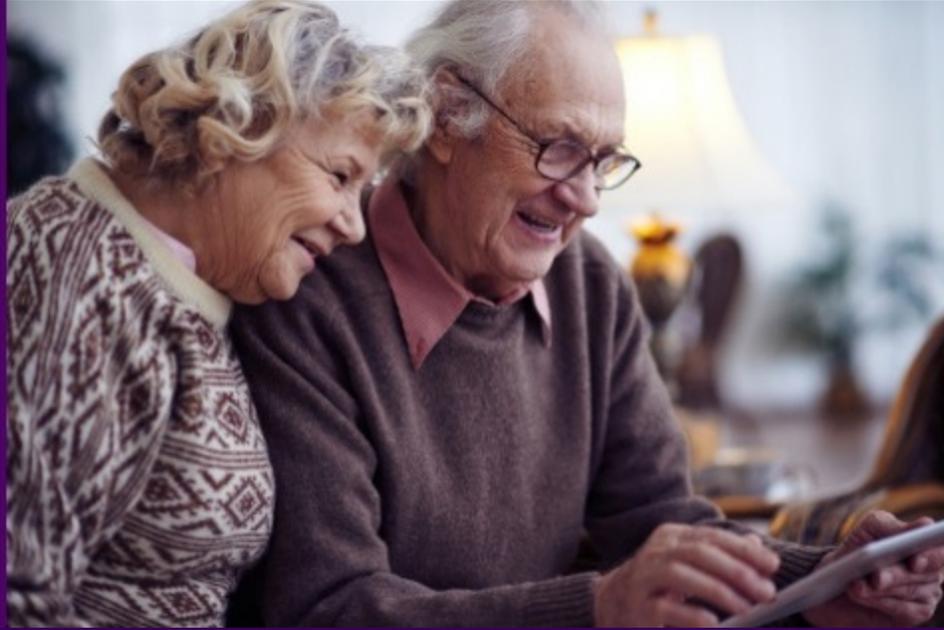


9TH ANNUAL



# CAREGIVER'S JOURNEY

A conference for Alzheimer's Caregivers & Healthcare Professionals

alzheimer's  association®

*Rhode Island Chapter  
Thursday, April 25, 2019  
Crowne Plaza Hotel  
Warwick, RI*



***is proud to be the Keynote Sponsor***

*Sponsored in part by the Division of Elderly Affairs, RI Department of Human Services, and with funds from the U.S. Administration on Aging.*



The Alzheimer's Association Rhode Island Chapter's Caregiver's Journey Conference Committee has been given the task of selecting high-quality presenters for our ninth annual Caregiver's Journey Conference. This conference is for both caregivers and professionals who dedicate their lives to caring for people with Alzheimer's Disease (AD) and other dementias. Caregivers are a diverse group. One size does not fit all. Yet, as different as we are, one aspect unites us: our concern for the quality of care for the people in our charge. Caring for someone with Alzheimer's disease or a related dementia is truly a labor of love.

Every family caregiver knows the shockwave that phone call at 3:00AM can bring. "Have the police found my dad wandering miles from home - or worse?" "Is mom being disruptive and fighting with staff in her long-term care facility again?" "Has my sister reached the breaking point taking care of our aging father?" These scenarios are, sadly, too familiar for the more than 53,000 family caregivers in Rhode Island. It is estimated that, last year, over 16.1 million family caregivers across the nation provided 18.4 billion hours of unpaid care to loved ones with Alzheimer's, eliminating an enormous institutional burden. This is a contribution to the nation valued at over \$232 billion. What would happen to the system if we were no longer able to provide this kind of care to our loved ones? We bear an enormous responsibility-equalled only by our contributions to America's healthcare system. Similarly, professional caregivers - those who work in assisted living facilities, nursing homes and hospitals, adult day services and community based programs and as private aides assisting families in their homes - bring a special set of skills and expertise, without which the system would suffer. (2018 Facts and Figures)

From our 24-hour Helpline (800-272-3900) to our diverse number of support groups, and from our dementia training for medical professionals to our free care educational seminars, the Chapter rightly places the highest priority on making sure that caregivers-unpaid and professional-have the tools to get the job done. Whether you are a family caregiver, a seasoned professional caregiver, or are new to the field, this conference promises to offer you the best and most interesting topics and presenters. Be sure to share your story today. Share your experience living with Alzheimer's or caring for a loved one with the disease; we may have opportunities for you to speak through our local Alzheimer's Association speakers bureau. We may also have opportunities for you to share your experiences with local and national media outlets. Your stories are powerful!

