SUPPORTING FAMILY CAREGIVERS

We Have An Intervention
(And an App)
For That!
Caregiver Supports are not “One Size Fits All”
Journey to the Summit

MT. EVEREST SUMMIT
8,848 metres

CAMP 4 SOUTH COL
8,000 metres

DEATH ZONE:
The lack of oxygen above 8000 metres can be fatal to climbers.

CAMP 3
7,162 metres

CAMP 2
6,400 metres

CAMP 1
5,943 metres

BASE CAMP
5,334 metres
Everyone is Unique

• There are many ways to “reach the summit”
• Every caregiving situation is unique
• Caregivers find and accept help in different ways
• Understand each caregiver’s unique strengths and needs
• Know all options available to offer best support
TWO PRIMARY PROGRAMS

• National Family Caregiver Support Program
• Wisconsin Alzheimer’s Family Caregiver Support Program
Caregiver Journey

What’s In Your Backpack?

- Respite For You
- Adaptive Equipment/Technology
- Support Groups, Memory Café’s
- Home Delivered Meals
- Caregiving Classes/Conferences
- Learning About The Disease/Condition
- Assistive Technology, Such As Lifeline
- Knowledgeable Guide
The Importance of Assessing Needs

- Ability to Perform Activities of Daily Living
  - Care Recipient and Caregiver
- Good Nutrition
- Adequate Sleep
- Physical Health
- Social Health
- Family/Friend Support
- Preparedness and Crisis Prevention
- Proper Education to Perform Tasks
Equipment and Planning

- Footwear
- Backpack
- Headwear
- Map – GPS
- Hiking Poles
- Insect Protection
- Sleeping Accommodations
- Bear Spray
- Emergency Kit
- Rope
- Flashlights
- Knife or other tools
- Musical Instrument/s

- How to Save/Pay for Trip

- When to Go
- Climb Alone or with Others
- What Route to Take
- How Many Miles/Day
- How Much Food/Water to Pack
- Understanding Changes in Weather Patterns
- What to do in case of an emergency
Accessing Supplies and Equipment

• National Family Caregiver Support Program
• Wisconsin Alzheimer’s Family Caregiver Support Program
National Family Caregiver Support Program (NFCSP)

- Older Americans Act program
- Support to caregivers
  - or people 60+ that are frail
  - for people with dementia
  - who are 55+ and caring for grandchildren/relatives
  - who are 55+ and caring for disabled adults
- No financial eligibility guidelines
- Can pay for respite, assistive devices/technology, training/education, transportation...anything to support the caregiver
- Contact ADRC or Aging Office
Alzheimer’s Family Caregiver Support Program (AFCSP)

• State funded program
• Supports caregivers of people with Alzheimer’s or other dementia

Eligibility
• Diagnosis of dementia
• Live in community
• Income under $48,000

• Can pay for respite, supplies, adaptive equipment, education/training, anything to make caregiving easier
Don’t Put Yourself Last

Caregivers are the Focus of Caregiver Support Programs

- Healthy diet
- Hobbies
- Friends
- Mental health
- Physical health
- Spiritual health
- Personal Safety
What Works for YOU?

Needs Assessment Helps Make Decisions

- Complete a self assessment or talk your situation through with someone
- What’s available?
- What’s realistic in your circumstances?
Caregiver Plan - Example

- Adult Day Services 2x/week – Tuesday and Thursday, 10am – 2pm
  - Caregiver plays cards (Tue afternoons)
  - Caregiver has lunch with friends or attends a support group (Thursdays)

- In-home personal care and respite 4 hrs on Fridays
  - Includes a bath for care recipient and dinner prep
  - Caregiver volunteers on Fridays

- Family visitor Sundays – son and daughter take turns visiting

- Church sends visitor and pastor brings communion 1x/month

- Arrange for medications to be mailed or delivered by pharmacy

- Install door alarms
Caregiver Plan (continued)

- Purchase games and activities of interest
- Powerful Tools for Caregivers class
- Online Support Group through Alzheimer’s Association
- Download CareZone app to keep track of medical information
Caregiver Interventions and Supports

- Education
- Connecting with Others
- Personal and Individualized Support
- Assistive Technology/Devices
Education

- Learn about the disease or condition
- Learn about caregiving
- Learn about resources
- Learn about self
- Help understand and cope with situation
Education

