Alzheimer’s and Dementia Educational Workshops

~ Speaker Information Kit ~

Carol Waarala, MSW, LMSW
Certified Specialist in Aging and Dementia Care

Seeking Positive Pathways
Thank you for your interest in hosting a much-needed informational and educational workshop for those on the dementia journey.

Alzheimer’s and other types of dementia claim more than the person diagnosed. They impact everyone in the family. Dementia is often looked at as a disease of loss with an emphasis on what a person can no longer do.

We don’t talk much about dementia so when it happens to someone we know, we aren’t sure how to talk to them or let them know we are there and we care. The years of negative social stigma has led many to believe a diagnosis of dementia means there’s nothing that can be done.

Perhaps the isolation that happens to the person with dementia and their loved ones takes as much from them as the disease. As we reduce the stigma of this disease, fear and misunderstanding will lose their power of casting a shadow of helplessness, devaluation, embarrassment, and disempowerment.

**THE MISSION OF SEEKING POSTIVE PATHWAYS**

*Together, let’s begin to break down the myths and stigma of dementia and focus on understanding the changes that are occurring, seeing the person first instead of the disease, emphasizing what is still there instead of what’s gone, and promoting strengths and what a person can still do!* 

You can select whatever format meets your goal:

- One Time or a Series - Workshop or Training - daily, weekly or monthly
- Lunch and Learn Programs
- Length of time from one hour to two and a half to three hours
- Training for Staff – working with persons with dementia and their families
- Workshops for those living with dementia and families
- Workshops for the community

**SPEAKING FEE:** $100 per hour

**TRAVEL FEE:** Fifty miles roundtrip free – 50 cents per additional mile

*If funding your presentation is an obstacle, you may choose to invite or have me invite a few vendors to join us and have them sponsor a table for a fee of $50 to help offset the speaking fee. The vendors will need a table for their materials and will be available before, after, and at break for your audience to visit and gather much-needed information about community resources and support like home health care, adult day care, housing, hospice, memory care, etc.*
Alzheimer’s and Dementia Speaker Bio
Carol Waarala, MSW, LMSW
Certified Specialist in Aging and Dementia

Carol is a retired medical social worker with a Master of Social Work Degree and a Gerontology Specialist in Aging Certification (1998) from the University of Michigan. She was part of a research team while at U of M which studied solution focused approaches to “problematic behavior” for persons with dementia in nursing homes. Their project was presented at the annual meeting of the Gerontological Society of America in November 1998 and published in the journal Social Work in 2003.

She credits many of her end-stage dementia patients with being her best teachers. Carol has also had hands-on experience as a family caregiver for her father who had Alzheimer’s and Vascular dementia for 20 years.

She worked as a hospice social worker and dementia speaker from 1998 to 2014. Carol has spoken to families, professional caregivers, and at conferences throughout the state about Alzheimer’s and other types of dementia. She received certification in Dementia Care from The Alzheimer’s Association and the Alzheimer’s Foundation of America.

As a retired hospice social worker, in 2015 Carol found a new mission in life and helped create a faith-based organization that provided a series of educational presentations on a variety of critical dementia subjects to churches in the Southeastern Michigan area. Her mission is to help remove the stigma, stereotype, discrimination, and isolation of dementia by creating dementia friendly churches and communities.

Carol continues her work with churches and appears as the keynote speaker in workshops throughout Southeast Michigan in libraries, dementia memory support facilities, civic organizations, and more.

Carol’s knowledge of dementia, tips for caregiving, and personal stories are blended into all her enlightening presentations. Audience members continually express their deep appreciation of the information they receive and leave feeling they have new resources and interventions to use in their personal journey with dementia.

Carol believes, “Until we find a cure for this disease, education and information are the best tools for creating a better understanding of all types of dementia and discovering ways of improving care for persons living with dementia and their families.”

