COMMUNITY CARE GUIDE

Family Care Navigation Packet

Plain-language help for families caring for an older adult or dependent loved one who is ill, in care, confused, unsafe, or not being listened to.

WHY THIS NAME

This is the official public product name. The subject is often elder care, but the person using the packet is usually a family member, friend, or caregiver navigating several systems at once. "Elder-care packet" remains accurate shorthand; it is not a separate packet.

Loved one / person receiving care _____
Main family contact _____
Phone _____
Facility / clinic / location _____
Date started _____

VISIBLE LIMITS - READ FIRST

This packet helps families organize, document, ask questions, and find the right help. It does not provide individualized triage, diagnose illness, give medical or legal advice, decide whether abuse, neglect, malpractice, or a licensing violation occurred, or replace facility staff, tribal staff, Ombudsman, APS, regulators, doctors, attorneys, benefits representatives, hospice, funeral professionals, or emergency responders. It also offers general practical suggestions for communication, presence, family coordination, and caregiver wellbeing. These are not individualized clinical, mental-health, legal, financial, or hands-on-care instructions and may not fit every person. If there is immediate danger, call 911.

Institute Public v2.3.0 | Institute-control successor | Adopted August 19, 2026 | Contacts last verified July 31, 2026. Use only the pages you need; the tear-outs work on their own.

2 Print Order and Contents

The first four pages are self-contained tear-outs. Use only the page you need; you do not have to complete the packet from beginning to end. Keep the rest as reference.

WHAT CHANGED IN v2.3.0

Institute-control and identity successor: adopted under LRI-PGM-001; added a named maintainer, Institute publication identity, a public correction route, and explicit predecessor history. The substantive family-navigation content of v2.2.1 is unchanged; contacts were not reverified for this governance-only release.

T1 Quick Start Guide

Use this page by itself when you are worried. You do not need to read or complete the rest of the packet first.

1	**Protect safety** Immediate danger, severe breathing trouble, serious injury, violence, inability to wake, stroke signs, or severe distress? Call 911. Stay if safe, then notify the responsible nurse, facility, clinic, or family contact.
2	**Record and contact** Write the date and time, what changed, names, location, and exact words if remembered. Then call the right first person: nurse or charge nurse, doctor or clinic, administrator, tribal support, or family point person.
3	**Confirm the next action** Ask what will happen, who owns it, by when, and what to do if it does not happen. Request immediate protection when needed. Follow up or escalate if no responsible action occurs.

FIRST CALLS

Immediate danger Call now; do not wait for the packet.	**911**
Pit River Tribe main office Ask for Social Services; extensions and staffing can change.	**530-335-5421**
California Long-Term Care Ombudsman 24/7 complaint referral for residents of long-term care facilities.	**1-800-231-4024**
California APS routing line Routes to the correct county for abuse, neglect, exploitation, or self-neglect outside long-term care facilities.	**1-833-401-0832**

T2

Large-Print First Calls

Use this page when someone needs the main numbers quickly.

Immediate danger	**911**
Nurse / charge nurse	_____
Doctor / clinic	_____
Family point person	_____
Pit River Tribe main office Ask for Social Services	**530-335-5421**
Pit River Health Service - Burney	**530-335-3651**
Pit River Health Service - XL / Alturas	**530-233-3223**
Ombudsman CRISISline - 24/7 Long-term care facility concerns	**1-800-231-4024**
California APS routing line Home, hospital, hotel, or community setting	**1-833-401-0832**
Community Care Licensing complaints Assisted living / RCFE / board-and-care	**1-844-538-8766**
CANHR long-term care information Consumer information and referrals	**800-474-1116**
California Aging Information Line Routes to local aging services	**1-800-510-2020**

CONFIRM FIRST

Numbers, hours, eligibility, and services can change. If a number does not work, call 211, the agency main office, or use the official website. Do not put private health or financial details into a public web form.

T3

Refrigerator Flowchart

When something feels wrong in a care facility, hospital, clinic, or home-care situation.

START
Your loved one seems suddenly ill, frightened, mistreated, ignored, confused, unsafe, or not listened to.

↓

1 - CHECK URGENCY
Immediate danger? Trouble breathing? Serious injury? Cannot wake? Stroke signs? Violence or threats? Severe pain or distress? If yes: call 911 now.

↓

2 - CALL THE PERSON RESPONSIBLE NOW
Facility: nurse / charge nurse. Hospital: bedside nurse / attending team / patient relations. Home: doctor / clinic / home-health supervisor. Ask what is documented and what will be done now.