Special thanks to our sponsors in part: the Division of Elderly Affairs, RI Department of Human Services, with funds from the U.S. Administration on Aging and our Keynote Sponsor, Rhode Island Geriatric Education Center. We are pleased to announce our keynote address "Dementia: It is not a Person's Name" will be presented by Joshua J. Freitas, M.Ed, BC-DEd, CAEd. This year, during lunch time we will have an update on the Rhode Island State Plan on Alzheimer's Disease and Related Dementias presented by Craig Dwyer of the Lt. Governor's office. In addition, we are offering a variety of workshops presented by experts in the field of Alzheimer's care. On behalf of our Conference committee, our Board, our staff and most importantly the people we serve, I thank you for your loyal and consistent support. I look forward to greeting you at the conference!

Sincerely,

A handwritten signature in cursive script that reads "Donna M. McGowan". The ink is dark and the background is light.

Donna M. McGowan  
Executive Director

# Caregiver's Journey 2019 - Alzheimer's Association, Rhode Island Chapter

**8:00AM-9:00AM**      **Registration and Breakfast / Visit Vendor Tables**

**9:00AM-9:15AM**      **Opening Remarks**

**9:15AM - 10:30AM**      **Keynote Address: Joshua J. Freitas, M.Ed, BC-DEd, CAEd.**  
**Dementia: It is Not a Person's Name** ♥ • ▲

**10:30AM - 10:45AM**      **Break: Visit Vendor Tables**

**10:45AM - 12:00PM**      **Breakout Session A**

*Note: Conference session content targets specific audiences. Please choose your sessions accordingly. Use the legend below as a reference:*

♥ Caregiver   ● Social Work   ▲ Nursing

## **A1: Walk In Their Shoes: Virtual Tour** ♥ ● ▲

Guides will take you through an experience to better create a positive environment for those with dementia. We will first talk about general challenges one faces with a dementia diagnosis. We will review U.S statistics on topics such as depression, arthritis, visual impairment and information regarding our use of oxygen levels when we are stressed. We will then guide you through the challenges of compromised vision, hearing and dexterity which all affect cognition.

**Presenter:** Amber Evans, MA, R-DMT, LCMHC

## **A2: The Importance of Early Detection and Taking Control of Your Care Planning** ♥ ●

This workshop will discuss the importance for health care providers to disclose a diagnosis of dementia to the person living with cognitive changes as well as their families. We will indicate what steps you can take to begin planning for the future and taking charge of your health. This workshop is for people who are concerned about talking to their doctors, those newly diagnosed with the disease and their care partners.

**Presenter:** Jenny Miller, MSW, CMC

## **A3: The Grief Journey of Dementia Caregivers** ♥ ● ▲

The incremental losses associated with caregiving for a person with dementia cause in us two types of grief responses simultaneously. The immediate grief that comes with the many losses accumulating as the dementia advances is accompanied by anticipatory grief that is due to our keen sense of the inevitable death ahead. Use of caregiver grief inventories can assist caregivers and the professionals working with them to identify grief responses and improve self awareness and self care for as they continue the arduous caregiver journey.

**Presenter:** Deanna Upchurch, MA

## **A4: Dementia 101** ♥ ● ▲

This workshop will provide an overview of Alzheimer's disease and related dementias. This includes the prevalence of Alzheimer's disease, stages of progression and examples of symptoms from beginning to late stage.

**Presenter:** Jonathan Drake, MD

## **A5: Be An Empowered Caregiver** ♥ ●

Do you know there are Federal and State funded programs to provide financial assistance? Do you know how to access them? Do you think you may qualify? If you answered NO to any of these questions, then you need to attend this workshop.

**Presenters:** Kelly Lee, MS, Brenda Lee O'Hara, Linnea Tuttle, BS, Maryam Attarpour

## **A6: Bring Back the Joy: The Power of Music** ♥ ● ▲

This presents an interactive workshop on music as a social/physiological intervention model. We will present the latest music/brain research and evidence-based study results of how music helps people with dementia and their care partners. We will provide you with tips and resources on how to incorporate music activities into daily life. PowerPoint slides illustrate current creative programs, music/brain research and evidence-based study results, tips, and resources. A discussion with Q&A wraps up the presentation.

