



# **SUPPORTING AMERICAN INDIANS AND ALASKA NATIVES WHO LIVE WITH DEMENTIA**

**POLICY TIPS AND RESOURCES  
FOR YOUR TRIBAL EMERGENCY  
AND DISASTER RESPONSE**

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**Blythe S. Winchester, MD, MPH, CMD, AGSF**

*(Eastern Band of Cherokee Indians)*

Director of Geriatrics Services, Cherokee  
Indian Hospital

Chief Clinical Consultant, Geriatrics and Palliative  
Care, Indian Health Service

**Aneva Turtle Hagberg, BS**

*(Eastern Band of Cherokee Indians)*

Health Operations Director, Public Health and Human Services  
Eastern Band of Cherokee Indians

**Chelsea C. White IV, MD, NRP, FAEMS, FACEP**

Director, UNM Center for Rural and Tribal EMS  
University of New Mexico Department of  
Emergency Medicine

**Tribal emergency management reviewer**

*(Anonymous)*

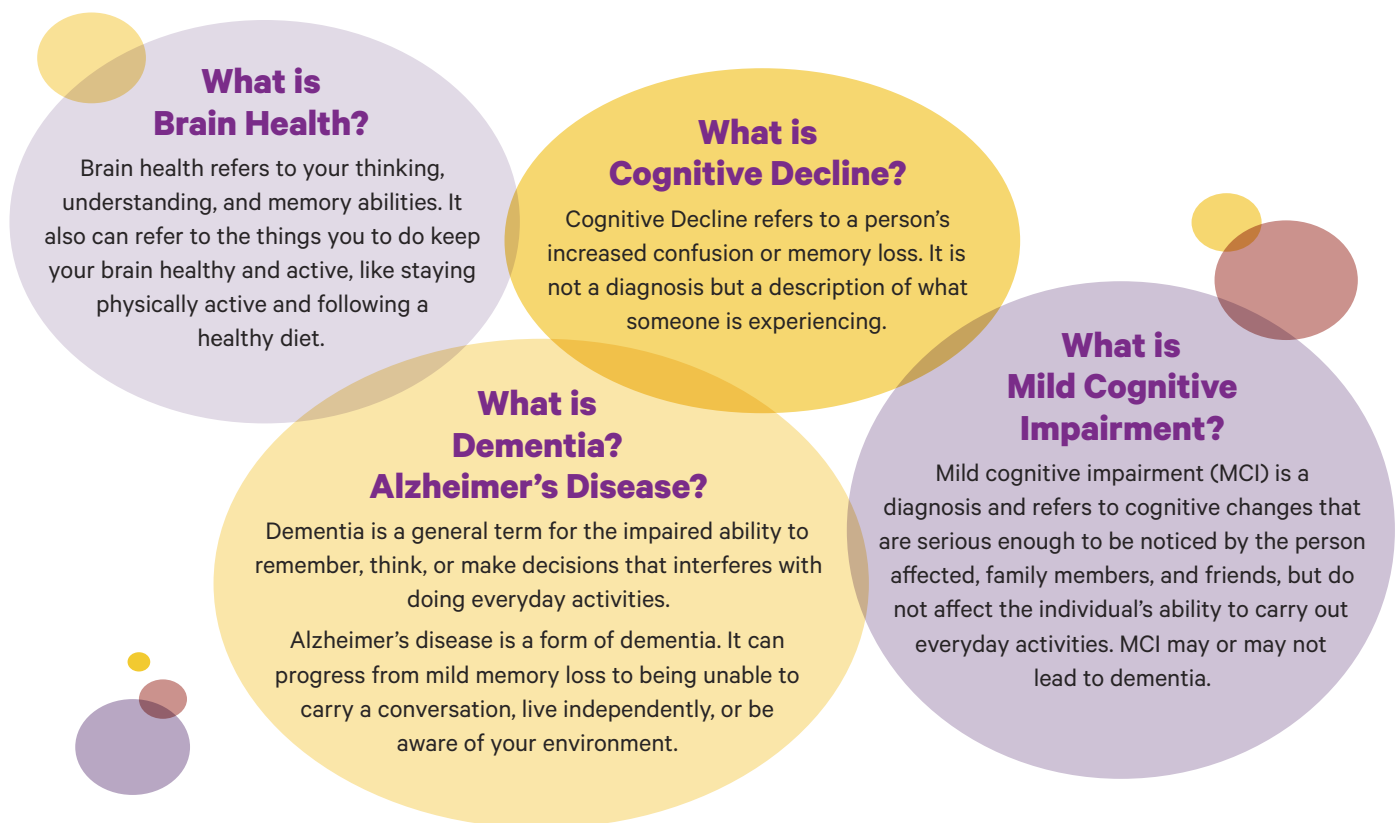


# INTRODUCTION

Emergency situations take many different forms, from natural disasters and extreme weather events, such as fires and floods, to terrorist events, epidemics and global pandemics. Each emergency poses unique challenges and necessitates unique responses. As sovereign entities, Tribal Nations are poised to direct emergency responses that best serve their citizens.

In general, populations with physical, cognitive and even economic limitations may be especially vulnerable during both acute and prolonged emergencies and may be at higher health and safety risks. People who live with dementia, Alzheimer's disease or other brain health challenges may have difficulty understanding and following directions during emergency situations, where communications are critical. They may also get overwhelmed and experience stress which can contribute to health and safety risks for themselves and responders. This resource serves as a quick reference for Tribal leaders and planners to consider how they can best support or accommodate people living with Alzheimer's Disease or another dementia during an emergency. The aim is to raise awareness of how American Indian and Alaska Native (AI/AN) people who live with dementia experience the world and offer possible strategies for policies to accommodate their needs.