↓

3 - REQUEST IMMEDIATE PROTECTION
Medical assessment, room change, separation, wellness check, supervisor review, interpreter, written plan, or administrator callback.

↓

4 - DID IT GET FIXED?
If yes, check again and keep notes. If no, no callback, or not sure, document and escalate. You do not have to wait when safety is deteriorating.

↓

5 - CALL OUTSIDE HELP THAT FITS THE SETTING
Long-term care: Ombudsman 1-800-231-4024. Home/community abuse or exploitation: APS 1-833-401-0832. Assisted living / RCFE: CCL 1-844-538-8766. Medical facility complaint: use CDPH Cal Health Find. Immediate crime or danger: 911.

↓

RETALIATION WARNING
If care, visits, communication, or treatment gets worse after a concern is raised, document the change and tell the Ombudsman, regulator, APS, attorney, or other outside helper. Do not argue alone with someone who is threatening or violent.

T4 Important Contacts and Write-In Numbers

Fill this out before a crisis if possible. Cross out old numbers and date corrections.

Person receiving care _____
Facility / clinic / agency _____
Room / unit _____
Nurse / charge nurse _____
Doctor / primary care _____
Administrator / supervisor _____
Social worker / case manager _____
Pharmacy _____
Main family contact _____
Backup family contact _____
Health-care agent / POA _____
Tribal / cultural / spiritual support _____
Ombudsman / advocate _____
APS / regulator _____
Transportation _____
Insurance / coverage _____
Veterans helper / CVSO _____
Other _____

KEEP THIS PAGE UPDATED
Put the most reliable number first. Add the date next to a new number. Reprint this page after a move, hospitalization, new diagnosis, new facility, death, or change in family authority.

PART I

Start Here

The first minutes matter more than the whole system. Check safety, write it down, and call the right first person.

IN THIS PART

5 The First 10 Minutes

Do not try to solve everything at once. Take the next right step.

SAFETY

☐ Call 911 for immediate danger, severe medical distress, violence, suspected stroke, trouble breathing, serious injury, or inability to wake.
☐ Stay with the person if safe. Do not drive someone in severe distress unless emergency dispatch tells you to.
☐ If the concern is in a facility or hospital, notify the nurse or charge nurse after emergency help is underway.

WRITE ONE CLEAR SENTENCE

Example: "At 2:15 p.m., she was much more confused than this morning, could not stand, and said her chest hurt. I told Nurse ____."

What I noticed _____
When it started / changed _____
Who I told _____

END EVERY CALL WITH FOUR FACTS

☐ Who is responsible now?
☐ What will happen next?
☐ When will it happen?
☐ When should I call back or escalate?

DO NOT WAIT FOR PERFECT WORDS
Families often hesitate because they are unsure whether a problem is medical, neglect, dementia, medication, conflict, or grief. You may state exactly what you observed and ask the responsible professional to assess it.

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How Fast Should We Get Help?

GENERAL ROUTING GUIDE - NOT INDIVIDUALIZED TRIAGE. Symptoms can have different causes and may change quickly. If unsure which row fits, use the more urgent row or call a nurse, clinic, or emergency service.

Route	Examples - general routing, not individualized triage
Emergency - call 911	Cannot wake; severe trouble breathing; new face droop, arm weakness, or speech trouble; severe chest pain; uncontrolled bleeding; seizure; violence; immediate self-harm danger; or a serious fall or head injury. **UNSURE? Call 911 or use the more urgent route.**
Call a nurse or clinician now / same day	Sudden confusion or abrupt behavior change; new or repeated falls; new inability to walk; fever with weakness; possible infection or dehydration; medication error; repeated vomiting; severe pain; concerning wound; or little food or fluid. **UNSURE? Use the emergency row.**
Ask the clinic when the person should be seen	Gradual memory, weight, mood, or sleep change; increasing help needed; medication questions; caregiver strain; or new trouble managing money, cooking, driving, or appointments. **UNSURE? Use the same-day row.**

USEFUL OBSERVATIONS

- ☐ What is different from normal?
- ☐ When was the person last known to be at their usual condition?
- ☐ What medications were taken, missed, changed, or newly started?
- ☐ Are they eating, drinking, urinating, breathing, walking, and communicating normally?
- ☐ Could pain, infection, dehydration, low oxygen, low blood sugar, medication, or injury be involved?

DEMENTIA DOES NOT EXPLAIN EVERY SUDDEN CHANGE

A sudden increase in confusion or a marked change from usual behavior can require urgent medical attention. Do not assume an abrupt change is only dementia; call the medical team or emergency services as the situation requires.