- **In-Person Training**
  - Powerful Tools for Caregivers
    - 6 week class
    - Learn ways to reduce stress, increase communication and care for self better
  - One day workshops
    - Alzheimer’s Association
    - Aging Office or ADRC

- **Educational Teleconference Calls**
  - Caregiver Teleconnect
  - Alzheimer’s Foundation of America
Education

• Conferences
  • State and Regional Alzheimer’s Conference
    • Shawano, Rhinelander, Eau Claire, Wausau
  • Local caregiver conference/appreciation, health fairs
    • Check with local ADRC

• DVD’s
  • Teepa Snow’s GEMS

• Books
  • Daily Comforts for Caregivers
  • Creating Moments of Joy
Education

• Online trainings
  • Alzheimer’s Association
  • Dementia Care Academy
  • Teepa Snow
  • UW Oshkosh – dementia training

• Health Promotion Classes
  • Wisconsin Institute for Healthy Aging
Support Groups

• **General Caregiver Support Group**
  • All types of caregivers

• **Caregiver Café**
  • Facilitated discussion group

• **Memory Café**
  • Social time for person with memory loss and their caregiver

• **Early Memory Loss Support Group**
  • For person with memory loss
Support Groups

- Alzheimer’s or Disease-based
  - Clinics or Hospitals

- Telephone Support Group
  - Alzheimer’s Association
    - last Tuesday at 10:00

- Online
  - Alzheimer’s Association – ALZConnected
  - Family Caregiver Alliance – group is in email format
  - Caring.com – various groups based on diseases or type of caregiving
It’s okay to use a little support!
Individualized Support

- Options Counseling
- Case Management
- Individual Counseling
- Respite
- Help with specific caregiving tasks
  - Specialized caregiving needed
  - Caregiver limitations
Respite for the Caregiver

*Respite* - *a short period of rest or relief from something difficult*

- A type of prevention program
- Use respite to recharge!
- Each caregiver needs something different
Respite

• Outside the home
  • Adult Day Care
  • Outings with group or temporary “caregiver”

• In-home
  • Activities of Daily Living
  • Chores/housekeeping
  • Social

• Overnight
  • In home or at facility
Caregiving Apps

- Help organize
- Provide quick tips/education
- Save time
- Stay connected with family and friends who help
Caregiving Apps

- Alzheimer’s Caregiver Buddy
- First Aid by American Red Cross
- CaringBridge
- Agefully – support and planning for adult children
- Pacifica – mindfulness app
- CareZone – organizes medical info
- Lotsa Helping Hands – works with a community of caregivers
Caregiver Buddy

**Caregiver Well Being**
- 4 areas addressed

**Communication**
- Tips for 3 stages

**Behaviors/Keeping Safe**
- Helps for 15 common behaviors

**Daily Care**
- Suggestions for 6 Activities of Daily Living (ADLs)

**Activities**
- Ideas and tips for activities

*Place for notes*

*Direct dial to toll free help line*
Caregiver Buddy - Examples

4 Activity Categories
• At home
• Types of Activities
• Planning Activities
• Quick Tips

Behaviors
• 15 common behavior challenges addressed

Activities
- Planning Activities
  - Focus on enjoyment, not achievement. Find activities that build on remaining skills and talents.
  - Encourage involvement in daily life: e.g., wiping counter tops or emptying wastebaskets.
  - Relate activity to work life: e.g., organizing or assemble a mailing.
  - Look for favorites.
  - Consider the time of day. Keep in mind that your typical daily routine may need to be changed somewhat.
- Activity Quick Tips

Behaviors
- Fixation/Obsessing
- Hallucinating
- Hoarding
- Misplacing Things
- Moodiness
- Pacing
- Pain
- Repetitive Actions/Behaviors
- Sleep Issues
- Sun Downning
- Wandering/Escaping

Notes | Live Help | share it!
Caregiver Buddy – Examples

Daily Care

Suggestions for Morning, Afternoon, Evening
- 6 specific ADL’s addressed:
  - Bathing
  - Dental Care
  - Dressing
  - Mealtime
  - Grooming
  - Toileting
- Additional ADL tips for caregivers

Communication

Tips for middle stage communication
- Allow ample time for responses so the person can think about what to say and how to say it.
- Engage the person in one-on-one conversation in a quiet place with minimal distractions.
- Be patient and supportive. Offering comfort and reassurance can encourage the person to explain his or her thoughts.
- Maintain good eye contact. It shows you care about what he or she is saying.
- Avoid criticizing and correcting. Instead, listen and try to find the meaning in what is being said. Repeat what was said to clarify the thought.