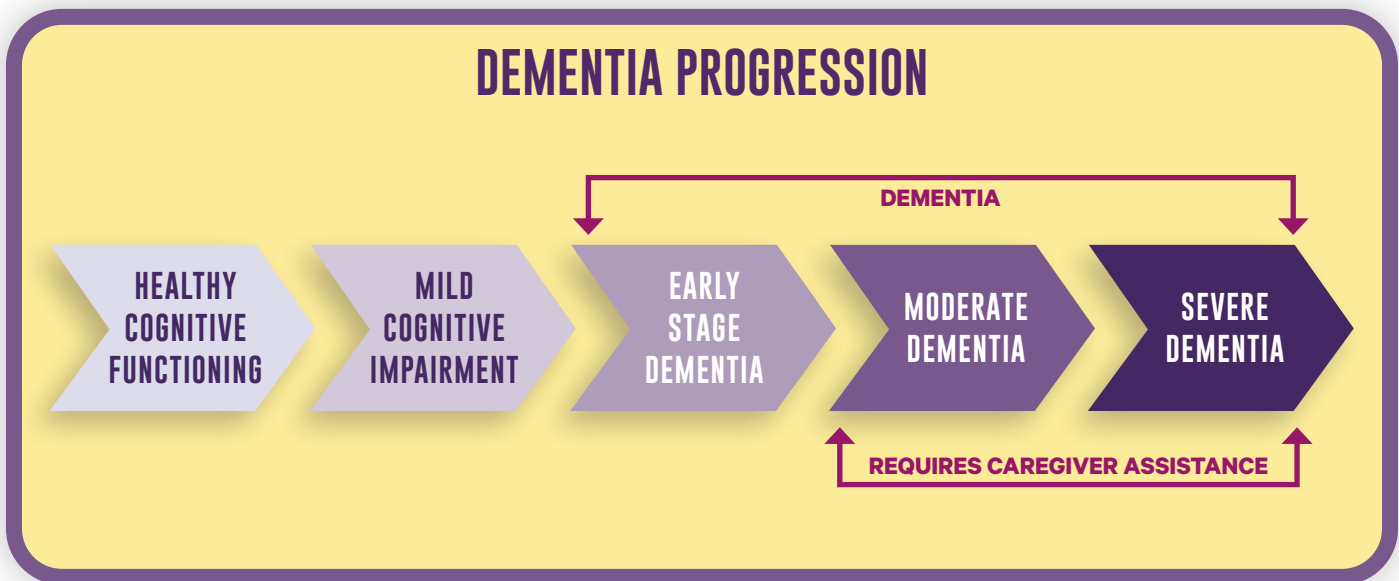
The following definitions help explain brain health and Western medical terms for cognitive (thinking and reasoning) changes that AI/ANs may experience (**FIGURE 1**):



**FIGURE 1 DEFINITIONS**



Many individuals living with dementia reside in community settings, such as in their own homes or in homes with family members. This is especially true in Tribal communities where multi-generational households are common. In the case of progressive dementias, such as Alzheimer's disease, a person may need ongoing support to help them with daily living, navigating the health system and for safety and protection **(FIGURE 2)**. As cognition changes, reliance upon family caregivers increases and caregivers become essential for all aspects of health and safety. This is particularly relevant in emergency situations where risks are higher.



**FIGURE 2 DEMENTIA PROGRESSION**

Providing care for a loved one can be demanding. The health, mental, social and economic effects on family caregivers are often so significant that caregiving is considered a public health priority as well. Policies supporting Native people living with dementia must incorporate their caregivers too for the best outcomes.







## Why Policy?

Emergencies and disasters may pose serious risks to the safety and well-being of AI/ANs living with dementia, particularly in rural Tribal communities where it may be more difficult to reach those at risk. Clear and concise policies and procedures can mitigate the risks for people with dementia and their caregivers.

Much of the emergency preparedness resources available are focused on advice and guidance for *individuals* to be prepared. While essential, reliance upon individual preparedness alone is not a sufficient strategy for an emergency response. At some point, interaction with responders is inevitable, even if it is physically distant as with mass communications or as involved as individual transport and sheltering. Systems and policies become especially important at those points of interaction.

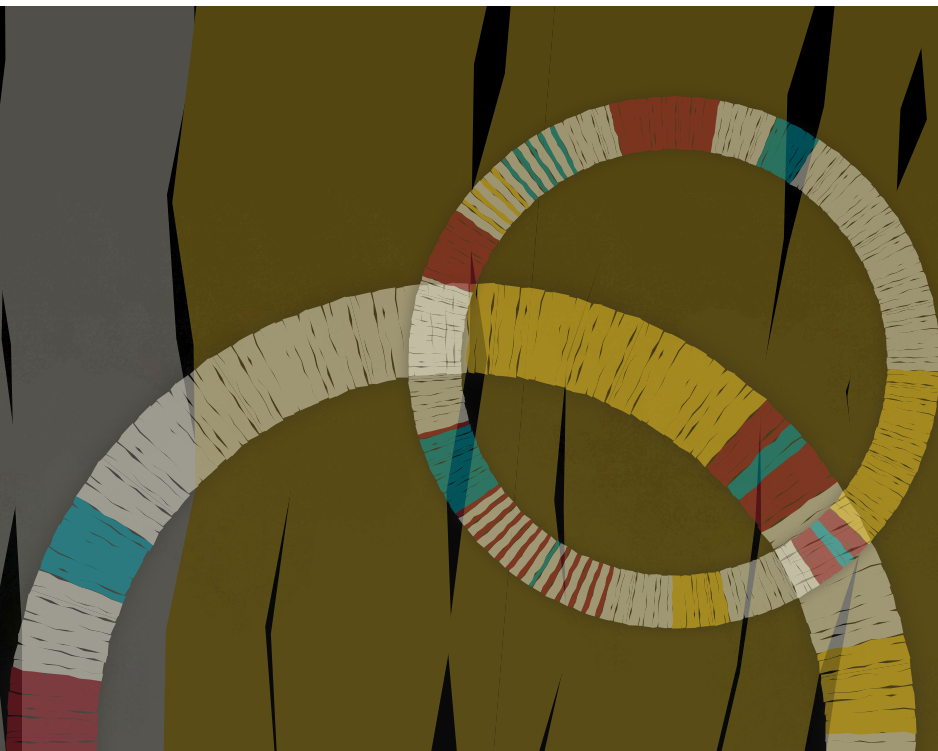
“Policy” is a broad term and can be understood as a law, regulation, procedure, administrative action, incentive, or voluntary practice of governments and other institutions.<sup>1</sup> Policies can be thought of as “hard-wiring” approaches and strategies into the practices of an organization. As such, the hard-wiring removes the uncertainty of solely relying on individual knowledge or a well-intentioned leader.<sup>2</sup>

This resource specifically focuses on how operational policies in times of emergencies or disasters can be leveraged to be inclusive and equitable for people who live with dementia and reside in Tribal community settings.

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1 <https://www.cdc.gov/policy/analysis/process/definition.html>

2 Substance Abuse and Mental Health Services Administration. SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach. HHS Publication No. (SMA) 14-4884. Rockville, MD: Substance Abuse and Mental Health Services Administration, 2014.





# HOW NATIVE PEOPLE LIVING WITH DEMENTIA MIGHT EXPERIENCE EMERGENCIES

Understanding the mental, physical, social and emotional experiences of people living with dementia during emergency situations can help Tribal planners and policy makers ensure their services are inclusive, equitable and have the best outcomes.

## MAY HAVE DIFFICULTY COMMUNICATING SYMPTOMS

May not recognize or be able to communicate that they have been injured or are unwell.