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Updated: July 2016
Carol has done over 1200 dementia presentations, in-services, workshops, training, continuing education presentations, and conferences while a hospice medical social worker and following her retirement in 2014 from hospice. She has served as the guest or keynote speaker for:

- Blue Cross Blue Shield, Wixom, MI
- Wayne State University Geriatric Institute, Detroit, MI
- Eastern Michigan University, Ypsilanti, MI
- Macomb Community College, Clinton Twp, MI
- Schoolcraft Community College, Livonia, MI
- The Information Center; Taylor, MI
- The Alzheimer’s Association, Southfield, MI and Ann Arbor, MI
- Comerica Bank, Novi, MI
- Archer Huntley Financial, Brighton MI
- Botsford Hospital, Farmington Hills, MI
- St. Mary’s Hospital, Livonia, MI
- Crittenton Hospital, Rochester, MI
- Detroit VA Hospital, Detroit, MI
- Lapeer Regional Hospital, Lapeer, MI
- Covenant Hospital, Saginaw, MI
- Parish Nurses from St. Joseph Hospital, Ann Arbor; Oakwood Hospital, Dearborn; and Parish Nurses in Frankenmuth
- UAW locals, Detroit, MI
- Detroit Area Agency on Aging, Detroit, MI
- Saginaw County Commission on Aging, Saginaw, MI
- Livingston County Commission on Aging Annual Caregiver Fair, Brighton, MI
- Multiple Odyssey and Gentiva Hospice Annual Dementia Care Conferences, Flint, MI
- MGA Conference (MI Guardianship Association)
- MHPCO Annual Conference (Michigan Hospice & Palliative Care Organization), Roscommon, MI
- HCAM/MCAL Conference (Health Care Associates of MI/MI Center for Assisted Living)
- MALA Annual Conference (MI Assisted Living Association), Lansing, MI
- NADONA/LTC Conference (National Association Directors of Nursing Administration in Long Term Care), Grand Rapids, MI
- FOCUS Residential Symposium, Frankenmuth, MI
- Interviewed on radio and cable TV several times
- Many of the senior living communities in the Detroit-Metro Area for staff training and in-services and family workshops and support groups
- Dementia Caregiver Conference 2015 – Lapeer MI
• Sunrise Assisted Living – Grosse Pt. MI – Making Sense of Dementia
• Memory Matters Symposium 2015 – Midland MI
• Wayne State University Institute of Gerontology (IOG) dementia training session for Waltonwood Senior Living, Michigan and North Carolina Memory Care Managers - 2016
• International Society for Key Women Educators Delta Kappa Gamma Detroit Metro Council - 2016 Spring Luncheon
• IHM Sisters Ethics Committee – IHM Motherhouse, Monroe MI - Spring 2016 Community Educational Program
• IHM Sisters Community – IHM Motherhouse, Monroe MI - Pastoral Care Community Program
• P.E.O. (Philanthropic Educational Organization) International Sisterhood – Plymouth MI 2016 Annual Spring Meeting
• Stewart Road Church of God – Monroe, MI (August 2016-March 2017)

Carol developed a 10-month faith-based dementia educational series to help create dementia-friendly churches. Between January 2014 and June 2016, Carol delivered 40 different church presentations on Alzheimer’s and dementia in the Metro-Detroit area (Macomb County, Northwest Wayne County, and Downriver) with over 5,000 attendees.

Carol is the Founder and Keynote Speaker for SEEKING POSITIVE PATHWAYS

A series of Alzheimer’s and Dementia Workshops designed for all audiences including memory support facilities, churches, professional organizations, and libraries.

Workshops that look at increasing the knowledge of Alzheimer’s and other dementias; understanding the progression and changes that happen due to the ongoing damage to the brain; recognizing pathways that lead to success rather and failure for persons living with dementia.
Recognizing every person with Alzheimer’s may lose cognitive abilities along with physical abilities, but there are many positive pathways that may connect us: emotions, respect, touch, sensory stimulation, music, art, nature, spirituality and more.

Paths that are discovered through empowerment - not dependency.
Paths that are discovered through recognizing and encouraging talents, skills and strengths - not assuming problems and deficits.
Paths that are discovered through honoring and respecting collaboration and partnerships - not through exclusion and disabling.
Workshop Selection Sheet

The following presentations are designed to be 2½ hours long (with a 15 minute break and 15 minute Q & A session at the end.) They can be modified to a shorter 1 or 1 ½ hour presentation if necessary. A spiral-bound booklet in color that goes with the presentation is available for a $5 donation to cover the cost of printing, assembly and binding.