**Presenter:** Jan Maier, BSN, RN, MPH

**12:00PM- 12:45PM**                      **Lunch/ Visit Vendor Tables**

**12:45PM- 1:00PM**                      **State Plan Update, Craig Dwyer, Lt. Governor's Office**

**1:00PM- 1:15PM**                      **Break: Visit Vendor Tables**

**1:15PM-2:30PM**                      **Breakout Session B**

*Note: Conference session content targets specific audiences. Please choose your sessions accordingly. Use the legend below as a reference:*

♥ Caregiver   ● Social Work   ▲ Nursing

**B1: A Walk In Their Shoes: Virtual Tour** ♥ ● ▲

Guides will take you through an experience to better create a positive environment for those with dementia. We will first talk about general challenges one faces with a dementia diagnosis. We will review U.S statistics on topics such as depression, arthritis, visual impairment and information regarding our use of oxygen levels when we are stressed. We will then guide you through the challenges of compromised vision, hearing and dexterity which all affect cognition.

**Presenter:** Amber Evans MA, R-DMT, LCMHC

**B2: Behaviors: The Good, Bad and How to Support Creative Interventions** ♥ ● ▲

This program will first share the importance of identifying the care-giving team. We will be discussing non-pharmacological approaches to supporting individuals who exhibit behaviors that manifests as a need or a distress. We will also be working through how we, as caregivers, can support the challenges of two common transitions: a residential move and the introduction of outside caregivers. A behavior map will be introduced which will give a step by step intervention plan supporting the family.

**Presenter:** Kelly McCarthy, BA

**B3: Legal and Financial Planning: Consideration When Caring for People with Dementia** ♥ ●

This presentation will address some important questions, such as "How can I protect assets if a nursing home placement becomes necessary? Is guardianship necessary? What about trusts?" We will examine the legal tools available for the caregiver, as well as destroy myths that prevent caregivers from effectively managing the affairs and protecting the assets of loved ones.

**Presenters:** Macrina Hjerpe, Esq

**B4: Dementia 101** ♥ ● ▲

This workshop will provide an overview of Alzheimer's disease and related dementias. This includes the prevalence of Alzheimer's disease, stages of progression and examples of symptoms from beginning to late stage.

**Presenter:** Jonathan Drake, MD

**B5: Now What? Unique Considerations in Providing Support for People with Intellectual Disabilities and Dementia** ♥ ● ▲

This workshop will provide the participants with an overview of unique considerations that are encountered by people with ID and their care partners (whether paid and unpaid) throughout this 'continuum of dementia;' starting with early suspicion and including inclusion in dementia-friendly communities. To address this need in Rhode island, a resource guide has been developed through a federal grant by Seven Hills Rhode Island. With appropriate support which will include discussion of the guide, the maintenance of crucial relationships and a focus on meaningful activity, the quality of life for a person with ID and dementia can be enhanced through the duration of the disease process.

**Presenter:** Kathy Service, RN, MS, FNP-BC, CDDN

**B6: Community Health Network: Disease Self Management and Prevention Programs** ♥ ●

This workshop will provide information on the Community Health Network (CHN) which provides Rhode Islanders access to evidence-based health and wellness programs. CHN programs provide participants with the necessary tools to take control of their health and help manage their health conditions by encouraging behaviors such as those related to nutrition and physical activity. CHN programs have been proven to work for people with chronic conditions such as arthritis, pre-diabetes, diabetes, asthma, and heart disease.

**Presenter:** Kelsey Dixon, MS, Jasmine Franco, MS, Laura Jones

# Caregiver's Journey 2019 - Alzheimer's Association, Rhode Island Chapter

2:30PM- 2:45PM

Break: Visit Vendor Tables

2:45PM - 4:00PM

Breakout Session C

*Note: Conference session content targets specific audiences. Please choose your sessions accordingly. Use the legend below as a reference:*

♥ Caregiver ● Social Work ▲ Nursing

## C1 A Walk In Their Shoes: Virtual Tour ♥ ● ▲

Guides will take you through an experience to better create a positive environment for those with dementia. We will first talk about general challenges one faces with a dementia diagnosis. Then review U.S. statistics on topics such as depression, arthritis, visual impairment and information regarding our use of oxygen levels when we are stressed. We will then guide you through the challenges of compromised vision, hearing and dexterity which all affect cognition.