## MAY BE UNABLE TO PROCESS INFORMATION

May have limited ability to understand directions and may forget them.

## HAVE MEMORY DIFFICULTIES

People may forget recently learned information. They often need clues about daily activities, even hydration.

## MAY BECOME UPSET OR AGITATED

Heightened emotions or confusion due to unfamiliar settings can lead to agitation.

## MAY EXPERIENCE PAIN DIFFERENTLY

May have a hypersensitive pain response that they are not able to communicate.

## ARE LIKELY TO HAVE ADDITIONAL HEALTH ISSUES

Chronic conditions, such as diabetes or heart disease, are common among people with dementia. Many people with dementia, and those who care for them, may be managing multiple health issues that must be considered.

IN  
EMERGENCY  
SITUATIONS  
PEOPLE WHO LIVE  
WITH DEMENTIA:



**MAY HAVE DIFFICULTY  
INTERPRETING WHAT THEY  
HEAR OR WITH VISION**

Loud, noisy rooms or situations may be disorienting. They may have a smaller field of vision.

**MAY HAVE  
DIFFICULTY WITH  
MULTIPLE TASKS**

This can pose difficulty in following a plan.

 **MENTAL**

 **PHYSICAL**

 **SOCIAL**

 **EMOTIONAL**

**CAN BE STRESSED, FRUSTRATED, AND OVERWHELMED**

This can be due to a reduced individuals' ability to recognize their environment and understand the context of the situation.

**MAY BE MORE LIKELY  
TO BECOME DEPRESSED**

Due to changed abilities, autonomy and isolation, some people living with dementia may become depressed.

**MAY WANDER OR BE  
PRONE TO GETTING LOST**

Memory difficulty and likelihood of becoming confused puts people at risk. The stress of emergency situations increases a person's potential to wander or hide.

**CAN DEVELOP  
DELERIUM EASILY OR  
HAVE HALLUCINATIONS**

Reorienting someone may be less effective than working with them in their reality.

**MAY RELY HEAVILY ON FAMILY MEMBERS OR CAREGIVERS**

Without their caregivers, people with dementia are at higher risk for poor health, injury, abuse and isolation. Complicating matters, they may not be able to remember their caregiver's name or how to reach them.



## TRIBAL POLICY TIPS FOR EMERGENCY MANAGEMENT

# SUMMARY OF TRIBAL POLICY TIPS

1

### **POLICY TIP #1:**

When requesting an emergency declaration and assessing the type of federal assistance that may be needed, consider the amount and type of assistance that will be required to support those in your Tribal community who live with dementia, ranging from communications, shelter and evacuation assistance to continuity of medical services. *[page 8]*

2

### **POLICY TIP #2:**

When identifying populations that may need specific services in disaster or emergency situations in planning documents, avoid terms such as “disabled” that may contribute to stigma. Seek out words or phrases in the Native language that may best fit the policy need. *[page 9]*

3

### **POLICY TIP #3:**

Adopt a function-based approach, or one that is based on individuals’ capabilities rather than labels when defining special populations in Tribal emergency operations plans and policies. *[page 9]*

4

### **POLICY TIP #4:**

Consider **CONNECTION** (to people, culture and nature) as a functional need during emergencies or disasters to preserve the protective effects of culture and belonging. *[page 11]*

5

### **POLICY TIP #5:**

Review and update Tribal emergency plans and procedures to include and accommodate American Indian and Alaska Native people who may have functional needs during an emergency. *[page 12]*

6

### **POLICY TIP #6:**

Considerations for the development and use of identification systems should include clear stipulations for:

- With whom the information will be shared.
- How information will be used.
- Security measures in place for protecting information.
- The type of help that might be available.
- Limitations on help (i.e., [if] help is not guaranteed). *[page 15]*



## TRIBAL POLICY TIPS FOR ACKNOWLEDGING PEOPLE'S UNIQUE VULNERABILITIES

7

### **POLICY TIP #7**

Incorporate culturally relevant dementia education and trauma-informed skill building in trainings for emergency responders. *[page 18]*

8

### **POLICY TIP #8**

Create Tribal emergency communication policies to direct the use of a variety of communication methods and strategies to be inclusive of American Indians and Alaska Natives who live with dementia. *[page 17]*

9

### **POLICY TIP #9:**

With the input of Tribal members living with dementia and their caregivers, examine and evaluate the design of facilities to increase access, simplify processes, connect to culture and reduce environmental stressors. *[page 19]*

10

### **POLICY TIP #10:**

Enable Tribal emergency policies that maintain a sense of familiarity, routine and security for those who live with dementia. *[page 20]*

## TRIBAL POLICY TIPS FOR ACKNOWLEDGING THE ROLE OF CAREGIVERS

11

### **POLICY TIP #11:**

Recognize and treat caregivers as partners by Tribal health, social service, public safety and emergency personnel. *[page 22]*

12

### **POLICY TIP #12:**

Create or extend Tribal policies to provide physical, emotional and financial relief for caregivers during emergencies. *[page 23]*

13

### **POLICY TIP #13:**

Create or amend health facility policies to provide the best possible scenarios to maintain the physical, social and emotional connection between the patient and caregiver. *[page 23]*





# EMERGENCY MANAGEMENT

## Emergency Declarations

Emergency declarations are the most pivotal policy moment for Tribes to activate their response to public health emergencies. As sovereign nations, Tribes may declare emergencies through multiple mechanisms (see Resources below). Once an emergency response is approved, a cascade of policies and procedures across the Tribe may be activated, such as through emergency operations plans and incident command systems. The incident command system allows responders from different agencies/entities to coordinate a response across Tribal entities and often with entities outside the Tribe. The response can affect practically every aspect of Tribal operations - communications, transportation, health services, social services, education, public works, etc. Including the needs of those who live with dementia is a crucial aspect of building equity in an emergency response.

When seeking federal emergency assistance, such as through the Stafford Disaster Relief and Emergency Assistance Act, a Tribe will work with the Federal Emergency Management Agency (FEMA). FEMA has assigned regional Tribal liaisons that are available for support and technical assistance. FEMA also offers technical “assistance from Regional Disability Integration Specialists or other Disability Integration Advisors to help Tribal representatives identify and meet the accessibility needs of all people with disabilities and those with accessibility and functional needs, to afford participation in Stafford Act assistance.”<sup>3</sup>



### POLICY TIP #1:

When requesting an emergency declaration and assessing the type of federal assistance that may be needed, consider the amount and type of assistance that will be required to support those who live with dementia, ranging from communications, shelter and evacuation assistance to continuity of medical services.