☐ A Caregiver’s Travel Guide: The Alzheimer’s Journey
☐ Aging in Place Successfully
☐ Almost Home
☐ Caregiver Burnout
☐ The Dementia Care Toolbox
☐ The Dementia Umbrella
☐ Finding the ME in Dementia
☐ Food for Thought
☐ Importance of Reaching Out
☐ Let’s Talk About It – Dementia, Communication and Changing Behaviors
☐ Let’s Talk About It – Dementia Myths and Stigma
☐ Living with the Diagnosis of Dementia
☐ Making Sense of Dementia
☐ Pain Management
☐ Sharing Meaningful Visits
☐ Understanding Alzheimer’s and When Hospice can Help
☐ What if you could Outsmart Alzheimer’s

☐ Interested in having Experiential Exercises included
☐ New Presentations being Developed (see page 15)

☐ Select your own topic about Alzheimer’s and Dementia

List Topic: ___________________________________________________________

Possible Dates: _______________________________________________________

Do you need help to offset the speaking fee with vendors? ___________
A CAREGIVER’S TRAVEL GUIDE
The Alzheimer’s Journey

Caring for a loved one with dementia is a journey that can be very long... sometimes as long as 20 years. The journey that begins with the loss of a few words or memories becomes a path with many twists and turns that challenge everyone involved. The demands this illness places on the persons with dementia and their caregivers are challenging in every way – emotionally, physically, and spiritually.

This presentation is a guided tour filled with information to help dementia caregivers better understand and survive one of the toughest journeys. You will also explore finding the positive attractions along the way. The presentation is divided into three parts:

Part 1: The Mystery Trip: Understanding Dementia of the Alzheimer’s Type and its Stages
Part 2: Who Made Me the Driver? The Unexpected Role of the Dementia Caregiver
Part 3: Bumps in the Road: Caregiver Tips for Preventing, Managing and Coping with Changing Behaviors

AGING IN PLACE SUCCESSFULLY
For Persons Living With Dementia

There are 22 million senior homeowners who are 65 years of age and older in the U.S. and 95% of them are 75 years old or older and want to stay in their own homes and communities. “Aging in Place” requires that the PLACE also needs to change to accommodate the CHANGES that come with AGING.

This presentation looks at:

- Aging in place and what that means
- Challenges of staying in your own home or a family member’s home as you age
- Independent senior living
- Impact of cognitive changes on where to live
- Progression and symptoms of Alzheimer’s (the #1 type of dementia) by stages
- Residential care options for persons living with dementia including advantages and care issues for each (Own home, Assisted living, Adult foster care, Memory Care, Nursing Home)
ALMOST HOME

Alzheimer’s is ultimately about the journey and not the destination. It’s about change; the fear and loss that comes with change; learning to simplify; learning the difference between “giving up” and “letting go.” It’s about resilience, trust, respect, and quality of life.

In the very late stages of an illness, the focus should be on quality of life and comfort instead of treatment and length of life. Hospice allows you to be aggressive in pain management and symptom control of your loved one.

Peaceful and comfortable. That is the best there is to offer to someone who is at the end of their journey and ALMOST HOME. Perhaps their expression of wanting and longing to “go home” has been their sense of getting closer to the end of their journey.

Alzheimer’s and other dementias can be long illnesses – long “walks of faith” that are ultimately about walking our loved one home. Some days are brighter than others; some paths bumpier than others. But there is great comfort in having walked another safely home.

CAREGIVER BURNOUT

Did you know that 70% of those with dementia are cared for by loved ones at home? Approximately 50% of those caregivers will die before the person with dementia. According to Paula Spencer, senior editor of Caring.com, “Stress and burnout are the most common problems for those who care for someone with Alzheimer’s disease.”

The Alzheimer’s Association’s Fact and Figures Report states, “In 2013, 15.5 million family and friends provided 17.7 billion hours of unpaid care to those with Alzheimer's and other dementias – care valued at $220.2 billion, which is nearly eight times the total revenue of McDonald’s in 2012. More than 60% of Alzheimer's and dementia caregivers are women. All caregivers of people with Alzheimer’s – both women and men – face a devastating toll. Due to the physical and emotional burden of caregiving, Alzheimer’s and dementia caregivers had $9.3 billion in additional health care costs of their own in 2013. Nearly 60% of Alzheimer’s and dementia caregivers rate the emotional stress of caregiving as high or very high, and more than one-third report symptoms of depression.”

