal service offerings for the residents.

Skilled Nursing Facilities (SNFs):

Can also be known as rehabilitation hospitals or acute care facilities. These facilities provide the most intensive level of care, both short term and long term and have medical staff on site to supervise medication management and rehabilitative therapies.

Module 6 – How Caregiving Impacts Relationships

Key Points

1. Prepare Yourself to Care: How Do You Prepare For The Unexpected?
2. Caregiving is About Relationships: Why Caregiving Is Like Having Two Relationships in One.
3. The Sandwich Generation: Raising A Family While Caring for An Aging Parent.
4. Setting Boundaries: Know When To Say NO!
5. People Say the Darndest Things! When The Disease Speaks For Your Care-Partner.
6. Mindset of a Caregiver: You Can Do Anything, But NOT Everything

Module 7 – Caregiving and Career

Plan ahead to protect your sanity...

Ten Tips

1. Know what to expect.
2. Look at your schedule.
3. Think about finances.
4. Hold a family meeting.
5. Discover community resources.
6. Research flextime.
7. Inform your employer of your situation.
8. Consider your career options.
9. Hire a back-up caregivers.
10. Know your legal rights.

Module 8 – Home Safety and Fall Prevention

Home Safety - Inside the Home

Bathrooms – grab bars, lighting, non-skid mats, easy access to appliances

Halls and Stairways – lighting, handrails, non-slip treads, no clutter

Bedrooms – lighting, clear paths to bathroom

Kitchens – lighting, easy access to cabinets and controls

Home Safety – Outside the Home

Paths and Entrances – lighting, low thresholds, clear paths

Emergency Plan – two exits, written plan, contact info, share with family and caregivers

10 Fall Prevention Myths and Tips

1. Myth 1 – Falling happens to other people, not to me.
2. Myth 2 – Falling is something normal that happens as you get older.
3. Myth 3 – If I limit my activity, I won't fall.
4. Myth 4 – As long as I stay at home, I can avoid falling.
5. Myth 5 – Muscle strength and flexibility can't be regained.
6. Myth 6 – Taking medications doesn't increase my risk of falling.
7. Myth 7 - I don't need to get my vision checked every year.
8. Myth 8 – Using a walker or can will make me more dependent.
9. Myth 9 – I don't need to talk to my family members or my health care provider, if I'm concerned about my risk of falling. I don't want to alarm them, and I want to keep my independence.

10. I don't need to talk to my parent, spouse or other older adult if I'm concerned about their risk of falling. It will hurt their feelings, and it's none of my business.

Fall Risk Prevention Strategies

Balance Training and Physical Activity

Medication Review and Management

Environmental/Home Modifications

Module 9 – Technology and Caregiving

Home Technology Categories

Entertainment – Multi-room, home theatre, gaming

Communication – Intercoms, home networks, telephone, internet access

Comfort – Security, lighting, HVAC

- Smoke, carbon monoxide, gas leak detectors

- Home security, video security

- HVAC temperature, zone controls

- Lighting – paths, doorways, garage, patio

Future direction – Telehealth, telemedicine

Module 10 – Financial Planning Issues

Key Points

1. The Financial Impact of Caregiving: Who Pays For What?
2. The Cost to Care: Soliciting Professional Help While On Your Caregiving Ride.
3. Protecting Your Assets: Why Planning For Long Term Care Support Is Essential To Protecting Your Asset.
4. Caregiving Debt: How To Avoid It; How To Deal With It.

Module 11 – Legal Matters

Key Points

1. First Responders and Important Documents: Where To Store Them and When To Update Them.
2. Health Information Portability and Accountability Act HIPAA: Why You Need A General HIPPA For ALL Your Medical Providers.
3. Life Documents: Powers of Attorney, Living Will, Health Care Proxy, Do Not Resuscitate Order DNRO
4. Post Life Documents: Last Will and Testament

Module 12 – LGBTQ Caregiving

Key Points

1. Differences/Similarities: Exploring The Differences LGBT Seniors And Their Caregivers (might) Face.
2. History: Today's LGBT Seniors Grew Up In A Time Much Different Than Today.
3. Issues/Concerns: Hostility, Sanctions, Non Validating Environment, Lack Of Support System
4. Fear/Isolation: The Impact On One's Physical, Mental, Financial, Spiritual and Social Well-Being.
5. Communication: Never Assume One's Own Sexual Identity.
6. Marriage Equality: Doesn't Marriage Equality "Level The Field"?

Module 13 – Hospice, Palliative Care and End of Life

10 Key Facts about Hospice

1. Hospice is a philosophy of care.
2. Signing up doesn't mean giving up all medical care.
3. You have to qualify for hospice, but you can opt out at any time.
4. If you start hospice and realize that it's not for you, you can quit.
5. You may live longer.
6. You can still see your regular doctor.
7. The goal of pain management in hospice is to enable you to live well – not sedate you.
8. Hospice can enrich and sometimes, salvage the last stage of life.
9. Hospice is for the entire family.
10. Hospice continues after death.

Palliative care is a resource for anyone living with a serious illness, at age stage of the condition without a specific prognosis.

You will have the palliative care administered by a care team of diverse professionals.

End of Life

Tips to make the most of the time.

1. Get comfortable.
2. Communicate your needs.
3. Decide who you would like to see.
4. Set goals for yourself.
5. Smile as much as possible.

Module 14 – Life After Caregiving

Key Points

1. Uncharted Waters: Take A Deep Breath, Settle Yourself and Locate Your Important Documents and Contacts.
2. Grief: Grief Is Personal and It Is Real And, In YOUR Time, You Will Be Okay.
3. The Importance of Self-Care: Learning To Be A Caregiver To Yourself.
4. It's An Honor To Be Caregiver: Why The Good Days Far Out-weighed The Bad Days During Caregiving.

Module 15 – Closing and Resources

Thank you for allowing us to share this information with you and we hope you have found valuable tips and reassurance.

Please check out the extensive list of resources at

<https://agesafeamerica.com/resources/>

and <https://agesafeamerica.com/FCE/>