THE CAREAWARE VIDEO SERIES

Help and Hope for Family Caregivers
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CareAware
A CAREGIVER SUPPORT SERVICE OF CICOA
The role of the unpaid, family caregiver can be isolating and confusing. Whether you are new to the role and feeling overwhelmed with a host of responsibilities that are unfamiliar or intimidating, or you have been a caregiver for a while but are open to learning new insights, resources and practical advice, we welcome you.

CareAware's Help and Hope for Family Caregivers, is a six-part video series and accompanying workbook to help meet the emotional, physical and logistical demands of caregiving. Each video features interviews with subject matter experts and real-life family caregivers.

This resource is designed for use in caregiver support groups, but it also is available for webinars, classes, community presentations and individual viewing. We offer this free for private, non-commercial use, because we know that family caregivers need this information to remain healthy and to provide proper care for their loved one.

If you are viewing the video series in the context of a caregiver support group, then we trust you know the value of sharing your story with others. If you are reviewing this material alone, let me encourage you to put into practice what you learn here.

Above all, please invite others to walk alongside you in your caregiving journey. Help and hope is available.

Orion Bell
President and CEO
CICOA Aging & In-Home Solutions

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Mary Guerriero Austrom, Ph.D.

Mary Guerriero Austrom is associate dean for diversity affairs and the Wesley P. Martin Professor of Alzheimer Disease Education in the department of psychiatry at the Indiana University School of Medicine. She’s also an adjunct professor at the Indiana University School of Nursing and an affiliated scientist at the Indiana University Center for Aging Research.

Her clinical and research interests include developing non-pharmacological interventions for patients and families providing care for Alzheimer’s patients in the home and in institutional settings. She has published more than 150 articles, book chapters and abstracts on her work. Austrom served on the National Alzheimer’s Association board for eight years and is actively involved with local and national organizations devoted to issues affecting the elderly, including the Gerontological Society of America and the International Psychogeriatric Association.

Orion Bell

Orion Bell, president and chief executive officer at CICOA Aging & In-Home Solutions, has more than 25 years experience in not-for-profit management. His expertise includes strategic planning, budget development and program administration. He also has a successful track record in marketing, financial development and volunteer administration.

Before joining CICOA, Bell served the American Red Cross in a variety of capacities including director of chapter operations support for the Great Lakes Service Area. He was CEO of the Fort Worth, Texas, chapter, executive director of the Topeka, Kan., chapter and assistant general manager of the Louisville, Ky., chapter.

H. Kennard Bennett, J.D.

Ken Bennett is a partner in the elder law firm Bennett & McClammer, LLP in Indianapolis. He’s also executive director and senior counsel for the Center for At-Risk Elders, Inc. (CARE), a nonprofit, lawyer-led team of advocates serving Indiana’s neglected, abused and exploited elders. He has practiced almost exclusively in the field of elder law since 1991 with a concentration in courtroom advocacy for at-risk elders.

He is on the advisory board of the Central Indiana Senior Fund, is executive director of the Indiana State Guardianship Association and is an active leader in the Indiana Adult Guardianship Services Project State Task Force. Bennett is past president of the Alzheimer’s Association of Greater Indiana, former chairman of the United Senior Action Foundation, and served as editor of the National Academy of Elder Law Attorneys legal journal.
**Malaz Boustani, M.D.**

Dr. Malaz Boustani is founding director of the Sandra Eskenazi Center for Brain Care Innovation. Building on his international expertise in brain care research and health care innovation, Boustani is leading the Sandra Eskenazi Center in developing and implementing a futuristic, cutting-edge model of brain care for the 21st century.

Boustani also is chief operating officer of the Indiana University Center for Health Innovation and Implementation Science, the associate director for the Center for Aging Research, and the Richard M. Fairbanks Professor in Aging Research. As director of the Eskenazi Health Center Healthy Aging Brain Center, he has improved the quality of brain care for more than 5,000 patients and their family caregivers.

Through his various leadership roles, Boustani focuses on the rapid translation and implementation of research discoveries into clinical practice, utilizing the tools of implementation science, medical informatics and public health.

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**Virginia A. Caine, M.D.**

Dr. Virginia A. Caine, who has worked tirelessly to promote and advance public health through innovative programs and unprecedented collaborations, is director of the Marion County Public Health Department and an associate professor of medicine at the Division of Infectious Diseases at the Indiana University School of Medicine. She also is past president of the American Public Health Association, the nation’s oldest and largest public health organization.

Caine is an active member of several national and state organizations such as the Center for Disease Control and Prevention, the National Medical Association, where she chairs the infectious-disease section, and the National Biodefense Science Board.

She has received many awards over her career, including being named the 2010 National Medical Association’s Physician of the Year. She was honored as one of Indiana’s Local Legends by the American Medical Women’s Association and National Library of Medicine, and she received the Indiana Commission for Women’s Salute to Women Torchbearer award.

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**Clifton Dennis, J.D.**

Elder law attorney Clifton Dennis is vice president of the CICOA advisory board, secretary of the Johnson County Council on Aging, and a member of the Marion County Council on Aging.

A member of the Indiana Bar Association and the Indiana Chapter of the National Academy of Elder Law Attorneys, he has volunteered for such organizations as the Ruth Lilly Hospice program and WFYI’s IRIS program.
Video Experts

Anita A. Harden, J.D.
An advocate for senior citizens, Anita A. Harden launched her own Indianapolis law practice in 2007 specializing in elder law. She’s also counsel with Coleman and Stevenson, LLP. She is the vice chair of CICOA’s Board of Directors and chairs CICOA’s public policy committee.

Harden has been a member of the National Academy of Elder Law Attorneys, the Indiana Chapter of the National Academy of Elder Law Attorneys, the Indiana State Bar and the Indiana State Bar Elder Law Section.