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Who Can Help, and When to Call

Choose the door by setting and problem. One call may lead to another.

Call	Use when
911 / emergency	Immediate danger, serious medical distress, violence, missing vulnerable person, or urgent crime.
Nurse / charge nurse	Immediate bedside care, symptoms, medication, missed care, pain, wound, food, hydration, or safety in a facility or hospital.
Doctor / clinic	Diagnosis, treatment, medication review, new symptoms, referral, capacity concerns, or care-plan changes.
Administrator / patient relations	Repeated communication failures, unresolved facility operations, visitation, records, discharge process, or staff-response concerns.
Ombudsman	Resident rights and complaints in nursing homes, assisted living, board-and-care, and other long-term care settings.
APS	Abuse, neglect, exploitation, abandonment, isolation, or self-neglect outside long-term care facilities.
Licensing / regulator	Facility licensing and regulatory complaints; the correct agency depends on the setting.
Attorney / legal aid	Decision-making authority, estate, benefits appeals, rights, retaliation, discharge, contracts, financial exploitation, or litigation questions.

ASK FOR A WARM HANDOFF

When an office says it is not responsible, ask: "Which office is responsible, what is its number, and can you transfer me or document the referral?"

8 Tribal and Family Support Services

Tribal, family, and cultural supports can work alongside medical and public systems.

PIT RIVER STARTING POINTS

Pit River Tribe main office Ask for Social Services or the relevant program. Main-office routing is safer than relying on an old extension.	**530-335-5421**
Pit River Health Service - Burney Medical, dental, behavioral health, outreach, senior nutrition, and related routing.	**530-335-3651**
Pit River Health Service - XL / Alturas Clinic routing for the Alturas area.	**530-233-3223**
PRHS transportation inquiries Eligibility and scheduling rules apply.	**530-335-0351**

WHAT FAMILY AND COMMUNITY SUPPORT CAN DO

- ☐ Coordinate rides, visits, food, laundry, calls, paperwork, and relief shifts.
- ☐ Help the elder communicate preferences, language, family history, beliefs, and cultural or spiritual needs.
- ☐ Sit in on calls, take notes, and repeat the agreed next step.
- ☐ Help locate documents, contact relatives, and identify who has legal authority.
- ☐ Protect private information; do not turn a public meeting or social-media post into a case file.

AUTHORITY MATTERS

Family, cultural, and tribal support can strengthen care, but no person should claim authority they do not have. Distinguish emotional or cultural authority from legal authority to make medical, financial, or benefits decisions.

PART II

Understand the System

The right response depends on where care is happening, who controls the service, and which outside office has jurisdiction.

IN THIS PART

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Identify the Setting First

The same problem may go to a different office depending on where it happened.

Setting	First doors
Home / family home	Doctor or clinic; home-health supervisor; APS for abuse, neglect, exploitation, or self-neglect; 911 for immediate danger.
Hospital / emergency department	Bedside nurse, charge nurse, attending team, case manager, patient relations, discharge planner; regulator or attorney if unresolved.
Skilled nursing / rehabilitation	Charge nurse, director of nursing, administrator, Ombudsman, CDPH complaint pathway, 911 or law enforcement for emergencies.
Assisted living / RCFE / board-and-care	Administrator, Ombudsman, Community Care Licensing, APS or law enforcement as appropriate.
Hospice / home health	Clinical supervisor, agency administrator, prescribing clinician, Medicare/insurance complaint path, regulator, or emergency services.
Adult day / transportation / contractor	Program supervisor, hiring facility or plan, licensing or contract complaint route, APS or police if abuse or exploitation is suspected.

WRITE THE SETTING EXACTLY

Facility / company name _____

Address / room / unit _____

License type if known _____

Who pays / authorized service _____

10 Who Is Responsible?

Care can be fragmented. Ask who owns each task and who supervises it.

Task	Possible owner
Medical decision	Doctor, nurse practitioner, physician assistant, or attending clinical team
Medication administration	Nurse / medication technician / pharmacy, depending on setting
Daily personal care	Facility care staff, home-care worker, family caregiver, or IHSS provider
Discharge plan	Hospital or facility case manager / social worker / discharge planner
Equipment and supplies	Medical equipment vendor, insurer, facility, hospice, or home-health agency
Transportation	Family, tribal program, plan vendor, facility contractor, or county service
Benefits and coverage	Insurer, Medi-Cal / Medicare office, VA, county eligibility worker, or accredited representative
Complaint response	Supervisor, administrator, patient relations, Ombudsman, APS, regulator, plan grievance unit, or attorney

USE THE OWNERSHIP SENTENCE

"Who is responsible for this task today, what is their direct number, and who supervises them if it does not happen?"