**Presenter:** Amber Evans MA, R-DMT, LCMHC

## C2 When It's No Longer Safe to Drive ♥ ● ▲

The number of older drivers has increased by 50% since 1999 and is projected to continue increasing. Although driving allows older adults to meet their mobility needs and to stay independent, several age-related functional impairments, medical conditions and medication side effects can compromise abilities. To understand and meet the safe mobility needs of older adult drivers, the AAA Foundation for Traffic Safety (AAAFTS) launched the Longitudinal Research on Aging Drivers study (LongROAD). AAA Northeast's Manager of Public Affairs and Traffic Safety will present the study's highlights and provide information on local resources that can guide individuals and caregivers through driving cessation while respecting quality of life.

**Presenter:** Diana Dias, MPA

## C3 Forget Me Nots: Legal and Financial Planning ♥ ●

In this workshop, the presenter will review the components of a basic estate plan (Will, Healthcare Power of Attorney, Financial Power of Attorney, HIPAA Release and Trusts, if necessary) the consequences of failing to plan, including the need for a guardianship proceeding and available options for veterans planning and advances, and crisis Medicaid planning. The listener will leave equipped with advice on how to avoid expenses associated with unnecessary guardianship, probate, estate tax, assisted living and nursing home expenses.

**Presenter:** Macrina Hjerpe, Esq.

## C4 Be Prepared: Home Safety and Transitions of Care ♥ ● ▲

Despite the lack of success in discovering disease modifying medications, behavioral science has shown significant advances in addressing many of the symptoms of neurodegenerative conditions, improving quality of life, reducing the use of antipsychotic medications, and advancing person-centered care throughout the disease process. The keys to a rewarding, happy and purposeful life, while learning to accommodate to the changes from a brain disorder, require an educated support system, an environment adapted to meet the individual's needs, the use of verbal and non-verbal communication, and flexible care providers. This presentation will demonstrate the benefits of non-pharmacological interventions in all areas of life and care, from the home to the hospital, for those living with and caring for neurodegenerative conditions.

**Presenters:** Laurie Gunter Mantz, OTR, CDP, CADDCT, CDCM

## C5 Be An Empowered Caregiver ♥ ●

Do you know there are Federal and State funded programs to provide financial assistance? Do you know how to access them? Do you think you may qualify? If you answered NO to any of these questions, then you need to attend this workshop.

**Presenters:** Kelly Lee, MS, Brenda Lee O'Hara, Linnea Tuttle, BS, Maryam Attanpour

## C6 Care Planning Through the Stages of Dementia ♥ ● ▲

There is no one-size-fits all formula when it comes to Alzheimer's care. Needs change at different stages of the disease and each family's situation is unique. Deciding on care can be a tough decision. This workshop will provide initial guidelines about key information, resources and care planning options.

**Presenter:** Bill Kirkpatrick, MSW

**Continuing Education Units are available for each workshop.** Please choose workshops based on your discipline to maximize the number of approved credits you can receive. Participants are required to sign-in, sign-out, and complete individual program Evaluation Forms for each approved workshop with corresponding CEU's in order to receive credit for workshop attendance. To receive total number of approved credits you must attend the entire conference.

## **Nurses**

This Education Activity is pending approval for Continuing Education hours by the Northeast Multi-State Division (NE-MSD), an accredited approver by the American Nurses Credentialing Center's Commission on Accreditation.

## **Social Workers**

This Education Activity is pending approval for Continuing Education hours for Social Work by the National Association of Social Work Rhode Island Chapter (NASW RI).

## Join the Fight Against Alzheimer's disease

Learn more about getting involved in clinical trials/research right here in Rhode Island. To learn more several clinical/research sites in RI will be on hand the day of the conference. Butler Hospital's Memory & Aging Program (MAP) will be GeneMatch swabbing throughout the entire conference. The purpose of the swab is to determine if people have a copy of a gene that may indicate a higher risk for development of Alzheimer's disease.