This presentation will look at the red flags that indicate a dementia caregiver needs a break, how to tell if you are headed for burnout, and valuable methods and resources to help reduce stress and burnout.
THE DEMENTIA CARE TOOLBOX

Whether you are a new care partner or a long-time care partner, you will need a toolbox to store ideas, tips, articles, opinions, facts, notes, data, hints, plans, goals, guidelines, advice, books to read, websites, warnings, suggestions, statistics, details, essentials, events, what to do, and what not to do.

According to Wikipedia, “A toolbox (also called tool chest or workbox) varies with the craft of the owner. The purpose of the toolbox is to organize, carry, and protect the owner’s tools used for trade, hobby or DIY.” While dementia care as a care partner may not be your trade or hobby, it does seem to become a DIY “do-it-yourself” experience.

Becoming the “dementia care partner” is usually a “learn-as-you-go” position that sneaks up on you as slowly as the dementia changes reveal themselves. The tools you collect during your time as a dementia partner will serve you well, but you must first find them, then collect them, and finally use them. Where do you begin? How do you know what you need when you don’t even know what you need?

Start with some basic information from good reliable sources. This hands-on presentation will help you with some suggestions on where to start to gather information that will help further educate you about Alzheimer’s and other types of dementia. Featured are a few helpful products or “tools” you might want to add to your Care Toolbox.

THE DEMENTIA UMBRELLA

Dementia is not a disease... it is a broad term to describe a group of symptoms that impair memory, behaviors, and thinking. Dementia symptoms include memory loss, confusion, personality changes and behavioral changes which interfere with the person’s social and working life. A number of different illnesses can result in dementia and each has its own features.

This presentation will look at the five most common types of dementia under the term “Dementia Umbrella” – Alzheimer’s, Vascular, Lewy Body, Frontotemporal, and Parkinson’s. We will explore the prevalence of each type of dementia along with the different characteristics of each type.
FINDING THE ME IN DEMENTIA

Sometimes life takes us off the beaten path. The unplanned intrusion of dementia into our lives not only can stop us in our tracks, but can certainly take us off the planned path we had imagined was our future.

 Cairns are man-made piles of rock, trail markers left by others to mark their paths and a way home on uncharted journeys. Today’s information will help us to build a cairn for ourselves and others – to mark newer paths in dementia care. Paths that are discovered through empowerment – not dependency. Paths that are discovered through recognizing and encouraging talents, skills and strengths – not assuming problems and deficits. Paths that are discovered through honoring and respecting collaboration and partnerships – not through exclusion and disabling.

We will look at the difference between dementia and Alzheimer’s, examine negative social stigma and ways to reduce it in order to better understand and respect the persons living with dementia.

FOOD FOR THOUGHT
Nutrition and Hydration Challenges Along the Dementia Journey

Alzheimer’s and other types of dementia can make good nutrition a challenge. 90% of persons with Alzheimer’s lose weight. Those with late-stage AD are at risk for malnutrition due to problems with eating and swallowing difficulties.

This presentation looks at: Mealtime challenges for persons with dementia; Possible causes for not eating - including vision changes; Maximizing nutrition; Tips for increasing calories for poor appetites; Environmental changes to improve mealtime; Weight gain by eating too much; Dehydration; Foods that can lead to choking.

Mealtime is about way more than eating. “Mealtimes are one of the most important temporal anchors that people with Alzheimer’s have, marking morning, mid-day, and evening each day.” ~ Sue Coppola, Dementia Expert
IMPORTANCE OF REACHING OUT
Using Music, Touch and Spirituality

Reaching out to someone with dementia is a way to reconnect and make them feel secure, safe, cherished, human, connected, grounded, and not alone. All that with simple touch. Touch is the first sense that we develop while we are still a fetus, before we have developed cognition, and it is one that still is recognized by a person with dementia.

Hearing is the second sense we develop as a fetus, and music connects us with past experiences and emotion. The power of music, including singing, unlocks memories and reaches parts of the brain better than other ways of communication.

Spirituality is complex and means different things for each one of us. For some it’s religion, for others it can be art, music, nature, and relationships. Spirituality is part of every human being.

So among the many changes that happen to someone with dementia, there is still a person in there! And the key to opening that part of the person can often be Touch, Music, and Spirituality.