11 Contractors and Outside Providers

Inside the room does not always mean under the same chain of command.

Transportation, hospice, home health, therapy, pharmacy, laboratory, medical equipment, dialysis, private caregivers, food delivery, and specialists may be separate companies.

Provider / company	Service	Supervisor / phone	Who hired / pays	Complaint path

QUESTIONS TO ASK

- ☐ Who supervises this person or service?
- ☐ Who signed the contract or authorized the service?
- ☐ Who receives incident reports and complaints?
- ☐ Does the facility, insurer, tribe, VA, or county have to coordinate the problem?
- ☐ What should happen while the companies decide who is responsible?

NO RESPONSIBILITY GAP

A family should not be left without care while organizations argue about contracts. Ask each actor to document the referral and identify the interim safety plan.

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Jargon Check

System words translated into everyday language.

System word	Plain meaning
Ombudsman	Independent resident advocate for long-term care facility problems.
APS	Adult Protective Services: county response to abuse, neglect, exploitation, abandonment, or self-neglect outside long-term care facilities.
CDPH	California Department of Public Health: regulates many health facilities, including skilled nursing and hospitals.
Community Care Licensing / CCL	California regulator for assisted living, residential care, board-and-care, and related settings.
Case manager / social worker	Helps with planning, referrals, discharge, services, coverage, and communication; exact authority varies.
Advance directive	Written instructions and designation of a health-care decision-maker for times when a person cannot speak for themselves.
POLST	Medical orders for seriously ill or frail people; completed with a clinician. It is not the same as a general advance directive.
Capacity	Ability to understand and make a particular decision. It can vary by decision and over time.
DPOA / power of attorney	Legal authority given to another person; health and financial powers are different.
Aid and Attendance	Possible additional VA pension payment for qualified Veterans or survivors who need daily help or are housebound.
Respite	Temporary relief for the caregiver.
Palliative care	Care focused on relief of symptoms, stress, and quality of life; it can occur with treatment.
Hospice	Comfort-focused care for a person who meets eligibility requirements and is approaching end of life.

PART III

Handle Problems

Calm documentation and correct routing can turn a frightening situation into a usable record and a clear next step.

IN THIS PART

13 Document a Concern

Write what happened, not what you think must have happened.

CORE RECORD

Date and time _____
Place / room / unit _____
What I saw, heard, or was told _____
Names and exact words _____
Symptoms, injuries, fear, or change _____
Who I notified _____
What protection I requested _____
What they promised _____
Deadline / callback time _____
What happened next _____

GOOD DOCUMENTATION

☐ Separate direct observation from what another person reported.
☐ Use exact dates, times, names, and quotes when available.
☐ Photograph only when lawful, safe, respectful, and permitted; protect privacy.
☐ Keep copies of messages, discharge papers, medication lists, incident numbers, and written decisions.
☐ Do not alter or exaggerate records. Corrections should be dated.

ONE-SENTENCE CONCERN

"At [time/place], I observed [specific fact]. I told [name]. I requested [action]. The promised next step was [action/time]."

14 Calm Escalation Scripts

Clear words reduce confusion and create an answerable request.

MEDICAL CHANGE
"This is a change from their normal condition. Who will assess them now, and when will I receive an update?"

IMMEDIATE PROTECTION
"While this is reviewed, I am requesting an immediate safety step: _____. Who can authorize that now?"

WRITTEN RECORD
"Please tell me what was documented and how I can request the relevant record or written decision."

NO CALLBACK
"The promised callback time passed. I need the responsible supervisor and a new time-bound plan."

JURISDICTION
"If your office is not responsible, which office is? Please provide the number and document the referral."

DISCHARGE
"I do not understand how this discharge is safe. Please explain the care needs, equipment, medications, transportation, follow-up, and appeal or review process in writing."

DEMENTIA
"Please do not assume this sudden change is only dementia. What medical causes have been assessed?"

AUTHORITY
"I am the designated health-care agent / family contact / support person. Here is the document or permission. What can you discuss with me, and what is still needed?"

RETALIATION
"Care or communication appears to have worsened after we raised a concern. I am documenting that change and requesting outside review."