## Registration and Payment Deadline: April 12, 2019

### **Registration and Payment is to be completed online or by mail**

Online registration is strongly encouraged

Please visit [alz.org/ri](http://alz.org/ri) to complete registration

- Registration includes keynote address, workshops, continental breakfast, lunch, and visiting vendor tables.
- All attendees must register to attend.
- There is no registration fee for family caregivers.
- Professional attendees are required to pay a fee.
- Respite care is available for persons with dementia and will be free of charge.
- To register a person for respite care during the day of the conference the application enclosed **must be submitted by mail** to:

**Alzheimer's Association-RI Chapter  
9th Annual Caregiver's Journey Conference  
245 Waterman Street, Suite 306  
Providence, RI 02906**

- **Early registration is encouraged. Space is limited. There are no same-day registrations.**

REGISTRATION APPLICATION

\*one registration form per attendee, available online at alz.org/ri

All Attendees Must Select One Choice From Each Session

Session A. 10:45AM - 12:00PM

Session Attending: \_\_\_\_\_

Session C. 2:45PM - 4:00PM

Session Attending: \_\_\_\_\_

Session B. 1:15PM - 2:30PM

Session Attending: \_\_\_\_\_

Please Print Legibly

Last Name: \_\_\_\_\_

First Name: \_\_\_\_\_

Street Address: \_\_\_\_\_ City: \_\_\_\_\_ State: \_\_\_\_\_ Zip: \_\_\_\_\_

Phone: \_\_\_\_\_ Email: \_\_\_\_\_ MI: \_\_\_\_\_

I \_\_\_\_\_ hereby grant full permission in perpetuity to the organizers of this event to use, re-use, publish and re-publish my name and image as a participant in the event in photographs, video or other recordings. I have read, understand, and agree to the terms of this agreement.

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Payment for Professionals Only

\*There is no charge for caregivers or people living with dementia

Registration will not be accepted after Friday April 12th, 2019. Registration is not completed unless payment is received. Please make checks payable to the Alzheimer's Association, RI Chapter. Payment available online with registration at alz.org/ri

Conference Registration for Professionals \_\_\_\_\_\$125 )

CEU: (CHECK ONE) \_\_\_LPN \_\_\_RN \_\_\_Social Work \_\_\_Other

Discipline: \_\_\_\_\_

Credentials: \_\_\_\_\_

Check off method of payment:

\_\_\_ Check

\_\_\_ Visa \_\_\_ Mastercard \_\_\_ Discover Card

Card #: \_\_\_\_\_ CV#: \_\_\_\_\_ Exp. Date: \_\_\_\_\_

Signature: \_\_\_\_\_

**Additional Demographic Information Required to Complete Registration for All Conference Attendees (excludes respite care participants)**

*This questionnaire is available online during registration process*

**Year of Birth:** \_\_\_\_\_

*(For questions below, circle answer.)*

**Gender:** Female | Male

**Race/Ethnicity:**

White/Caucasian	Black/African-American	Hispanic/Latino	Mexican/Mexican American
Cuban	Puerto Rican	Other Hispanic/Latino	Asian
Chinese	Japanese	Korean/Vietnamese	Other Asian
Native Hawaiian/Other Pacific Islander	American Indian/Alaskan Native	Two or more races	Other

**Do you personally identify as Lesbian, Gay, Bisexual, or Transgender?** Yes | No

**Highest Level of Education:**

Less Than High School	Some High School	High School (diploma, GED)	Associates
Bachelors	Masters	Doctorate	Medical Degree

**Choose the one that best describes you. I am:**

Physician	Social Worker	Nurse	Student
Allied Health Worker	Care Partner (Family/Friend)	Person with Alzheimer's or Related Dementia	Administrator
CNA	PCA (Personal Care Attendant)	Direct Support Professional	Other

**Have you or the person you care for been diagnosed with:**

Alzheimer's Disease | A Related Dementia | Suspected, but no diagnosis | No Diagnosis

**If you or the person you care for has been diagnosed with Alzheimer's disease or a related dementia, please list the approximate date of diagnosis:** \_\_\_\_\_

**Age of Attendee:** Under 60 | Age 60-74 | Age 75-84 | Age 85+

**If you are a caregiver, please tell us who you are in relation to the person you care for. I am:**

Husband	Wife	Son/Son-in-law	Daughter/Daughter-in-law
Other Relative	Non-Relative	Not a Caregiver	Relationship Missing