LET’S TALK ABOUT IT
Dementia, Communication and Changing Behaviors

ALZHEIMER’S… WHAT A DIFFICULT ILLNESS!
No one understands WHY anyone gets dementia of any kind. Scientists are still trying to figure out WHAT it is in order to prevent or cure it. And we certainly don’t know WHO will get it.

That pretty much means we are all in the dark when it comes to dementia. So we can STAY IN THE DARK with no answers and let the stigma of dementia grow, devouring us and our loved ones (and it will). Or we can bring LIGHT TO THE DARKNESS by learning about dementia so we can begin to SEE WITH OUR HEARTS what our eyes cannot see.

KNOWLEDGE is mandatory to understanding this disease. But DEEPLY UNDERSTANDING… now there’s the beginning of being able to separate the person from the disease. SEEING THE PERSON allows us to CHANGE. To begin to let go of “what was” and “what’s not working.” TO SEE WITH OUR HEARTS WHAT IS STILL THERE!
LET’S TALK ABOUT IT
Dementia Myths and Stigma

There are many types of dementia and it is perceived in many different ways:

- As a disease of the brain
- As a part of normal aging
- As a mental illness

DEMENTIA IS SPOKEN OF AS... something dreaded, a curse, a burden, the long good-bye, a battle, a plague, a living death.

All these negatives cause increased isolation, fear, shame, silence, ignorance, loneliness, frustration, anger, feelings of worthlessness, and many more. Why do we use all the negative labels, stereotypes and stigma surrounding dementia? Part of it is lack of knowledge, part is having misconceptions about dementia, and part of it is the history of how people with dementia have been treated. Part of it is fear and ignorance.

This presentation will examine where all these negatives have come from and explore many of the misconceptions about dementia. We can’t cure dementia, but through education and knowledge we can help break down the isolation and stigma of this disease.

LIVING WITH A DIAGNOSIS OF DEMENTIA
What You and Your Loved Ones Need to Know

How can anyone tell you the secret to your living with the diagnosis of dementia? For each one of us, the impact of that moment is very personal. How do any of us go on when bad things happen? Where do we find the strength and courage to face the unknown of a diagnosis like dementia of the Alzheimer’s type?

Somehow... we just do! Where does that strength come from? I don’t have the answers – the answers lie within you and that’s part of the journey; searching for and bringing the answers to life.

And so you begin “living with a diagnosis of dementia” either as the person with dementia, the care partner, the family, or the friend. This I do know... we cannot change what’s happening, but we can change our knowledge, understanding and expectations.

Although this disease is known for having so much loss, we can learn to focus on what’s still there. That is what helps make a difference between “living” and “living well” with a diagnosis of dementia.
MAKING SENSE OF DEMENTIA
Our Five Sense Organs - Eyes, Ears, Skin, Taste Buds, Nose

When a person develops dementia of the Alzheimer’s type, it is often labeled as a memory disease. And why is memory failing? Because the brain is failing. This brain failure is caused by a neurological disease that is gradual and progressive, affecting each person in a different way, and will cause damage throughout the brain. This means that the brain that controlled all our senses will change and be compromised and this will impact our abilities and quality of life.

As dementia damages our five senses, which helped us process information our whole life, we experience changes in sight, hearing/balance, touch, taste, and smell. Over time, these changes diminish the way we communicate and cause us to disengage with others and with life. Often this disengagement appears as though there is no longer a person there.

So how do you connect with someone with dementia? THROUGH THOSE SAME FIVE SENSES. The senses are super resilient, but often need some stimulation from others to awaken them.

PAIN MANAGEMENT
End-Stage Alzheimer Disease

Because pain has been under-recognized for persons with Alzheimer’s and other dementias, it has been under-treated. Research is now showing that pain is a common cause of changed behaviors that occur in 90% of persons with dementia. Oftentimes these behaviors are called difficult, problematic, combative, aggressive, etc. – all implying non-compliance on the part of the person living with dementia. The first thing that should be evaluated when these “changes” in behavior occur is unmet pain needs.