END OF LIFE
"Our priorities are comfort, dignity, family presence, and these cultural or spiritual practices: _____. Who will place them in the care plan?"

15

What to Expect When You Report

A report may create a referral, investigation, care conference, grievance, or no immediate action.

Stage	What it may mean
Intake	The office records basic facts and decides whether it has jurisdiction.
Urgency review	Immediate danger may be routed to emergency services or law enforcement.
Referral	The concern may be transferred to another office. Ask for the name, number, and reference number.
Investigation / review	Staff may interview people, inspect records, visit a site, or ask for documents. Timeframes vary.
Outcome	You may receive a finding, corrective action, explanation, closure letter, or limited information because of privacy rules.
Appeal / follow-up	Some decisions have grievance, appeal, reconsideration, or legal-review routes. Ask about deadlines in writing.

RECORD THESE FACTS

Office and phone _____
Date and time reported _____
Intake person _____
Case / reference number _____
What they accepted _____
What they declined / referred _____
Expected response date _____
Follow-up date _____

NO OUTCOME PROMISE
This packet cannot promise that an agency will investigate, agree, disclose its work, or provide a remedy. Its purpose is to improve routing, clarity, documentation, and follow-through.

16 Safety and Rights by County

Pit River ancestral lands and service routes cross several counties. Use statewide routing when unsure.

California APS routing line Enter the ZIP code to reach the correct county.	**1-833-401-0832**
Shasta County APS - 24/7 Official county abuse hotline.	**530-225-5798**
Siskiyou APS / IHSS - business hours Official county Adult Services office; use the statewide APS line above after hours.	**530-841-4010**
Long-Term Care Ombudsman CRISISline 24/7 complaint referral for facility residents.	**1-800-231-4024**
Community Care Licensing complaints Assisted living / RCFE / board-and-care and related settings.	**1-844-538-8766**

WRITE-IN LOCAL NUMBERS

Modoc / Lassen: use the statewide APS routing line above until a current direct local line is confirmed.
Local APS direct number (optional) _____
Local Ombudsman office _____
Local law enforcement non-emergency _____
County veterans service office _____
Legal aid / elder-law referral _____

WHICH PROTECTION SYSTEM?
Long-term care facility complaints usually begin with the Ombudsman and the appropriate licensing agency. Abuse, neglect, exploitation, or self-neglect in a home, hospital, hotel, or community setting usually begins with county APS. Immediate danger or crime goes to 911 or law enforcement.

17 Money Safety: Red Flags of Financial Exploitation

Pause before signing, transferring, paying, or changing ownership.

WARNING SIGNS ARE NOT FINDINGS

A checked item does not prove exploitation, abuse, theft, incapacity, or wrongdoing. It does not authorize a family member to take control of another person's money, property, communication, documents, or care.

- ☐ New "friend," caregiver, relative, or salesperson controlling calls, mail, banking, or access.
- ☐ Unexplained withdrawals, cards, loans, account changes, beneficiary changes, or missing property.
- ☐ Pressure to sign a deed, power of attorney, contract, reverse mortgage, annuity, trust, or benefits document quickly.
- ☐ Someone using fear of losing benefits to sell financial products or move assets.
- ☐ A caregiver being paid outside the agreed arrangement or isolating the elder from other people.
- ☐ Bills unpaid despite adequate income; sudden shutoffs, eviction notices, or loss of medication and food.
- ☐ Identity theft, romance scams, contractor scams, gift-card demands, or government impersonation.

WHAT TO DO

When family members disagree about money, payment, access, authority, or isolation, preserve specific records and involve APS, an elder-law attorney, or another qualified neutral party. Do not use this page as proof against someone or confront a person alone when there may be danger.

- ☐ If money may be leaving now, call the bank or card issuer fraud department using a verified number.
- ☐ Preserve statements, messages, receipts, names, dates, account alerts, contracts, and the exact event that caused concern.
- ☐ Request independent review from APS; call law enforcement for suspected crime or immediate danger.
- ☐ Ask an elder-law attorney, legal aid, benefits counselor, or accredited VA representative before changing property, assets, or authority papers.
- ☐ Do not confront a threatening person alone or take control based only on this checklist.

SCRIPT: "I am concerned about these specific things I observed. I am not asking this packet to determine what happened. Who can review the situation independently, and what records should I preserve?"

BENEFITS WARNING

Eligibility rules for Medi-Cal, VA pension, SSI, housing, and other programs are complex. Do not move or give away money or property based only on a salesperson or unverified consultant.