Before opening her firm, she was deputy attorney general at the Indiana Attorney General’s Office and chief legal counsel and deputy commissioner of administrative services and human relations at the Indiana Bureau of Motor Vehicles.

Harden also was a congressional aide for U.S. Rep. Julia Carson in Indianapolis and U.S. Rep. Sheila Jackson Lee in Houston. Prior to her legal and political careers, she was a public information officer and assistant to the Indianapolis Public Schools’ superintendent.

Mary Hershberger
Mary Hershberger first learned the challenges of mental illness as an advocate and caregiver for a family member recovering from a severe mental illness.

Hershberger, who is retired, volunteers for the National Alliance on Mental Illness (NAMI), where for many years she has been a support group facilitator and instructor in NAMI’s Family-to-Family class.

Marina Keers
Marina Keers, executive director of Hendricks County Senior Services, has experienced the challenges and joys of family caregiving first-hand, and now she champions the needs of aging adults and is an advocate of individual self-sufficiency.

Before joining Hendricks County Senior Services in 2012, she worked in fundraising and development for the nonprofits Coburn Place Safe Haven and Sheltering Wings.

Claire E. Lewis, J.D.
Claire E. Lewis has more than 30 years of experience in elder law and a long list of accolades for her work, including being selected as one of the “Best Lawyers in America” for elder law by U.S. News & World Report and a “Super Attorney in Elder Law,” for 11 consecutive years, by Indianapolis Monthly magazine.

Lewis served on the CICOA Board of Directors for six years and is a former member of the Board of Directors of the Alzheimer’s Association of Indiana.

She was named a Fellow of the Indiana State Bar Foundation in 2010 and a Master Fellow in 2014, joining an elite group of Indiana attorneys. Lewis is a founding member and first chair of the Indiana State Bar Association’s elder law section and leads the public policy committee. She
also is a founding member and president of the Indiana chapter of the National Academy of Elder Law Attorneys (NAELA).

Lewis headed the Indiana sub-state Ombudsman Program for Central Indiana, promoting quality of care and nursing home residents’ rights for Indiana’s most vulnerable citizens.

Mandla Moyo

Mandla Moyo is the community outreach director at AARP Indiana, a nonprofit, non-partisan membership organization that helps people 50 and older have independence, achieve goals and live better lives.

Moyo has focused his career in the nonprofit sector. He worked with Kid One Transport and the American Diabetes Association in Birmingham, Ala., and the National Association of Community Health Centers and Lupus Foundation in Washington, D.C. He has a strong background in community affairs, government relations, advocacy and volunteer management.

Cynthia Oetjen, J.D.

Cindy Oetjen is deputy director for Adult Protective Services (APS) in the Marion County Prosecutor’s Office. She began working in APS in 2013, after six years as the supervisor of the sex crimes unit.

Oetjen began her career with the prosecutor’s office in 2002 when she was an intern in the domestic violence unit. She was a deputy prosecutor for two years before becoming a sex crimes and child abuse prosecutor, handling cases ranging from child molestation and rape to child physical abuse and death.

Kathy Pellman

Kathy Pellman is founding director at Still Waters Adult Day Center in Indianapolis, which operates as a ministry of Castleton United Methodist Church and serves more than 40 older adults. She has more than 10 years of leadership experience in community and home-based services for the elderly in Central Indiana. Pellman is a member of the Indiana Association of Adult Day Services’ board of directors.

Sharon Pierce

Sharon Pierce has been president and CEO of The Villages of Indiana since 1993. Prior to joining The Villages, she was the deputy director of the Indiana Division of Family & Children, overseeing the state’s 92-county child welfare system. A passionate advocate for vulnerable children and their families, Pierce has served on the national board of directors of both the Child Welfare League of America and Prevent Child Abuse America.
Andrea Qualitza
Andrea Qualitza is the director of Adult Protective Services (APS) for the Marion County Prosecutor’s Office, where she manages and supervises a staff of seven investigators and an intake coordinator who cover Boone, Marion, Hendricks and Marion counties.

Qualitza has dedicated her career to working with the elderly and physically, mentally and developmentally disabled persons and has coordinated specialized programs to assist them with daily living skills. She has been a task instructor for the Indiana University School of Social Work and is an instructor for the Marion County Sheriff’s Department. She also serves on the Adult Guardianship Coalition Advisory Board and coordinates educational training for Indiana University Health Family Medicine residents during their geriatric rotation.

Denise Saxman
Denise Saxman, LCSW, is director of family programs at the Alzheimer’s Association of Greater Indiana, where she has spent seven years working with people with dementia and their families. She provides disease education, care planning and assistance with resources.

In addition to supervising two social workers and managing the 24/7 Helpline, Saxman runs an early-stage psycho-educational group in Indianapolis. She has been a presenter for both professional and community education programs related to Alzheimer’s and other dementias, and she has participated in many national chapter initiatives.

Before joining the Alzheimer’s Association, she worked 10 years as a home hospice social worker in Maryland. She started her career as the HIV/AIDS social worker at Wishard Health Services (now Eskenazi Health) in Indianapolis.

Nancy Stone
Nancy Stone is the program director for Indiana’s Senior Medicare Patrol (SMP), a statewide program that helps Medicare and Medicaid beneficiaries avoid, detect, prevent and report health care fraud.

Stone has worked in the nonprofit sector in Central Indiana for more than 15 years. She has experience in project management, outreach, training, fundraising and business development. Before joining SMP, she worked at WorkOne on the Indiana STEM (Science, Technology, Engineering and Math) workforce development grant.

She also worked at About Special Kids, where she was responsible for the Family-to-Family Health Information Center, leading the Care Coordination Project, and serving on the management team.
Christine Turo-Shields

With nearly three decades of clinical social work experience, Christine Turo-Shields, ACSW, LCSW, LCAC, co-owns and operates Kenosis Counseling Center, Inc., a community-based private practice. Her specialty includes treating anxiety, depression and grief, especially among caregivers. She also has expertise in trauma, including certification in Eye Movement Desensitization and Reprocessing, a highly effective therapy.