- Basic Communication Information
- Tips for communicating in:
  - Early Stage
  - Middle Stage
  - Late Stage
First Aid – American Red Cross

Offers education and assistance in following categories

- **Learn** first aid for 20 situations
- **Prepare** for 20 emergencies
- **Emergency** first aid instruction for 20 scenarios
- **Quizzes** let you test your knowledge
- **Hospitals near you** when location is turned on
First Aid – American Red Cross

Covers 20 scenarios
- Allergies/anaphylaxis
- Asthma attack
- Bleeding
- Broken Bone
- Burns
- Choking
- Concussion/Head injury
- CPR – unresponsive not breathing
- Diabetic emergency
- Distress
- Heart attack
- Heat stroke
- Hypothermia
- Meningitis
- Poisoning/harmful substances
- Seizure/epilepsy
- Stings/bites
- Strains and sprains
- Stroke
- Unresponsive
First Aid – American Red Cross - Examples

Learn

- Diabetic emergency
  1. Give them something containing sugar. Acceptable forms of sugar include:
     - Glucose tablets
     - Candies that can be chewed
     - Fruit juice
     - Fruit strips
     - Regular (non-diet) soda
     - Milk
  2. Reassure the person. Call 911 if in doubt or they don’t improve, have trouble breathing or lose consciousness.

- Unresponsive and breathing
- FAQ
- What is diabetes?

Prepare for Emergency

- Emergency kit
  - Some suggested items to get you started...
    - Water—at least a 3-day supply; one gallon per person per day
    - Food—at least a 3-day supply of nonperishable, easy-to-prepare food.
    - Flashlight
    - Battery powered or handcrank radio (NOAA Weather Radio, if possible)
    - Extra batteries
    - First aid kit
    - Medications (7-day supply) and necessary medical items

Emergency Instruction

- Bleeding
  1. Put pressure on the wound with whatever is available to stop or slow down the flow of blood.
  2. If the bleeding is severe, call 911 as soon as possible, or get someone else to do it.
  3. Keep pressure on the wound until help arrives.

Call 911
CareZone

Organize health information for self or others

- Basic Information
- Medications (scan bottles)
  - Track when meds were taken – reminder to take them
  - Reminders for reorders
- Insurance Cards (scan)
- Drivers Licenses (scan)
- Allergies
- Conditions
CareZone - features

- Stores medication information
- Contact information for Doctors, Pharmacy, etc.
- Photos and files
CareZone - features

• **Trackers**
  - Blood Glucose
  - Blood Pressure
  - Pain
  - Headache
  - Mood
  - Temperature
  - Sleep
  - Nausea
  - Seizure
  - Blood O2
  - Height
  - Weight

• **Journal** for observations

• **Share** info with others via email
Lotsa Helping Hands

- Set up a community of people to share in the care of your loved one
- Coordinate care by requesting help with tasks
- Relay information to the group by posting announcements
- Share photos
- Extend well-wishes
Agefully (coming soon!)

• Being created by UW-Madison School of Nursing
• Evidence-based guidance, support and planning tool for adult children caring for aging parents
• Connects caregivers to research and expertise
• Helps them anticipate needs, explore options and prepare for future
Agefully - features

• Assessments: Questions about a specific situation or concern

• Plans: Interactive checklists that can be shared
Agefully - features

• Articles
  • Learn: Explain different aspects of each topic
  • Talk: Help start and continue often-difficult conversations
  • Solve: Describe different ways to address needs and problems
Agefully Timeline

Pilot test #1
- Summer 2017
- 50 caregivers
- Ozaukee, Portage, Sheboygan, Brown and Milwaukee Counties

Pilot test #2
- Early 2018
- 50 caregivers via markets

Sustainability
- Business model and market decisions
- Marketing efforts
- Product launch 2018

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Pacifica

Daily tools for stress and anxiety

• Based on Cognitive Behavioral Therapy and Meditation
• “Guided Paths” offered daily
• Track sleep, health, mood
• Write Goals – Hope Board
Pacifica

• Guided Meditation Exercises
  • Relaxation
  • Mindfulness
  • Stressful Situations
  • Calm Down
  • Inner Strength

• Connect with a community
  • Discussions or Chat Groups
Find the supports right for you on your journey to the summit!

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