PART IV Ongoing Care Binder

A working record for visits, calls, medicines, authority, dementia, Veteran care, caregiver capacity, documents, and maintenance.

Use only the pages that help. You do not have to complete the packet from beginning to end. The tear-outs work by themselves during a crisis; these binder pages are optional reference and continuity tools. Keep private case details with the family, not with the Institute.

INCLUDED IN THIS PART

CORE RULE

A need is not covered merely because a family member exists. Name the owner, capacity, backup, next action, and date.

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Daily / Weekly Tracking Log

Track changes, calls, promises, and follow-up without writing a novel.

Date / time	Concern or change	Who was called / action	Promise / deadline	Done?

USE PATTERNS, NOT ONLY CRISES

A short daily record can show repeated missed medication, falls, weight loss, confusion, delayed call lights, pain, lack of food or fluids, caregiver exhaustion, or improvements that would be hard to remember later.

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Visit Log: How Did They Feel?

Presence is care. Observation is protection. Some visits are just for love.

Date / time _____

Who visited / called _____

Notice	Notes
Body	Pain, weakness, breathing, skin, injuries, hunger, thirst, hygiene, sleep, mobility
Mood	Afraid, calm, withdrawn, relieved, angry, sad, confused, engaged
Room / home	Clean, safe, comfortable, respectful, needed items within reach
Care response	Call light, toileting, meals, medications, wound care, therapy, communication
Connection	Conversation, prayer, stories, music, language, laughter, quiet, outdoor time
Follow-up	What changed? Who needs to be called? What should be brought next time?

Main change / concern _____

What helped today _____

Follow-up owner and date _____

Time spent just being present _____

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Call Log

Write names, promises, reference numbers, and deadlines.

Date / time	Office / number	Person	What was said / promised	Follow-up

BEFORE HANGING UP

☐ Repeat the next step in your own words.
☐ Ask for the person's name, title, direct number, and reference number.
☐ Write the deadline and who owns it.
☐ Ask what to do if the promised step does not happen.

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Medication and Diagnosis Sheet

Keep one current list and bring it to every appointment and care transition.

Full legal name _____
Date of birth _____
Allergies _____
Pharmacy _____
Primary clinician _____
Emergency contact _____

Medication	Dose / time	Why taken	Prescriber	Started / changed	Notes

DIAGNOSES AND IMPORTANT HISTORY

Diagnosis / condition	Clinician	Date / status	What family should know

MEDICATION SAFETY
After any hospitalization, facility move, hospice enrollment, or new diagnosis, compare the old list, discharge list, pharmacy list, and what is actually being given. Ask who reconciled the medications.

22

Papers That Protect Choices

Papers do not replace family love. They make authority and wishes easier to honor.

Paper	Purpose
Advance health-care directive	Names a decision-maker and records health-care wishes for when the person cannot speak.
HIPAA / information authorization	Allows specified people to receive health information; provider forms vary.
POLST	Medical orders for a seriously ill or frail person, completed with a clinician.
Financial power of attorney	May authorize financial actions; scope, timing, and safeguards matter.
Will / trust / beneficiary records	Directs property or benefits; requires appropriate legal guidance.
VA / benefits representative appointment	Allows an accredited representative to assist with a VA claim.
Funeral / burial / cultural wishes	Records practical, family, spiritual, tribal, and ceremonial preferences.

RECORD LOCATION AND AUTHORITY

Health-care agent _____
Backup agent _____
Financial agent _____
Attorney / legal aid _____
Where originals are kept _____
Who has copies _____
Date last reviewed _____

CAPACITY AND CONSENT
Do not pressure a person to sign. When capacity is uncertain, seek appropriate clinical and legal advice. Authority for health decisions, finances, benefits, and estate matters may be held by different people.

23 Memory Loss and Dementia: A Starting Point

Notice patterns, rule out treatable causes, protect safety, and preserve dignity.

SEEK URGENT MEDICAL HELP FOR SUDDEN CHANGE

☐ Abrupt confusion, sleepiness, agitation, hallucinations, weakness, fever, fall, pain, dehydration, or inability to function as usual.
☐ New speech trouble, facial droop, one-sided weakness, severe headache, chest pain, breathing trouble, or inability to wake.

TRACK GRADUAL CHANGES

☐ Repeating questions, missed appointments, getting lost, unsafe driving, stove or medication problems.
☐ Trouble managing money, scams, unpaid bills, unusual purchases, or giving away property.
☐ Changes in judgment, mood, sleep, hygiene, eating, language, or ability to complete familiar tasks.
☐ Caregiver stress, conflict, exhaustion, or inability to provide safe supervision.