Turo-Shields is an Indiana board member for the American Foundation of Suicide Prevention as well as a member of the Family Advocacy Outreach Network through the National Center for Missing and Exploited Children. She provides community training and clinical supervision for personal and professional caregivers, focusing on the need for “R&R”—resilience and rejuvenation.

Monica Woodsworth

Monica Woodsworth directs the caregiver support and RSVP programs at Catholic Charities in Indianapolis, where she facilitates two caregiver support groups and helps families identify available caregiving resources. Through the Senior Corps program RSVP, she works with adults 55 and older interested in exploring and connecting with volunteer opportunities.
Son’s generous offer leads to two-year journey ‘Raising Dad’

Some days — no, every day — you just have to laugh. It’s perhaps the best way to cope when you’re caring for a loved one. At least that’s what Mark Lee learned over the two years he spent caring for his dad, who had Alzheimer’s disease.

Mark’s dad, Jim, began showing signs of Alzheimer’s in early 2000, when he gradually started forgetting things. He once took pride in remembering the names of everyone he greeted as the church usher, but he began to struggle. His physical health was failing too. It also was taking a toll on his wife, Joan, who had been caring for him at home.

In late 2011, he was hospitalized for what his family thought was pneumonia. He was there a week, and during that time his memory failed even more. He lost strength. Joan was no longer able to care for him at home, and he moved into a rehabilitation facility.

Jim had been there for three weeks when Mark decided he just couldn’t watch him continue to deteriorate. He didn’t want his dad to live in a nursing home for the rest of his life.

“I volunteered my services that I would move in, if we could move him back home,” Mark said. He calls their journey “Raising Dad” and chronicled it in a blog he started after Jim’s death in 2013. It also was published in a local weekly newspaper.

Mark wrote about the challenges of caring for his dad and about how Alzheimer’s patients not only lose their memories, but also can lose a sense of themselves. He experienced that first-hand — often. When he was frustrated, Mark’s once-mild-mannered, loving father would sling hateful words.

“It’s difficult to do while you’re caring for the person, but I think humor is probably the most important thing,” Mark said. “You’re not making fun of the one you love, but laughing with them, or laughing at the situation. When you lose your humor, you’ve almost lost the battle.”

While there were days Mark questioned his decision to move home, he doesn’t regret it.

“I consider myself so fortunate to be able to do what I did — and to be with him the last two years,” he said.

Jim died four days after he and Joan celebrated their 59th wedding anniversary. Mark is now working on a book about his dad.
Daughter leaves life in California to care for her parents

Mimi Ventresca was enjoying life in San Diego. She’d retired after working more than 30 years for the U.S. Department of Veteran Affairs, so she spent time in the sunshine, hanging out with friends, walking her dog, going to the gym and taking it easy. That all changed in December 2009 when her mother suffered a stroke. Mimi came back home to Indianapolis to help. She planned to stay for just a little while, but that changed, too.

She calls it all a blessing. She was present when her mother died in 2013. Now Mimi tends to her 95-year-old father, who needs 24-hour care. She gave up California sunshine, privacy and freedom, but she’d have it no other way.

The oldest of 11 children, Mimi is a natural caregiver. Plus, she has developed a community to help out. Her brother James also lives at home. Her sister Karen, who lives next door, cooks for them twice a week. Often they all share a family meal together. Sister Betty from Lady of Grace provides therapy. Mike from a home health agency comes twice a week and takes her father on walks. Kevin from St. Vincent Life Journey takes her dad’s vitals and has become eyes and ears for his doctor. Good friends who own a cleaning business come once a month to clean the house thoroughly. CICOA Aging & In-Home Solutions delivers a noon meal, and a neighbor brings a casserole every Thursday.

Mimi’s brother Brian is in charge of medication management, and brother Dante, who lives only a few blocks away, takes care of their dad’s hygiene.

The team came together through grace and providence, Mimi said. And she did a little pleading and begging last Christmas when the whole family was together. Since everyone has his or her own role, it’s been a real life changer for her — and it’s been good for her father, too. The collaboration allows Mimi’s dad to stay home, and it’s how she manages his round-the-clock care.

“It kind of just fell into place,” she said. “You get a plan going, and then it’s always evolving, and you accommodate, and it gets better and better.”

She didn’t have a support system when she was caring for her mother, and it was a struggle. She recalls going to a counselor in 2011 who told her she had to take a break and get out of the house. Mimi heeded the advice and now walks all three of the family’s dogs every day. She has learned “the art of the pause” and makes it a point to get away by herself, even if it’s just a few minutes of quiet time in another room.

“I wouldn’t change a minute of the time I got to spend with Mother or the time I have with Daddy,” Mimi said. “The fulfilling thing to me is giving back to them, like they gave to us.”
Despite disability, family is active and adventurous

If there’s anything Katy and Dustin Duncan have learned as parents of a child with disabilities, it’s to live in the now and not let disability slow them down. Their 6-year-old son, Ryder, was born with Oral-Facial-Digital Syndrome (OFD) and spent his first five months of life in the hospital. Three months after he came home, the family headed to Disney World, even though they had to take along what seemed like a hospital’s worth of supplies.

Ryder is on a ventilator 24 hours a day and needs constant care. Like an infant, he can’t be left in a room alone, even for a second, in case he harms himself. He likes to pull himself up on the sofa, then slide back to the floor, which obstructs his breathing. He’s not able to speak and has a hearing deficit. His only nutrition comes through a feeding tube.

But just about anywhere his parents and older sister go, Ryder goes. That means taking along the emergency bag that’s always stocked with extra tracheostomy tubes, just in case. And there have been emergencies.

“I got to change a trach in San Diego on a Make-a-Wish trip on a tour bus. That was fun for everyone,” Dustin recalled, adding that it all has become routine.