For years the theory was that persons with dementia experience less pain or none at all. WRONG! This presentation looks at nonverbal pain cues and successful non-pharmacological interventions that work. The PAIN-AD assessment tool is introduced and explained to help assess pain on a level of 0 to 10.
SHARING MEANINGFUL VISITS
In the Dementia Care Setting

We don’t talk much about dementia, so when it happens to someone we know, we aren’t sure how to talk to them or let them know we are there and we care. The years of negative social stigma have led many to believe a diagnosis of dementia means there’s nothing that can be done. Perhaps the isolation that happens to the person with dementia and their loved ones takes as much from them as the disease.

Did you know that you can make a difference visiting someone with dementia? However, a survey by the Alzheimer’s Society found that 42% of us think there is no point in keeping up contact at this stage. But the survey found that visits from family and friends stimulated feelings of happiness, comfort, and security.

This presentation offers ways to improve visits and many helpful communication tips and looks at changing behaviors and why they occur. Learning about how the damage to the brain causes the changes we see helps us to understand the person living with dementia better – which helps us recognize the person and abilities that are still there.

UNDERSTANDING ALZHEIMER’S
And When Hospice Can Help

Every 66 seconds someone in America develops Alzheimer’s according to the 2016 Annual Alzheimer’s Association Facts and Figures Report. Alzheimer’s disease is the most common cause of dementia. It is estimated that 5.3 million Americans have Alzheimer’s type dementia, and that number is growing.

Sadly, we don’t know why someone gets this progressive brain disorder or how to stop it. Our best frontline defense currently is to understand the disease itself and learn about resources and interventions that will help families care for their loved one with dementia.

This presentation will help you better understand the different types of dementia, the risks for developing Alzheimer’s, how it’s diagnosed, the stages and progression, changes in behavior, resources that may help, caregiver burnout, and hospice care.
WHAT IF YOU COULD OUTSMART ALZHEIMER’S

Aging, gender and genetics are all risks of getting Alzheimer’s that we can’t control. But there are many things we can do to improve our general body and brain health and possibly reduce or delay the development of dementia.

Scientists report that if we can delay the onset of Alzheimer’s disease by five years, we could reduce the total number of persons living with dementia by 50%. If we could delay the onset by ten years, we may be able to eliminate it.

This presentation will raise your awareness that you can make a difference in lowering your risks and risk factors for developing Alzheimer’s or perhaps at least delay its onset.

What if you could outsmart Alzheimer’s? It’s worth trying!

New Presentations Being Developed

- SAFETY FIRST: Physical and Emotional Safety Needs in Dementia Care
- SEEING THROUGH ANOTHER’S EYES: Vision Changes Due to the Damage of Dementia
- THE ABCs OF ALZHEIMER’S: Activities, Behaviors, and Communication
- I’M LOST: Walking, Wandering, and Elopement – Motion Blindness
- DEMENTIA AND NEW TECHNOLOGY: Assistive Devices – Prompts and Reminders; Leisure Activities – Music, Games, Reminiscence; Safety – Alarms, Monitors; and Ethics and Informed Consent of New Technology
EXPERIENTIAL EXERCISES

Carol utilizes experiential exercises as part of her presentations. These unique hands-on activities may help those attending to better understand some of the feelings, emotions, and frustrations experienced by those who are living with dementia. We will explore changes in vision, hearing, fine motor skills, ability to sequence activities, and many more in an effort to better understand why certain behaviors occur and how to best approach them or better yet, not trigger them.

- Aging Simulation
- Communication Breakdown
- Distraction/Loss of Focus
- Dollar Bill vs Dollar Change
- Glass Half Full
- Grief/Loss Exercise
- Language Breakdown
- Maple Tree/Oak Tree
- Numbers – Understanding how things work
- Optical Illusions
- Sequence Breakdown – Make a Peanut Butter Sandwich
- This is Me – Not Just Memory Loss
- Umbrella Terms
- Vision Changes
- What dementia may feel like at the beginning stage – confusion, anger, loss of concentration, disorientation

Reflections

- Big Rocks
- Blind Men and the Elephant
- Boiling Frog
- Cracked Water Pot
- Importance of Laughter
- Relaxation
- Starfish
NOTES
“Fishtail Mountain”
Himalayas, Nepal – Greg Brave, Photographer
used with permission

“Over every mountain there is a path, although it may not be seen from the valley.”
~Theodore Roethke

ALZHEIMER’S and DEMENTIA SPEAKER
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SEEKING POSITIVE PATHWAYS