HOW TO COMMUNICATE

☐ Approach calmly, identify yourself, and use one question or step at a time.
☐ Do not shame, quiz, corner, or argue over every incorrect detail.
☐ Reduce noise, explain before touching, allow time, and offer simple choices.
☐ Use familiar people, language, songs, foods, objects, routines, and cultural practices when welcomed.

Alzheimer's Association 24/7 Helpline Information, support, and local resources.	**800-272-3900**

NATIVE CAREGIVER RESOURCE
NICOA offers Savvy Caregiver in Indian Country resources. Ask tribal health, elder services, Area Agency on Aging, and the clinic about caregiver education, respite, and local support.

24 Veteran Elder Care: Start Here

Military service may open doors for care, caregiver support, pension, survivor help, and burial planning.

PURPOSE

The family does not need to understand the whole VA system before asking for help. This page identifies the Veteran connection, gathers basic facts, and routes the family to free or VA-accredited help. It does not decide eligibility.

WRITE DOWN WHAT THE FAMILY KNOWS

Veteran's full name _____
Branch of service _____
Approximate service dates _____
DD-214 / discharge papers location _____
VA health care enrolled? ☐ **Yes** ☐ **No** ☐ **Unsure** _____
VA disability or pension? ☐ **Yes** ☐ **No** ☐ **Unsure** _____
Spouse / surviving spouse _____
VA file / claim number _____
Main family helper and phone _____

ASK ABOUT DOORS THAT MAY MATTER

VA HEALTH AND ELDER CARE

Enrollment, geriatrics, home-based primary care, home health aides, adult day health, respite, palliative care, hospice coordination, and long-term care options.

PENSION AND AID AND ATTENDANCE

Possible added monthly pension for qualified Veterans or survivors who need daily help or are housebound.

CAREGIVER SUPPORT

Education, coaching, support, respite information, and connection to a local VA caregiver team.

BURIAL AND SURVIVOR HELP

Pre-need eligibility, cemetery options, flag, marker, burial allowance, Survivors Pension, DIC, and bereavement support.

24A Veteran Elder Care: Call and Document

Use during dementia care, hospital discharge, home-care planning, hospice, or after a death.

MyVA411 main information line 24/7 VA front door.	**800-698-2411**
VA benefits hotline Monday-Friday, 8 a.m.-9 p.m. ET.	**800-827-1000**
VA Caregiver Support Line Monday-Friday, 8 a.m.-8 p.m. ET.	**855-260-3274**
Veterans Crisis Line 24/7; text 838255.	**988, then press 1**

CALL SCRIPT

"Hello. I am helping a Veteran, surviving spouse, or family member with an elder-care problem involving [home care / dementia / discharge / facility care / hospice / death]. We do not know the correct program name. Can you identify the right office, documents, deadline, and next step?"

GATHER WHAT IS AVAILABLE

- ☐ DD-214 or other discharge papers
- ☐ Veteran legal name, date of birth, service dates, and VA file number
- ☐ Marriage or death certificate when relevant
- ☐ Medication list, diagnoses, doctor notes, and discharge papers
- ☐ Notes showing help needed with bathing, dressing, eating, mobility, toileting, medication, supervision, or safety
- ☐ Authority papers and income / asset information only when requested by the proper helper

PROTECT THE FAMILY

Use a County Veterans Service Office, VA-recognized VSO, VA office, tribal Veterans representative, or other VA-accredited helper. VSO claims assistance is free. Pause when someone guarantees approval, charges to submit an initial claim, pressures asset transfers, or combines benefits advice with financial-product sales.

24B Care Team + Caregiver Capacity

Name the roles, test real capacity, and make a backup before a need is treated as covered.

CORE RULE

A care plan is incomplete if it says what the person needs but not who can safely provide it, for how long, and what happens if that person cannot continue. Being family does not automatically mean being available, willing, physically able, trained, or legally authorized to provide every kind of care.