### RESOURCES

- [Emergency Declarations and Tribes: Mechanisms Under Tribal and Federal Law](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4703113/)
- [Tribal Affairs | FEMA.gov](https://www.fema.gov/about/organization/tribes)

<sup>3</sup> FEMA (2017). Tribal Declarations Pilot Guidance. p.6



## Identifying Vulnerable Populations

One important policy strategy to ensure everyone is provided aid, services and communications equitably during an emergency or disaster is to ensure that vulnerable Tribal populations are identified in emergency policies and procedures.

Emergency operations plans may direct healthcare services or programs to adjust services for specific segments of the population. For example, terms that have been used include people with “special needs” “special populations” “disabled” “handicapped” “vulnerable” or “at risk individuals”. “Children” and “elders” have also been used as broad categories.

As emergency policies may span across several Tribal divisions, programs and services, they may include communications, transportation, healthcare, social services, and public safety, among others.

While there is no single definition of how specific populations should be defined by the community, consider using less stigmatizing terms such as “people living with disabilities” or “people/populations experiencing risks” rather than language that defines people by their conditions. For Alzheimer’s disease and other dementias, expressing these needs as “unique vulnerabilities related to dementia” adds specificity and clarity, whereas a broad “special needs” category may not work because it cannot be operationalized.<sup>4</sup> There may be a word or phrase in the Native language that best describes people with unique vulnerabilities which could be used.

2

### POLICY TIP #2:

When identifying populations that may need specific services in disaster or emergency situations, avoid terms such as “disabled” that may contribute to stigma. Seek out words or phrases in the Native language that may best fit the policy need.

## A Functional-Needs Approach

A function-based approach reflects providing services based on the capabilities of an individual, not a person’s condition or demographic label (children, the elderly, homeless, diabetic, etc.). For example, people who use assistive devices such as wheelchairs may include people of all ages and health status. This need is a factor in providing services such as transportation during an emergency, regardless of age or health status.

3

### POLICY TIP #3:

Adopt a function-based approach, or one that is based on individuals’ capabilities rather than labels when defining special populations in Tribal emergency operations plans and policies.

The National Response Framework (NRF), the federal guide to emergency planning, used by many Tribes, describes a whole community approach that includes serving, among others,

<sup>4</sup> Kailas, June Isaacson, Enders, Alexandra. 2007. Moving Beyond “Special Needs”: A Function-Based Framework for Emergency Management and Planning. *Journal of Disability Policy Studies* Vol. 17/No. 4/ Pp. 230–237



individuals with access and functional needs. Access and functional needs refer to persons who may have additional needs before, during, and after an incident in functional areas, including but not limited to:

- Communication
- Maintaining health
- Maintaining independence and self-determination<sup>5</sup>
- Support
- Transportation

## Functional Needs



### COMMUNICATION

Tribal members who have limitations that interfere with the receipt of and response to information will need that information provided in methods they can understand and use. They may not be able to hear verbal announcements, see directional signs, or understand how to get assistance because of hearing, vision, speech, cognitive, intellectual limitations, and/or limited English proficiency. Their own ability to communicate may be limited as well.



### MAINTAINING HEALTH AND MEDICAL CARE

Tribal members who are not self-sufficient or who do not have adequate support from caregivers, family, or friends may need assistance from trained medical professionals with managing health conditions. *Note that people who rely upon electricity to power their medical devices may need additional considerations such as access to portable generators.*



### MAINTAINING INDEPENDENCE AND SELF-DETERMINATION

Tribal members requiring support to be independent in daily activities may lose this support during the course of an emergency or a disaster. This support may include supplies, medical equipment, and/or attendants or caregivers. Supplying needed support to these individuals will enable them to maintain their pre-disaster level of independence. *Note that maintaining independence, such as living in their home may be possible only through the direct assistance of a caregiver.* Self-determination reflects a core value that aims to promote an individual's capacity for control over their own lives. People who live with dementia may need supervision.



### SUPPORT

Before, during, and after an emergency, Tribal members may lose the support of caregivers, family, or friends or may be unable to cope in a new environment (particularly if they have dementia or psychiatric conditions such as schizophrenia or intense anxiety). If separated from their caregivers, people living with dementia may be unable to identify themselves and, when in danger, may lack the cognitive ability to assess the situation and react appropriately.

<sup>5</sup> [Dept. of Homeland Security. 2019. National Response Framework, 4th Ed., p.5](#)





## TRANSPORTATION

Tribal members who cannot drive or who do not have a vehicle may require transportation support for successful evacuation. This support may include **accessible** vehicles (e.g., lift equipped or vehicles suitable for transporting individuals who use oxygen) or information about how and where to access mass transportation during an evacuation.<sup>6</sup>

### "CONNECTION" AS A FUNCTIONAL NEED

Tribal nations may wish to identify additional functional needs specific to their populations such as:



## CONNECTION

Closures, physical distancing and stay at home orders, and loss of life have isolated people from connections to their families, their peers, and their Native language speakers, cultural leaders, and even nature. Additionally, people may be disconnected from regular activities they depend upon for social, emotional, spiritual and cultural connection such as elder lunch programs, ceremonies, social gatherings and subsistence activities. Losing connection to community, activities and nature can have effects on mental and physical health. Stress and social isolation can also negatively impact health and immune function.<sup>7</sup> In Tribal cultures where interconnectedness is deeply understood and highly valued, losing connection affects the entire community.

4

### POLICY TIP #4:

Consider **CONNECTION** (to people, culture and nature) as a functional need during emergencies or disasters to preserve the protective effects of culture and belonging.

### EXAMPLE

People may find connection in people, language, and meaningful objects. An example of the consideration of connection would be a transportation policy that allows people to carry medicine bags with them during transport.

## RESOURCES

- [The National Response Framework](https://www.fema.gov/emergency-managers/national-preparedness/frameworks/response)  
<https://www.fema.gov/emergency-managers/national-preparedness/frameworks/response>
- [The Partnership for Inclusive Disaster Strategies](https://disasterstrategies.org/)  
<https://disasterstrategies.org/>

6 Federal Highway Administration. U.S. Department of Transportation. "Evacuating Populations with Special Needs, Routes to Effective Evacuation Planning Primer Series." April 2009.  
[https://ops.fhwa.dot.gov/publications/fhwahop09022/sn1\\_overview.htm](https://ops.fhwa.dot.gov/publications/fhwahop09022/sn1_overview.htm)

7 Holt-Lunstad et al. (2010) concluded that the influence of social relationships on the risk for death is comparable to the risk caused by other factors like smoking and alcohol use, and greater than the risk associated with obesity and lack of exercise. Likewise, other researchers have highlighted the detrimental impact of social isolation and loneliness on various illnesses, including cardiovascular, inflammatory, neuroendocrine, and cognitive disorders (Bhatti and Haq, 2017; Xia and Li, 2018).