It didn’t used to be that way. They knew something wasn’t right during Katy’s pregnancy but didn’t find out what it was until Ryder’s birth. He was whisked away to the neonatal intensive care unit, where medical personnel had to open up his airway. That first day, his parents weren’t sure whether he’d even survive.

Over five months, they learned how to care for their son.

“Neither one of us had any kind of medical background,” Dustin said. “I don’t even like scary movies, so seeing this stuff was kind of creepy, dealing with the trach, a hole in someone’s neck. It took a little bit of getting used to at first, but now it’s second nature.”

CICOA Aging & In-Home Solutions coordinates Ryder’s care at home and at school, and the agency also provides respite care, so the Duncans can spend time with their daughter.

“Sometimes people think of CICOA as aged disabled, but not the young disabled,” Katy said. As they’ve learned, CICOA provides assistance for all ages. That help not only allows Ryder to receive the care he needs, but it also gives Katy (an accountant) and Dustin (who works in sales) the chance to continue their careers.

“It took a little while to get used to everything, but now it’s normal,” Dustin said.

Still, they have had to make sacrifices. The family has to plan everything, from the restaurants they go to — some don’t have enough handicap parking spots, for example, and others are too crowded — to what they need to bring along to ensure Ryder has everything he’ll need.

“Literally, everything we do is thought out before we do it,” Katy said. “You can’t run upstairs to do a load of laundry without taking him with you.”

They can’t even sleep through the night. Ryder still wakes up frequently, and if his equipment malfunctions they have to respond immediately. But one thing they learned when they became parents of a disabled child was that they needed to press on. And that’s what they’ve done.

“He goes everywhere we go. He really does everything we do,” Katy said. That even includes going down the slide during Jolly Days at the Children’s Museum of Indianapolis, sitting on one of their laps, his ventilator in tow.
Boy born without limbs grows up to live independently

When Jane Scott had her first child 27 years ago, she wasn’t prepared for what followed. Her son, Brandon, was born without legs or arms. It’s such a rare congenital condition, there is no name for it.

At first, she could think only about what Brandon wouldn’t be able to do. But quickly, she and her husband made an important decision: Rather than let their son feel sorry for himself, they were going to help him be as independent as possible. They also wanted to make sure their family was surrounded by people who had a positive attitude.

All that work and determination has paid off.

A graduate of Ball State University, Brandon now has a job, drives a car — with special equipment — and recently got married. He’s done it all with the help of his parents, his two younger sisters, loyal friends, a canine companion, professional caregivers and a whole lot of perseverance.

“The caregiving my parents provided to me as I was growing up really helped prepare me for where I am right now,” Brandon said. “One of the things we always talked about growing up is thinking outside of the box. They always taught me different ways to accomplish things.”

And they didn’t cut him a lot a slack. When he was little and it was time to put away toys, Brandon was expected to carry them to the bottom of the stairs, and then someone else would take them upstairs. He needed to learn his task was important too, Jane said.

It hasn’t been an easy journey. Brandon has undergone more than 20 surgeries and countless doctor’s appointments. The rest of the family had to make sacrifices.

The situation was a challenge emotionally too. It was hard for Jane to watch other kids Brandon’s age accomplish milestones that her son hadn’t reached yet — or might never be able to reach. Each time, she and her husband would go through a grieving process, and then they had to refocus.

To help her get through those times, she relied on other parents of special needs children.

“There is an alone factor. I had lots of family; I had lots of friends that were willing to be there for us, but no one really understands what I’m going through emotionally, physically,” Jane said. “When you are talking to another parent of a child with special needs — even someone with a different diagnosis — there is a connection there. There’s a heart-to-heart connection, and you can say things the way you can’t with other people.”

As deputy director of the nonprofit About Special Kids, Jane has become a real proponent of helping parents connect, whether it’s in a support group or one-on-one. Making that connection was a huge part of helping her cope with the challenges of caring for her special needs child.
Caring for mom and daughter brings challenges and blessings

Karen Hill was feeling proud of her daughter Andrea’s accomplishments. She’d recently graduated from high school and was getting ready for college — something no one ever thought she’d be able to do. Andrea was born with Prader-Willi Syndrome, a rare condition that causes her to feel hungry all the time, among other challenges. Andrea had overcome so much.

Then her world came crumbling down.

Andrea was having a routine, outpatient surgery under general anesthesia when she went into respiratory failure and then a coma.

“Lord, if you hear me, save my child. Please, I don’t care how, but I need to keep her. Just don’t take her from me now,” Karen prayed as Andrea was rushed into surgery.

She survived, but her life would never be the same. The challenges she and her family had already faced couldn’t even compare to the daily trials they would now encounter.

Andrea was on a ventilator 16 hours a day and had to have a tracheostomy. This former college-bound teen was now child-like and would need around-the-clock attention. Karen quickly had to learn to care for her daughter.

“With the new challenges Andrea was being faced with, I needed help,” Karen said. “So my mom came.”

Doris moved in with her daughter and four grandchildren (Andrea has a sister and two brothers) to help keep the household going. But, it wasn’t long after that Doris’ health began to deteriorate, and she also needed care.

“In the beginning, I thought I was a help, but as it turned out, she had to help me,” Doris said. “She’s a jewel. A daughter of all daughters.”

Karen found herself a member of the sandwich generation — caring for her children and her mother.

“How can I deny her the care that she needs now when she so graciously helped me with the needs I had?”

Karen, who works in accounts receivable at the post office, begins her day about 2:30 a.m., when she checks to make sure her mother and daughter are resting comfortably before leaving for work. She’s thankful for CICOA, which provides professional caregivers so her mom and daughter get the help they need to stay at home.

“CICOA has been amazing from the very start,” Karen said. “It’s really become an extended family.”

Karen said she’s not sure how the family would have managed without the assistance, and she certainly would not have been able to support her son, who is a gifted dancer, or her younger daughter in their activities.