**Return this form with registration application**

**APPLICATION FOR RESPITE CARE**

For persons with Memory Loss Available at Caregiver's Journey Conference

**Caregivers: Bring your loved one who is diagnosed with dementia for a full day of activities with our dementia trained personnel. While you attend the conference, they will enjoy a day of learning, activities and fun.**

Participant's Name: \_\_\_\_\_ Participant's Date of Birth: \_\_\_\_\_

Caregiver's Name: \_\_\_\_\_ Caregiver's Day of Conference Contact #: \_\_\_\_\_

Caregiver's Relationship to

Participant: \_\_\_\_\_

Participant's Medical History:

Does the participant need assistance with ambulating? \_\_\_\_\_

Do they use an assistive device? Cane\_\_\_ Walker\_\_\_ Wheelchair\_\_\_

Does the participant have a special diet or require assistance with eating? \_\_\_\_\_ If so, please explain:

Allergies to food or medications? If so, please list:

Visual Impairments? \_\_\_\_\_ Hearing loss? \_\_\_\_\_ Communication difficulties? If so, please explain:

Does the participant require bathroom assistance? \_\_\_\_\_ Reminder? \_\_\_\_\_ Physical Assistance? \_\_\_\_\_

Please list the participant's hobbies & interests past and present:

Is there anything your loved one would find upsetting? \_\_\_\_\_

In the event that your loved one becomes anxious or upset, what do you find helps to comfort them?

Is there additional information you would like to share to help us make their day a good experience?

Please list the participant's approximate date of diagnosis: \_\_\_\_\_ Participant's Gender: \_\_\_\_\_

Does participant personally identify as Lesbian, Gay, Bisexual, or Transgender? Yes | No

Please Circle Participant's Highest Level of Education:

Less Than High School	Some High School	High School (diploma, GED)	Associates
Bachelors	Masters	Doctorate	Medical Degree

Please Circle Participant's Race/Ethnicity:

White/Caucasian	Black/African-American	Hispanic/Latino	Mexican/Mexican American
Cuban	Puerto Rican	Other Hispanic/Latino	Asian
Chinese	Japanese	Korean/Vietnamese	Other Asian
Native Hawaiian/Other Pacific Islander	American Indian/Alaskan Native	Two or more races	Other

**Assumption of Risk, Release, Permission**

*In consideration of being allowed to participate in respite, I hereby expressly assume all risks of personal injury, death or property loss arising for my loved one's participation. I represent that my loved one is physically fit and able to participate in this event. I hereby release and agree not to sue Alzheimer's Association, its chapters, their respective officers, directors, volunteers, employees, sponsors and agents, from or in connection with any and all liability and claims arising out of my loved one's attendance in this event. I grant full permission to the organization of this event to use and publish my loved one's name and image as a participant in photographs, video, online, or other media or recordings.*

Signature \_\_\_\_\_ Date \_\_\_\_\_ I am the spouse and/or responsible party of Participant, and I hereby consent to his/her attendance. I have read the foregoing agreement and I hereby agree on behalf of my loved one and myself to its terms.

NONPROFIT ORG  
U.S. POSTAGE PAID  
PROVIDENCE, RI  
PERMIT NO. 2484

**24/7 Helpline**

For more information call  
1-800-272-3900  
or visit [www.alz.org/ri](http://www.alz.org/ri)

**Current Resident Or:**

SAVE THE DATE - 2019 WALK TO END ALZHEIMER'S  
Saturday, September 14, 2019 Miscunamicut State Beach, Westerly, RI  
Sunday, September 15, 2019 Fort Adams State Park, Newport, RI  
Sunday, October 06, 2019 Roger Williams Park, Providence, RI  
Sign up today at [www.alz.org/ri/walk](http://www.alz.org/ri/walk)



SAVE THE DATE - 2019 THE LONGEST DAY  
June 21, 2019  
Sign up at [alz.org/theongestday](http://alz.org/theongestday)



alzheimer's association®  
Rhode Island Chapter

9TH ANNUAL  
"CAREGIVER'S JOURNEY"  
A CONFERENCE FOR ALZHEIMER'S CAREGIVERS &  
HEALTHCARE PROFESSIONALS

APRIL 25, 2019  
CROWNE PLAZA HOTEL  
WARWICK, RI