## Emergency Management Plans

Emergency preparedness and response refers to the steps taken, before, during and after natural and human-made disasters or emergencies to ensure public safety. There are four phases of emergency management that complete the life cycle of a disaster/emergency. These four phases are mitigation, preparedness, response, and recovery. (Figure 3). A Tribe may have a separate plan for each phase or a combined plan which includes all phases. Building policy components throughout each phase to meet the needs of all populations allows for a more equitable response and better outcomes for all who may be affected.



**FIGURE 3 EMERGENCY MANAGEMENT CYCLE**

1) **Mitigation** — preventing or reducing the effects of future disasters/emergencies

2) **Preparedness** — preparing equipment and resources for when a disaster or emergency occurs;

3) **Response** — responding to a disaster/emergency and;

4) **Recovery** — recovering from a disaster/emergency.

### 5

#### **POLICY TIP #5:**

Review and update Tribal emergency plans and procedures to include and accommodate American Indian and Alaska Native people who may have functional needs during an emergency.

#### **EXAMPLES**

In order to ensure all groups are represented, a Tribe may wish to use an existing committee or establish a new one to advocate for those with functional needs. Sample policy language could read “A committee of representatives from the community and programs who serve people with functional needs will inform the operations command. The committee will consist of a representative from the community, the Aging Program, Social Services, Health Services, Disability Services, Mental Health Services, Foster Care and Education.” Or, as related to communications, sample language could include: “The Tribal Public Information Officer will consult with subject matter experts on communications messages and channels for reaching people with functional needs, such as needs related to communication, maintaining health, maintaining independence, self-determination and security, transportation and maintaining connection to culture.”



## PREPAREDNESS RESOURCES

- Tribal Community Emergency Preparedness Toolbox (The American Indian Health Commission, Washington State) <https://aihc-wa.com/aihc-emergency-preparedness/>
- Administration for Community Living General Emergency Preparedness Resources <https://acl.gov/emergencypreparedness>

## Response Resources

- PUBLIC HEALTH WORKBOOK: To Define, Locate, and Reach Special, Vulnerable, and At-risk Populations in an Emergency (Centers for Disease Control and Prevention) (CDC) [https://emergency.cdc.gov/workbook/pdf/ph\\_workbookfinal.pdf](https://emergency.cdc.gov/workbook/pdf/ph_workbookfinal.pdf)
- Bureau of Indian Affairs Emergency Management <https://www.bia.gov/bia/ojs/emd>

## Recovery Resources

- Pre-Disaster Recovery Planning Guide for Tribal Governments, Federal Emergency Management Agency (FEMA) <https://www.fema.gov/sites/default/files/2020-07/pre-disaster-recovery-planning-guide-for-tribal-government.pdf>

## Mitigation Resources

- TRIBAL MITIGATION Planning Handbook [https://www.fema.gov/sites/default/files/2020-06/fema-tribal-planning-handbook\\_05-2019.pdf](https://www.fema.gov/sites/default/files/2020-06/fema-tribal-planning-handbook_05-2019.pdf)





## USE OF IDENTIFICATION SYSTEMS

Many people who live with dementia are at risk of wandering and becoming disoriented in their surroundings, which may become even more of a risk during a crisis. During emergency or disaster situations, they may become separated from their caregivers.



Knowing who and where the Tribal populations with unique vulnerabilities are located, such as those living with dementia, can be crucial to protecting their health and safety and that of those who care for them. Maintaining accurate address and contact lists, or registries, can be challenging from a logistical and civil rights perspective. When health information is involved, the Health Insurance Portability and Accountability Act (HIPPA) will factor in as well. Developing an identification system for emergencies is complicated and it is best to include multiple partners and legal experts, if accessible, for planning. Community Health Representatives and family members are often the most knowledgeable about peoples' functional needs in their communities and should also be included in designing or adopting identification systems.

A registry is a *voluntary* database of individuals who meet the eligibility requirements for receiving additional emergency response services based on specific needs. Registries or lists may already be available through health systems (e.g. diabetes registries), transportation systems or existing emergency management registries. It is likely that multiple layers in the response effort may require access to different types of lists, or registries. For example, those responsible for evacuation will benefit more from location data and those responsible for medication management may benefit more from accurate contact information. The need for data sharing agreements should be considered as well.

Registries and lists have limitations. For example, disease registries that rely upon diagnoses or conditions doesn't necessarily speak to individuals' functional needs during an emergency. Similarly, there may be individuals who are not "registered" anywhere who have significant needs during emergencies. Additionally, a registry is useful if continually updated. As Alzheimer's and dementia is undercounted in Indian Country and services may be underdeveloped, relying solely upon an Alzheimer's registry may not be the most useful in emergency situations in serving this population. Using additional means to identify people with cognitive difficulties who may need functional assistance would be a sensible action.

An identification system needs to identify not only the person but their assistive equipment *and* their supportive people. For example, someone who uses a walker or oxygen tank will require transportation that can accommodate their equipment. Similarly, someone who has difficulty following complex directions or is easily agitated, such as with dementia, may need their family member or caregiver to be present. Just as an emergency response would accommodate someone's walker or use of oxygen, accommodating someone's family member or caregiver may be equally life-sustaining for an individual with brain health challenges.



The nature of the emergency will also factor in who needs to be identified and how they will be identified. COVID-19 contact tracing has concentrated new attention and technologies to quickly locate and communicate with at-risk individuals. These procedures and case management technologies may be an excellent source for adapting to other emergency situations.

Other identification strategies include medical jewelry and wallet cards to assist emergency personnel in quickly identifying medical needs. They often include diagnoses, transplants, implants, medications, and importantly, emergency contact information. They may simply be engraved with information or more high tech with a scannable QR code. For example, the Alzheimer's Association offers a bracelet that includes a 24/7 wandering support system. As medical jewelry is customizable, they can include functional needs, and family or caregiver's information. Temporary bracelets may also be effective in situations where large numbers of people are being moved or served at once.

## PRIVACY CONCERNS

Protecting the privacy and rights of Tribal members doesn't diminish during an emergency. Concerns about privacy could be a factor of why someone may or may not volunteer their personal and health information. This could affect the buy-in and uptake of an identification system. Note that identification systems operating outside the authority of the Tribe may have Tribal data sovereignty considerations as well.