Talking to her mother every day and seeing the smile on her daughter’s face when she walks into the room are gifts that keep Karen going.

“It’s a challenge on a daily basis, but it’s a blessing,” she said.
Caregiver Well-Being Tool

The following tool can be used to quickly screen for stress that results from caregiving. A score of 17 or higher reflects high burden and high risk and indicates the need for more in-depth assessment by a healthcare professional to determine the appropriate intervention and follow-up.

**INSTRUCTIONS:** The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way: never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

### Zarit Burden Scale

<table>
<thead>
<tr>
<th>Statement</th>
<th>NEVER</th>
<th>RARELY</th>
<th>SOMETIMES</th>
<th>QUITE FREQUENTLY</th>
<th>NEARLY ALWAYS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you feel that, because of the time you spend with your relative, you don’t have enough time for yourself?</td>
<td>0 ( ___ )</td>
<td>1 ( ___ )</td>
<td>2 ( ___ )</td>
<td>3 ( ___ )</td>
<td>4 ( ___ )</td>
</tr>
<tr>
<td>2. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?</td>
<td>0 ( ___ )</td>
<td>1 ( ___ )</td>
<td>2 ( ___ )</td>
<td>3 ( ___ )</td>
<td>4 ( ___ )</td>
</tr>
<tr>
<td>3. Do you feel angry when you are around your relative?</td>
<td>0 ( ___ )</td>
<td>1 ( ___ )</td>
<td>2 ( ___ )</td>
<td>3 ( ___ )</td>
<td>4 ( ___ )</td>
</tr>
<tr>
<td>4. Do you feel that your relative currently affects your relationship with other family members?</td>
<td>0 ( ___ )</td>
<td>1 ( ___ )</td>
<td>2 ( ___ )</td>
<td>3 ( ___ )</td>
<td>4 ( ___ )</td>
</tr>
<tr>
<td>5. Do you feel strained when you are around your relative?</td>
<td>0 ( ___ )</td>
<td>1 ( ___ )</td>
<td>2 ( ___ )</td>
<td>3 ( ___ )</td>
<td>4 ( ___ )</td>
</tr>
<tr>
<td>6. Do you feel that your health has suffered because of your involvement with your relative?</td>
<td>0 ( ___ )</td>
<td>1 ( ___ )</td>
<td>2 ( ___ )</td>
<td>3 ( ___ )</td>
<td>4 ( ___ )</td>
</tr>
<tr>
<td>7. Do you feel that you don’t have as much privacy as you would like, because of your relative?</td>
<td>0 ( ___ )</td>
<td>1 ( ___ )</td>
<td>2 ( ___ )</td>
<td>3 ( ___ )</td>
<td>4 ( ___ )</td>
</tr>
<tr>
<td>8. Do you feel that your social life has suffered because you are caring for your relative?</td>
<td>0 ( ___ )</td>
<td>1 ( ___ )</td>
<td>2 ( ___ )</td>
<td>3 ( ___ )</td>
<td>4 ( ___ )</td>
</tr>
<tr>
<td>9. Do you feel that you have lost control of your life since your relative’s illness?</td>
<td>0 ( ___ )</td>
<td>1 ( ___ )</td>
<td>2 ( ___ )</td>
<td>3 ( ___ )</td>
<td>4 ( ___ )</td>
</tr>
<tr>
<td>10. Do you feel uncertain about what to do about your relative?</td>
<td>0 ( ___ )</td>
<td>1 ( ___ )</td>
<td>2 ( ___ )</td>
<td>3 ( ___ )</td>
<td>4 ( ___ )</td>
</tr>
<tr>
<td>11. Do you feel that you should be doing more for your relative?</td>
<td>0 ( ___ )</td>
<td>1 ( ___ )</td>
<td>2 ( ___ )</td>
<td>3 ( ___ )</td>
<td>4 ( ___ )</td>
</tr>
<tr>
<td>12. Do you feel that you could do a better job in caring for your relative?</td>
<td>0 ( ___ )</td>
<td>1 ( ___ )</td>
<td>2 ( ___ )</td>
<td>3 ( ___ )</td>
<td>4 ( ___ )</td>
</tr>
</tbody>
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**ADD COLUMNS**

____ + ____ + ____ + ____

**TOTAL** (cumulative total of all columns*)

____

* A score of 17 or higher reflects high burden and high risk

VIDEO #1—The Journey of Caregiving—Insights for the Road Ahead

1. I’m not a caregiver
   a. Caregiving may begin suddenly with a crisis, or it may evolve slowly over time.
   b. Caregivers may find it difficult to embrace the role because they are “just” a spouse, a daughter, a son and not a professional caregiver.
   c. Some move into the role naturally; others out of a sense of duty.
   d. You may be a caregiver without caring for someone physically if you are managing some aspect of his or her affairs.

2. Loss of normal
   a. Each change—and each anticipated change—is a loss which must be grieved.
   b. Your own needs and desires may be set aside, which can result in a host of negative emotions.
   c. Loss of normal can also have positive outcomes.

3. Am I doing the right thing?
   a. You face new responsibilities which may be unfamiliar or intimidating to you.
   b. Learn as much as you can about your loved one’s illness or disability and how to be a caregiver.
   c. Determine which needs you can meet, and where you’ll need help.
   d. Consider making home accessibility modifications to make your environment as safe as possible for the care recipient.
   e. Do the best you can.

4. Special circumstances
   a. The sandwich generation typically is caring for an aging parent and a child at the same time.
   b. Long distance caregivers face challenges in providing support from a distance.
   c. Grandparents raising grandchildren face unique challenges, as well.

5. Encourage independence
   a. Taking over tasks your loved one can do can lead to increased dependency, depression, and a loss of self esteem or functional ability.
   b. Let the care recipient do what they are capable of doing.