### 6

## POLICY TIP #6:

Considerations for the development and use of identification systems should include clear stipulations for:

- With whom the information will be shared.
- How information will be used.
- Security measures in place for protecting information.
- The type of help that might be available.
- Limitations on help (i.e., [if] help is not guaranteed).<sup>8</sup>

## IDENTIFICATION SYSTEMS RESOURCES

- US Department of Health and Human Services (HHS) Health Information Privacy: [Emergency Response | HHS.gov](https://www.hhs.gov/hipaa/for-professionals/special-topics/emergency-preparedness/index.html)  
<https://www.hhs.gov/hipaa/for-professionals/special-topics/emergency-preparedness/index.html>
- [Planning for an Emergency: Strategies for Identifying and Engaging At-Risk Groups A guidance document for Emergency Managers](https://www.cdc.gov/nceh/hsb/disaster/atriskguidance.pdf) (CDC)  
<https://www.cdc.gov/nceh/hsb/disaster/atriskguidance.pdf>
- [Contact Tracing: Using Digital Tools](https://www.cdc.gov/coronavirus/2019-ncov/downloads/digital-contact-tracing.pdf) (CDC)  
<https://www.cdc.gov/coronavirus/2019-ncov/downloads/digital-contact-tracing.pdf>

8 Centers for Disease Control and Prevention (CDC). Planning for an Emergency: Strategies for Identifying and Engaging At-Risk Groups. A guidance document for Emergency Managers: First edition. Atlanta (GA): CDC; 2015. p. 6



# EDUCATION AND TRAINING

Education and training is a cornerstone of an effective public health emergency response. People living with dementia may experience memory loss and confusion, and how that is interpreted and responded to respectfully may be unique to the culture and history of the community. Emergency responders, public safety, healthcare and social services staff will benefit from understanding how people with dementia in their community experience and navigate the world.

Training policies may include all Tribal employees, specific divisions, departments or programs or be required in emergency preparedness plans for those involved in response efforts. They may include specific trainings or just require a training on the topic of dementia. While there is an abundance of information and training on Alzheimer's and dementia, incorporating a cultural component may require the addition of building skills to develop cultural insights (see Training Resources).

## TRAINING RESOURCES

- For adapting trainings, see [Culture and Caregiving: Adapting the Savvy Program to Native Culture](https://www.nicoa.org/elder-resources/savvy-caregiver/culture-and-caregiving-adapting-the-savvy-program-to-native-culture/) (National Indian Council on Aging).

<https://www.nicoa.org/elder-resources/savvy-caregiver/culture-and-caregiving-adapting-the-savvy-program-to-native-culture/>

- [NIHB Brain Health Action Institute for Tribal Nations Online Module](https://nihb.org/brain-health/online-module/story.html), see, Unit 3, Cultural Considerations for Brain Health in Indian Country

<https://nihb.org/brain-health/online-module/story.html>

- [Approaching Alzheimer's: First Responder Training](https://training.alz.org/products/4021/approaching-alzheimers-first-respondertraining) (Alzheimer's Association)

<https://training.alz.org/products/4021/approaching-alzheimers-first-respondertraining>.

- [The Savvy Caregiver](https://www.nicoa.org/elder-resources/savvy-caregiver/culture-and-caregiving-adapting-the-savvy-program-to-native-culture/), (National Indian Council on Aging)

<https://www.nicoa.org/elder-resources/savvy-caregiver/culture-and-caregiving-adapting-the-savvy-program-to-native-culture/>

- [Dementia Dialogues®](https://sc.edu/study/colleges_schools/public_health/research/research_centers/office_for_the_study_of_aging/projects_programs/dementia_dialogues/index.php) is a 5-module online course for caregivers, medical professionals, emergency responders, family members, service professionals, among others.

[https://sc.edu/study/colleges\\_schools/public\\_health/research/research\\_centers/office\\_for\\_the\\_study\\_of\\_aging/projects\\_programs/dementia\\_dialogues/index.php](https://sc.edu/study/colleges_schools/public_health/research/research_centers/office_for_the_study_of_aging/projects_programs/dementia_dialogues/index.php)



## Trauma-informed Approaches

Emergencies themselves can be traumatic events, but American Indians and Alaska Natives' individual and collective histories may also be underlying factors affecting how someone might react or behave. For example, if someone 'acts out' or doesn't cooperate, you should consider if past or current trauma may be shaping their response and try to eliminate or minimize potential triggers (i.e. loud noises, chaotic settings, family separation, etc.). Understanding how past and present trauma affects people, and developing trauma-informed skills for staff across the response system can contribute to both better short-term and long-term outcomes.



### **POLICY TIP #7:**

Incorporate culturally relevant dementia education and trauma-informed skill building in trainings for emergency responders.

### **TRAUMA TRAINING RESOURCES**

- Substance Abuse and Mental Health Services Administration's (SAMHSA) Concept of Trauma and Guidance for a Trauma-Informed Approach  
[https://ncsacw.samhsa.gov/userfiles/files/SAMHSA\\_Trauma.pdf](https://ncsacw.samhsa.gov/userfiles/files/SAMHSA_Trauma.pdf)
- Tips for Disaster Responders: UNDERSTANDING HISTORICAL TRAUMA WHEN RESPONDING TO AN EVENT IN INDIAN COUNTRY (SAMSHA)  
<https://store.samhsa.gov/sites/default/files/d7/priv/sma14-4866.pdf>
- 6 Guiding Principles To A Trauma-Informed Approach (CDC, SAMSHA)  
[https://www.cdc.gov/cpr/infographics/00\\_docs/TRAINING\\_EMERGENCY\\_RESPONDERS\\_FINAL.pdf](https://www.cdc.gov/cpr/infographics/00_docs/TRAINING_EMERGENCY_RESPONDERS_FINAL.pdf)

## 6 GUIDING PRINCIPLES TO A TRAUMA-INFORMED APPROACH



CDC Center for Preparedness and Response.





# COMMUNICATION

Communication access addresses the needs of individuals who require assistance, with the receipt of information they can understand and use due to hearing, vision, speech, cognitive, or intellectual disability, and/or with limited English.<sup>9</sup> Regardless of the emergency, some level of communication will be necessary to convey important information and instructions. The need for community members to adequately receive and understand communications underpins a successful emergency response. A variety of communication methods will likely be needed. The use of translators or the use of the native language may also be necessary, not only for the messaging to be fully understood but also to retain connection to the Tribal culture. Native speakers and language programs may be an excellent source for developing messaging. For those living with dementia, they may have trouble following directions or may forget them. They may respond better to visuals, familiar faces, familiar scenes or objects.

Strategies for Communicating with people living with dementia:

- If instructions are needed to be followed, communications that are simple and one step at a time.
- Use of visuals
- Speaking slowly
- Avoid fear-based communications; use words and phrases to provide reassurance
- Communications that connect to past positive events or familiar people or living things; ones that trigger positive emotions;
- Incorporating traditional stories or lessons in communications
- Use native language and offer translation services when needed
- Recognize that caregivers or family members may be instrumental in interpreting messaging.

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## POLICY TIP #8:

Create Tribal emergency communication policies to direct the use of a variety of communication methods and strategies to be inclusive of American Indians and Alaska Natives who live with dementia.

## COMMUNICATION RESOURCES

- [Effective Communications for People with Disabilities: Before, During, and After Emergencies | NCD.gov](https://www.ncd.gov/publications/2014/05272014)  
<https://www.ncd.gov/publications/2014/05272014>
- [Ensuring Language Access And Effective Communication During Response And Recovery: A Checklist For Emergency Responders](https://www.hhs.gov/guidance/document/ensuring-language-access-and-effective-communication-during-response-and-recovery)  
<https://www.hhs.gov/guidance/document/ensuring-language-access-and-effective-communication-during-response-and-recovery>

<sup>9</sup> Kailes, June Isaacson. “Defining Functional Needs – Updating CMIST By June Isaacson Kailes Disability Policy Consultant.” The Partnership for Inclusive Disaster Strategies. July 13, 2020.



# MEDICAL FACILITY ACCESS

Emergency or disaster situations may hamper maintaining health in many ways. People may lose access to medications, supplies, mobility devices and family members or caregivers. There may be changes to the way care is accessed or access itself may be limited due to safety protocols.

People who live with dementia may be sensitive to their surroundings. Noisy, confusing, unfamiliar environments may be overwhelming and may cause stress. The set up and flow of a healthcare facility, whether permanent or temporary, can contribute to someone's ability to fully access care. Facility design is also a way to support the safety and security for those who live with dementia, through elements that connect to culture.

Seeking the input of those who live with dementia and their caregivers is a best practice planning strategy that can inform design elements that contribute to a dementia-friendly facility.



## POLICY TIP #9:

With the input of Tribal members living with dementia and their caregivers, examine and evaluate the design of facilities to increase access, simplify processes, connect to culture and reduce environmental stressors.

## EXAMPLES

- Facility policies that allow patients to remain in a familiar environment such as their vehicle rather than a busy, noisy waiting area.
- Patient flow processes that reduce movement throughout the facility and limit the number of interactions with multiple healthcare staff.
- Policies that recognize the importance of and allow traditional medicine practices.

## RESOURCES

- Community Engagement – Primary Healthcare Performance Initiative (references SouthCentral Foundation's Nuka System of Care)

<https://improvingphc.org/improvement-strategies/population-health-management/community-engagement>

- Universal Design in Healthcare Institutions Manual – United Nations Development Programme

[https://www.ua.undp.org/content/ukraine/en/home/library/democratic\\_governance/universal-design-in-health-care-institutions.html](https://www.ua.undp.org/content/ukraine/en/home/library/democratic_governance/universal-design-in-health-care-institutions.html)

- Universal Design for Healthcare Facilities – Joint Commission of Accreditation of Healthcare Facilities

<https://cs.uwaterloo.ca/~jhoey/teaching/cs793/wiki/uploads/universal-design-for-health-care-facilities-1.pdf>



## SAFETY AND SUPPORT

Providing safety and support may differ according to individual need. This may often include supervision for people who live with dementia and who may rely upon a trusted family member or caregiver for daily living. Safety and support may also be needed by those who find it difficult to cope in new or strange environments. Routine and familiarity are essential to those living with dementia.

“Daily routines help reduce stress and anxiety. Persons [living] with dementia thrive on familiarity. Familiarity is important because dementia gradually impairs a person’s ability to plan, initiate, and complete an activity. By creating an environment of familiar routines and activities, it allows them to feel comforted and calm. If they can still perform an activity, they can still retain their sense of control and independence”.<sup>10</sup>

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### POLICY TIP #10:

Enable Tribal emergency policies that maintain a sense of familiarity, routine and security for those who live with dementia.

### EXAMPLES:

- Emergency evacuation policies that limit, reduce or defer any changes in familiar environments. Moving a person from their familiar and secure environment as a last option.
- If relocation is unavoidable, policies should involve and allow caregivers in relocation options and procedures.
- Implement policies that allow medicine bags, healing or protective objects, and people and activities that make the person feel secure and comfortable. This may be especially relevant for transportation and sheltering policies.
- Emergency operations or temporary facility procedures that maintain routines and activities of daily living.

10 Alzheimer’s Project ForOurCaregivers.com. THE IMPORTANCE OF ROUTINE AND FAMILIARITY TO PERSONS WITH DEMENTIA. June, 2020. <https://www.alzheimersproject.org/news/the-importance-of-routine-and-familiarity-to-persons-with-dementia/> Accessed 5/11/21







# FAMILY MEMBERS AND CAREGIVERS

For people living with Alzheimer's disease and other dementias, carrying out tasks of daily living may become more difficult as their symptoms worsen. In these cases, a caregiver can assist with these tasks and ensure a greater quality of life for them. Because caregivers are critical to the wellbeing of people with cognitive impairments, it is vital to be inclusive of their roles and experiences when forming policies for emergency situations.

## WHO AND WHAT ARE CAREGIVERS?

Caregivers can come from many backgrounds and serve during any stage of dementia. They may be a professional caregiver, in which case, they are paid to provide services to support those living with challenges. More common, caregivers can be informal such as friends or family members who do not receive any form of financial compensation in exchange for their care. When someone lives with family members, in multi-generational households, there may be several people taking responsibility for a loved one. In Tribal communities, family members may not consider themselves caregivers but simply fulfilling their role as relatives.

Defining “caregiver” is important when considering including them in policies. In an example from a Tribal code, “Caregiver” means: (A) a person who is required by law, contract, or tribal custom to provide services or resources to an elder or vulnerable adult; or (B) a person who volunteers to provide services or resources to an elder or vulnerable adult; or (C) an institution or agency which is required by law or agreement to provide services or resources to an elder or vulnerable adult; or D) a person who has undertaken authority to act for the elder or vulnerable adult under a power of attorney, conservatorship, guardianship, representative payee, protective payee, or similar relationship.<sup>11</sup>

### The following are some statistics related to U.S. caregivers:

- Nearly one-third of caregivers are 65 years or older;
- Approximately two-thirds of dementia caregivers are women and over one-third are daughters;
- Approximately 40% of dementia caregivers have a college degree or a higher education;
- 41% of caregivers have a household income of \$50,000 or less;
- Nearly one-fourth of dementia caregivers also care for a child in addition to an aging parent.<sup>12</sup>
- In 2017, about 41 million family caregivers in the United States provided an estimated 34 billion hours of care to an adult with limitations in daily activities. The estimated economic value of their unpaid contribution was approximately \$470 billion.<sup>13</sup>