6. Know your limits
   a. Asking for help can be awkward, but it is essential to providing quality care for the long haul.
   b. A caregiver support program is an opportunity to share difficult emotions and learn from more experienced caregivers.
   c. You need a break.
Getting your “ducks in a row” means knowing and assembling key documents so you can access them quickly in emergency situations or when the need arises.

2. **Organization tips**
   a. Assemble key documents in one place.
   b. Include emergency contact information for key people: lawyers, accountants, attorneys, family members, etc.
   c. Make a record of online accounts, usernames and passwords.
   d. Keep documents in an accessible location (i.e.—not a safety deposit box).
   e. Consider cloud storage services for document sharing and calendaring.

3. **Learn what services are covered by Medicare or Medicaid vs. long term care insurance.**

4. **Key legal documents**
   a. A will is a statement of what you would like done with your possessions upon your death.
   b. Durable power of attorney grants the authority to make legal decisions on your behalf in case of incapacity. Its authority ends at death.
   c. The healthcare power of attorney allows you to make health care decisions on behalf of another.
   d. A special needs trust enables you to leave money or property to an adult or minor with a disability without affecting their eligibility for Supplemental Security Income (SSI) or Medicaid benefits.
   e. A guardianship is a court process appointing a guardian to manage a person and his or her estate if the individual becomes incapacitated and no power of attorney exists.

5. **Advance directives**
   a. Advance directives allow you to indicate your wishes for end-of-life care ahead of time.
   b. A living will expresses what medical treatments may be taken at end of life to extend life.
   c. A DNR order stands for “Do Not Resuscitate” and states that you do not want CPR administered if your heart stops.
   d. Other decisions to consider include whether, at end of life, you prefer to be at home, in a hospice facility, a nursing home or hospital.
   e. Funeral planning and burial wishes are advance directives.
   f. If death is a difficult topic for your family to discuss, consider creative ways to engage your loved ones in these conversations.

6. **Physicians Orders on Scope of Treatment (POST)** is a form you create with your physician to indicate end-of-life decisions throughout the medical system.

7. **Care, Advise, Record and Enable (CARE) Act**
   a. Indiana’s CARE Act requires hospitals to allow patients to designate the name of a family caregiver.
   b. Among other things, the designated caregiver must be notified when the individual is discharged from a hospital and instructed concerning any necessary after care.
VIDEO #3—The Feelings of Caregiving—Dealing with Negative Emotions

1. Caregivers often experience a host of negative feelings or emotions.
   a. These negative emotions increase stress levels and may result in poor health consequences.
   b. Taking care of your emotional health can make you a more effective caregiver.

2. Negative emotions caregivers commonly face:
   a. Grief
      i. Grief often starts with the moment of diagnosis.
      ii. Grief is an ongoing process and must be attended to throughout your caregiving journey as you experience additional losses.
   b. Anger
      i. May be related to your loved one, the disease process, your losses or your situation.
   c. Emotional/physical exhaustion
      i. Sleep may be disrupted.
      ii. Exhaustion can manifest itself through anxiety or depression.
      iii. Exhaustion is often accompanied by increased irritability.
   d. Social isolation
      i. Your world may become very small.
      ii. You may think no one understands what you are going through.
      iii. You may feel trapped.
      iv. You may lose friendships.
   e. Strained relationships
      i. Families may disagree on how to care for the loved one.
      ii. Families often have poor communication/negotiation skills.
      iii. Some family members may be motivated by self-interest.
      iv. When there is a child with a disability in the home, healthy siblings may feel neglected.
      v. Some family members may not understand or approve of the decisions you make.
   f. Guilt
      i. Caregivers may feel guilty about experiencing other negative emotions.
      ii. Caregivers may think, “I haven’t done enough.”
      iii. Caregivers may feel guilty about taking care of themselves.
      iv. Caregivers may feel guilty about placing a loved one in institutional care.

3. Focus on cultivating positive emotions.
   a. Recognize you are making a choice.
   b. Look for meaning in your caregiving role.
NOTES:
VIDEO #4—Oxygen Masks—Attend to Your Needs First

1. A person who experiences chronic stress over an extended period of time is at greater risk for developing a life-threatening illness.
   a. Look at caregiving as full-time work, and consider whether you have the capacity to work two or more full-time jobs.
   b. Be realistic about what you can and can’t do as a caregiver.
   c. Build a response team.

2. Who should be on your response team?
   a. Family
   b. Friends: faith community, colleagues, co-workers, neighbors
   c. Professionals: physicians, nurses, care managers, social workers, aging care professionals, lawyers, etc.
   d. Remember to say thank you.

3. Respite care provides a temporary break from the burden of caregiving.
   a. Respite is essential to the primary caregiver’s health and well-being.
   b. Respite can delay the institutionalization of the care recipient.
   c. Respite can reduce the incidence of abuse and neglect due to caregiver burnout.
   d. Respite may be informal or formal.

4. Caregiver Health Prevention Bundle
   a. Respite: Every week, a caregiver needs a minimum of eight hours of respite time in one block.
   b. Support group: Every month, a caregiver should attend a caregiver support group with people in similar circumstances.
   c. Crisis plan: Diseases and disabilities often follow a progression, so it is easy to predict what kinds of crises you are likely to face in the future. Work with your providers to create a crisis plan for how to address these issues before they arise.
   d. Problem-solving: Learn to make better decisions with better outcomes through improved problem-solving strategies.

5. Take care of yourself.
   a. Exercise to reduce stress.
   b. Eat a healthy diet.
   c. Get plenty of rest.
   d. Take time for yourself.
   e. Stay connected to others.
   f. Maintain your sense of humor.
   g. Practice your faith.
VIDEO #5—Preventing the Unthinkable—How to Prevent Abuse

1. The caregiver and care recipient share a unique bond.
   a. Breaking the bond by abuse can have disastrous consequences.
   b. The typical kinds of abuse related to caregiving are physical, emotional, neglect and financial.

2. Signs that your loved one is being abused physically:
   a. Trust your senses.
   b. Look for sudden changes in behavior (recoiling in fear).
   c. Look for unexplained injuries or bruising.
   d. Is the person dressing inappropriately for the weather?
   e. Is the person sensitive to touch?

3. Seniors are less likely to report abuse.
   a. They may be embarrassed.
   b. They may be intimidated.
   c. They may feel like it is their fault.
   d. They may be protecting the perpetrator.
   e. They may think it is an isolated incident.
   f. They may be unable to express themselves.

4. Physical or emotional abuse also may be directed toward the caregiver.
   a. People with cognitive disabilities may express agitation verbally or physically.
   b. The caregiver may inadvertently trigger the aggressive response.
   c. Problem solving may help alleviate the situation in the future.
   d. Tell a doctor about the aggression to make sure the care recipient is on the appropriate medication.
   e. Don't argue with someone suffering from a cognitive disability. Try diverting them instead.
   f. Keep your answers simple.

5. Monitor your stress level.
   a. Screaming, yelling, or touching your loved one inappropriately means your stress level is high and you should seek help.
   b. We tend to lash out at the ones with whom we are most comfortable.
   c. Don't make it personal.

6. What if they refuse to cooperate with your care?
   a. Pick your battles.
   b. They may be reacting to a loss of independence.
   c. Everyone has bad days.
   d. Give them a choice.
   e. Show them respect.
   f. Ask for outside help.
   g. Simplify things.
   h. Don't ask open-ended questions.
i. Redirect conversation to break a repetitive cycle.

j. Maintain good medication management.

k. Redirect dangerous behaviors.

7. Financial exploitation can happen to people of all means.
   a. Family members may have a sense of entitlement to mom’s or dad’s assets.
   b. In poorer communities, the Social Security check may be the family’s only income stream.
   c. Older adults may not receive the care they need because the family is using the elder’s funds on themselves.
   d. If you suspect identity fraud:
      i. Put a credit freeze on the account.
      ii. Check credit reports for free at AnnualCreditReport.com.
   e. Don’t mix your money with your care recipient’s money.
   f. Keep receipts.

8. When in doubt, call Adult Protective Services. (Indiana Hotline: 800-992-6978)
1. Who should be in your caregiving network?
   a. People who have expertise in caregiving
   b. People who support you emotionally: friends, faith community, co-workers, neighbors
   c. Friends of your loved one

2. Professional resources to consult:
   a. The Area Agency on Aging in your community—available by zip code at n4a.org
   b. Your employer
   c. Social workers
   d. Educators
   e. Attorneys
   f. Connect2Help211 is an online service directory connecting people who need human services with providers.
   g. For children with special needs:
      i. IN*Source provides Indiana families and service providers the information and training necessary to assure effective educational programs and appropriate services for children and young adults with disabilities.
      ii. Family Voices is a national nonprofit, family-led organization promoting quality health care for all youth, particularly those with special health care needs.
      iii. About Special Kids (ASK) is Indiana's parent-to-parent organization that gives support and provides information and resources to families of children with special needs.
      iv. The Villages is the largest child and family services organization in Indiana. Among its many services, The Villages provides support services to kinship caregivers, including grandparents raising grandchildren.
   h. Medical professionals
   i. Disease-specific and disability-specific organizations
   j. The State Health Insurance Assistance Program (SHIP) provides free, unbiased counseling for people with Medicare about coverage, enrollment, eligibility and claims.
   k. Senior centers
   l. The Veterans Administration and Veteran County Service Officers provide a variety of services and benefits to honorably discharged veterans of the U.S. military and their dependents.
   m. The Indiana Long Term Care Ombudsman provides advocacy for people living in nursing facilities.
   n. AARP
   o. Adult day service providers
   p. Catholic Charities
   q. Support groups
NOTES:
Small Group Discussion Guide

We are honored you are watching the CareAware video series, “Help and Hope for Family Caregivers.” If you are using this series in the context of a caregiver support group or other small group setting, this section contains useful hints for facilitators.

**Group recommendations:**

- A caregiver support group is an opportunity to share difficult emotions and learn from more experienced caregivers. You may find it helpful to have a supply of nametags and tissues available.
- Each session should last at least 90 minutes. This allows time to view the video and have group discussion afterwards. Depending on the size and needs of your group, you may find that a two-hour block of time is preferable.
- Each participant should have their own copy of the workbook. Workbooks contain an outline for note taking, brief bios of our subject matter experts, and stories about the caregivers featured in each video.
- A pdf of the workbook and publicity posters may be downloaded without charge at www.cicoa.org/careaware/caregiver-videos.
- Effective group facilitators should have some personal experience with family caregiving but should not assume the role of a counselor.
- There is little reference to faith in the videos. However, if you are watching this in the context of a faith community setting, our hope is that a minister or lay leader will bring your faith perspective into the conversation.

**Video #1—The Journey of Caregiving (Time: 37 minutes)**

**Key points:**

- Caregivers may find it difficult to embrace their role.
- Each change is a loss which must be grieved.
- Learn as much as you can about your loved one’s illness or disability.
- Some caregivers face unique challenges because of special circumstances (sandwich generation, long distance caregiving, grandparents raising grandchildren).
- Encourage your loved one’s independence.
- Ask for help.

**Icebreaker questions (choose one):**

- What is the farthest you have ever traveled from home?
- What is the most unusual vehicle you have ever traveled in or animal you have ridden on?
- What is the oddest thing you have ever eaten?
Discussion questions:
• Tell us about your caregiving experience. (Who is your loved one? Did caregiving start as a result of a crisis or develop slowly over time?)
• What is a loss you are grieving right now about your situation?
• What is something you can do to encourage your loved one’s independence?
• How are you at asking for help?
• Review the Caregiver Weekly Check Up on pg. 30.