<sup>11</sup> Lummi Nation Code of Laws. Title 5B. Elder and Vulnerable Adult Protection Code  
[https://narf.org/nill/codes/lummi/5B\\_Elder.pdf](https://narf.org/nill/codes/lummi/5B_Elder.pdf)

<sup>12</sup> Alzheimer's Association. (2021). 2021 Alzheimer's disease facts and figures. Alzheimer's Dementia, 17(3)

<sup>13</sup> Recognition of Family Caregivers in Managed Long-Term Services and Supports. AARP Public Policy Institute, April 2020. <https://www.aarp.org/content/dam/aarp/ppi/2020/04/recognition-of-family-caregivers.doi.10.26419-2Fppi.00090.001.pdf> accessed 3/16/21



## UNIQUE RISKS FOR CAREGIVERS

Caregivers provide an essential role in helping those who live with dementia, but the work can have a considerable impact on their own health. The stress caregivers may experience can come from primary stressors, such as patient behavior symptoms or secondary stressors that are unrelated to their elder's diagnosis, such as social isolation. While caregiving in Indian Country is not well studied, dementia caregivers may be subject to general health risks such as depression, anxiety, insomnia, chronic stress, social isolation, and feelings of loneliness. These risks may consequently predispose caregivers to develop certain health conditions such as cardiovascular disease, stroke, or systemic inflammation.<sup>14</sup>

## CAREGIVING IN EMERGENCY SITUATIONS

Caregivers can be highly instrumental in emergency situations. They can provide functional and communication support to the situation and provide emotional support and advocacy for the person they support. While not comprehensive, below are several policy options to ensure the health of the caregiver is maintained in emergency situations:

Partnerships between Indian Health Service and/or Tribal health personnel and family caregivers are needed to achieve high quality and sustainable care. According to the World Health Organization (WHO), partnerships in care should be based on trust, equality, mutual understanding, shared goals, and shared accountability. This is reflected in policy documents, such as the [United Kingdom strategy for family caregivers](#), which emphasizes that healthcare personnel should consider family caregivers as partners in care and recognize their unique expertise.<sup>15</sup>

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### POLICY TIP #11:

Recognize and treat caregivers as partners by Tribal health, social service, public safety and emergency personnel.

The closure policies of the COVID-19 pandemic left many people without the support they rely upon for the physical and emotional needs for their family members. Fitness centers and programs, cultural programs and elder lunch sites were closed, leaving the caregivers with the responsibility of finding ways to meet those needs as well as meeting the new needs of the pandemic. While many programs stepped up with wellness packages and food delivery, caregivers may have borne the brunt of the added stress to an already high stress situation. Policies that recognize and support the caregiver role can help reduce this stress and the negative health effects produced by stress. These may include workplace policies that provide additional time off for family caregiving, financial compensation programs for caregivers who expend resources to meet the needs of their family members, and respite programs.

14 Kovaleva M, Spangler S, Clevenger C, Hepburn K. Chronic Stress, Social Isolation, and Perceived Loneliness in Dementia Caregivers. *J Psychosoc Nurs Ment Health Serv*. 2018 Oct 1;56(10):36-43..

15 Häikiö, K., Sagbakken, M., & Rugkåsa, J. (2020). Family caregivers' involvement strategies in response to sub-optimal health services to older adults living with dementia — a qualitative study. *BMC Geriatrics*, 20(1), 290. <https://doi.org/10.1186/s12877-020-01663-z>



For a Tribal policy example, the Swinomish Tribe recognizes the relationship between elders and their families and caregivers by including services for families and caregivers as needed in their elder protection plans.<sup>16</sup>

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### **POLICY TIP #12:**

Create or extend Tribal policies to provide physical, emotional and financial relief for caregivers during emergencies.

Separation from caregivers poses physical, mental and emotional risks to those living with dementia. Stress and social isolation can negatively impact health and immune function, and so reducing social isolation is essential during a time when individuals require strong immune function to fight off threats such as a novel virus.<sup>17</sup>

COVID-19 isolation policies in facilities challenged the relationship between caregivers and patients to heartbreaking points of people dying alone in hospital beds while caregivers and family members watched from the windows or said their goodbyes on the phone. The effects of these policies on family members and healthcare personnel who had to enforce these policies will not be known for some time.

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### **POLICY TIP #13:**

Create or amend health facility policies to provide the best possible scenarios to maintain the physical, social and emotional connection between the patient and caregiver.

## **CAREGIVING RESOURCES**

- Services for Native Americans (OAA Title VI) (The Administration for Community Living caregiver services grants).  
<https://acl.gov/programs/services-native-americans-oaa-title-vi>
- National Indian Council on Aging LTSS Compass, Caregivers Corner  
<https://nicoaltsscompass.org/community-resources/caregivers-corner/>
- State Policy Innovations to Support Family Caregivers (National Academy for State Health Policy)  
<https://www.nashp.org/state-policy-innovations-to-support-family-caregivers/>
- Recognition of Family Caregivers in Managed Long-Term Services and Supports American Association of Retired People (AARP)  
<https://www.aarp.org/content/dam/aarp/ppi/2020/04/recognition-of-family-care-givers.doi.10.26419-2Fppi.00090.001.pdf>

<sup>16</sup> Swinomish Tribal Code, 7-12.210 Services for the Family or Caregiver. [https://narf.org/nill/codes/swinomishcode/7\\_12.pdf](https://narf.org/nill/codes/swinomishcode/7_12.pdf), accessed 5/9/21.

<sup>17</sup> Maya Gordon, Maya, Kroon, Matthew, Reilly, Carolyn, Clair, Ruta. (2021). The effects of social isolation on well-being and life satisfaction during pandemic. HUMANITIES AND SOCIAL SCIENCES COMMUNICATIONS | 8:28 | <https://doi.org/10.1057/s41599-021-00710-3>




## CONCLUSION

Tribal Nations are known for caring for all in their communities. This value of inclusion extends throughout Tribal programs and services. People who live with brain health challenges and dementia, including Alzheimer's disease, may have unique vulnerabilities when faced with a disaster or emergency. Communications, transportation, and medical care access may be challenging during these times. Caregivers, such as family members, are often so integral to someone's ability to navigate the situation that they may not be able to function well or at all without their caregivers. Understanding and recognizing the capabilities and needs of those who live with dementia, including their need for connection to people, culture and nature, is essential for positive social, emotional and physical outcomes. Accounting for those needs in Tribal policies and procedures is vital to a smooth, just and equitable emergency response.







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