Video #2—Ducks in a Row (Time: 29 minutes)

Key points:
• Getting your “ducks in a row” means knowing and assembling key documents so you can access them quickly in emergency situations or when the need arises.
• Learn what services are covered by Medicare or Medicaid vs. long term care insurance.
• Key legal documents to know: will, durable power of attorney, healthcare power of attorney, special needs trust, guardianship.
• Advance directives allow you to indicate your wishes for end-of-life care ahead of time.
• Physicians Orders on Scope of Treatment (POST) is a form created with your physician to indicate end-of-life decisions throughout the medical system.
• Indiana’s Care, Advise, Record and Enable (CARE) Act requires hospitals to allow patients to designate the name of a family caregiver.

Icebreaker questions (choose one):
• How many species of ducks can you name?
• What’s your favorite thing to do in the summer?
• Name something on your bucket list.

Discussion questions:
• Have you had any difficulty with end-of-life discussions with your loved ones?
• Do you have any suggestions for organizing or sharing key documents?
• What challenges do you face with this subject?
• What point in the video was helpful to you?
• Review the Caregiver Weekly Check Up on pg. 30.

Video #3—The Feelings of Caregiving (Time: 22 minutes)

Key points:
• Caregivers often experience a host of negative emotions that increase stress and may result in poor health consequences.
• Some of the negative emotions caregivers commonly face are: grief, anger, emotional/physical exhaustion, social isolation, strained relationships and guilt.
• Focus on cultivating positive emotions to reduce stress.
Icebreaker questions (choose one):
- What is your favorite ride at an amusement park?
- Who is your favorite superhero and why?
- What is one thing you really like about yourself?

Discussion questions:
- What negative emotions do you struggle with related to caregiving?
- How is stress affecting you?
- What point in the video was most meaningful to you?
- What do you find meaningful about your role as a caregiver?
- What helps you maintain a positive focus?
- Review the Caregiver Weekly Check Up on pg. 30.

Video #4—Oxygen Masks (Time: 34 minutes)

Key points:
- It’s important to be realistic about what you can and can’t do as a caregiver.
- Build a response team.
- Respite care provides a temporary break from the burden of caregiving.
- Practice the Caregiver Health Prevention Bundle.
- Take care of yourself.

Icebreaker questions (choose one):
- What is your worst travel experience?
- What is your favorite vacation spot?
- What is your favorite snack food?

Discussion questions:
- What oxygen mask do you need to put on?
- Do you have a response team?
- If you could take one job off your plate, what would you remove?
- How can you involve others in your caregiving tasks?
- What struck you about Dr. Boustani’s Caregiver Health Prevention Bundle?
- Review the Caregiver Weekly Check Up on pg. 30.

Video #5—Preventing the Unthinkable (Time: 33 minutes)

Key points:
- Breaking the bond between a caregiver and care recipient by abuse can have disastrous consequences.
- Recognize signs that your loved one is being physically abused.
- Seniors are less likely to report abuse.
• Abuse also may be directed toward the caregiver.
• Monitor your stress level.
• What if they refuse to cooperate with your care?
• Financial exploitation can happen to people of all means.

Icebreaker questions (choose one):
• What’s the worst weather-related storm you have ever experienced?
• If you designed an obstacle course, what would be your signature obstacle?
• What is your favorite pet?

Discussion questions:
• What was most meaningful to you in this video?
• Do you often find yourself frustrated or angry with your loved one?
• Have you been the recipient of abuse from your loved one?
• Several experts in the video said, “Pick your battles.” What is a battle you are fighting that you can let go?
• Has your loved one been the victim of financial exploitation by family, friends or strangers? What safeguards can you put in place to address this?
• Review the Caregiver Weekly Check Up on pg. 30.

Video #6—Know Your Resources (Time: 28 minutes)

Key points:
• Who should be in your caregiving network?
• Research professional resources in your community.

Icebreaker questions (choose one):
• If you were an Olympic athlete, what sport would you compete in?
• If you could have dinner with one famous person still living, who would it be?
• If your life was a movie, what kind of music would be in the soundtrack?

Discussion questions:
• Who is in your support network?
• What have you found to be a helpful resource?
• What challenge are you facing that an outside resource can potentially help with?
• Does your employer have an employee assistance program? Have you ever used it for counseling about your caregiving role?
• As a result of the CareAware video series, what is one change you will make as a caregiver?
• Review the Caregiver Weekly Check Up on pg. 30.
**Caregiver Weekly Check Up**

Date: ___________________________

Periodically reviewing the questions below may help you be more aware of what is happening in your caregiving journey and find perspective to make better decisions. Even if you don't journal, you may find it helpful to discuss these questions with a small group, healthcare professional, or other supports.

**How did the past week go for you in the following areas?**

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<thead>
<tr>
<th>Area</th>
<th>NOT APPLICABLE</th>
<th>POOR</th>
<th>FAIR</th>
<th>GOOD</th>
<th>EXCELLENT</th>
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</thead>
<tbody>
<tr>
<td>Emotionally (grief, anger, depression, guilt, other emotions)</td>
<td>(___)</td>
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<td>Physically (sleep, diet, exercise, hydration, overall health)</td>
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<tr>
<td>Mentally (memory, concentration, respite opportunities)</td>
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<td>Relationally (how caregiving impacts other significant relationships)</td>
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<td>Financially (worries related to current or future financial health)</td>
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<td>Vocationally (balancing responsibilities of caregiving and work)</td>
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<td>Spiritually (relationship with God, your faith community, or belief system)</td>
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</tr>
</tbody>
</table>

1. In the areas where you indicated poor or fair, what practical steps can you take to produce a better outcome?

2. What caregiving situations have been frustrating or stressful this week?

3. Are the things that you turn to for comfort making your situation better or worse?

4. What can you ask for help with to relieve some of your caregiver burden?

5. Who do you need to thank this week?