1 ROLE MAP

Role	Name / contact	What this person owns
Care coordinator	_____	Overall plan, calls, schedule
Medical contact	_____	Clinicians, medicines, changes
Hands-on caregiver	_____	Agreed daily care only
Paperwork helper	_____	Applications, records, follow-up
Transportation	_____	Rides, pickup, backup ride
Decision-maker / cultural support	_____	Only authority actually held; preserve person's wishes

2 CAPACITY SCREEN

Task / need	Who can do it?	Willing / able / trained?	Backup / uncovered
Meals / household / errands	_____	☐ yes ☐ no ☐ needs training	_____
Transportation / appointments	_____	☐ yes ☐ no ☐ needs training	_____
Bathing / dressing / toileting	_____	☐ yes ☐ no ☐ needs training	_____
Supervision / evening / overnight	_____	☐ yes ☐ no ☐ needs training	_____
Medicine, equipment, lifting, or skilled task	_____	☐ yes ☐ no ☐ needs training	_____

CAPACITY SCRIPT

"I can provide _____. I cannot safely provide _____. I need training, equipment, another person, or professional support for _____. Please do not treat an uncovered task as covered."

3 IF YOU CANNOT BE THERE

Choose one local point person; write the primary clinician or agency contact; set a check-in schedule; keep the private care record in one known place; and name a backup if the local person becomes unavailable.

If one caregiver is carrying more than can continue, ask about respite, paid home care, adult day services, home health or hospice support, transportation, or redistribution of tasks. Caregiver strain is a care-plan reliability issue, not a private failure.

24C Family Care Documents Locator

Find the paper without putting sensitive numbers on a public worksheet.

USE THIS PAGE

Mark what exists, where it is kept, who can access it, and when it was last checked. Do not delay an urgent call because a document is missing; ask what can be done now and what exact paper is still required.

1 DOCUMENT LOCATOR

Document / record	Have / need	Where kept	Who can access	Last checked
Photo ID / insurance cards	☐ / ☐	_____	_____	_____
Medication + diagnosis list	☐ / ☐	_____	_____	_____
Hospital / visit / discharge papers	☐ / ☐	_____	_____	_____
Advance directive / health-care agent	☐ / ☐	_____	_____	_____
Financial POA / other authority papers	☐ / ☐	_____	_____	_____
VA / DD-214 / Veteran papers	☐ / ☐	_____	_____	_____
IHSS / home-care / service papers	☐ / ☐	_____	_____	_____
Home health / hospice / facility records	☐ / ☐	_____	_____	_____
Marriage / death certificate if needed	☐ / ☐	_____	_____	_____
Funeral / cemetery / pre-need papers	☐ / ☐	_____	_____	_____
Tribal / benefits / application papers	☐ / ☐	_____	_____	_____

PRIVACY RULE

Do not write Social Security numbers, passwords, PINs, full bank or card numbers, private medical details, or protected cultural information on this public locator. Record only where the secure information is kept and who is authorized to reach it.

2 WHEN AN OFFICE ASKS FOR A DOCUMENT

Ask: “Which exact document do you need? Does it need a signature, current date, certification, or original? Who can provide it? Is there a deadline? What can move forward while we get it?”

25

Maintaining the Packet Over Time

Care changes. The packet should change with it.

Item	Last checked	Checked by	Correction needed?
Pit River Social Services			
Pit River Health Service			
Ombudsman / APS / licensing			
County and local numbers			
VA numbers and accredited help			
Dementia / caregiver resources			
Family contacts and authority			
Medication and diagnoses			
Hospice / after-death plan			

REVIEW TRIGGERS

☐ After any move, hospitalization, emergency visit, new diagnosis, major medication change, hospice enrollment, death, or change in legal authority.
☐ Before every public print run: verify all phone numbers, hours, web links, eligibility descriptions, and local partners.
☐ Reprint tear-out pages and logs when full. Cross out old information rather than leaving two current-looking versions.
☐ Record who adopted a correction and the date.

VERSION RULE
The newest dated, reviewed master is the canonical public packet. Older copies remain historical, not co-equal masters.

H1 Coming Home Safely

A hospital-to-home and temporary-care bridge for families, caregivers, and community helpers.

WHAT THIS INSERT DOES

Use this when a loved one is leaving a hospital, rehabilitation stay, emergency department, or other care setting and the home, caregiving, equipment, or services are not fully ready. It helps the family identify gaps, assign owners, ask clear questions, and build a temporary bridge. It does not make discharge medically or legally safe, promise services or payment, or require a relative to accept care they cannot safely provide.

1 BEFORE THE PERSON LEAVES

☐ Destination is clear: exact address, entrance, room, and who will be present when the person arrives.
☐ The person receiving care has been asked what they want, what they fear, and who they want involved.
☐ The available caregiver has stated what they can safely do, cannot do, and when they are available.
☐ Written instructions cover medicines, equipment, food or fluid limits, activity, wound or symptom care, warning signs, and after-hours calls.
☐ Transportation, prescriptions, equipment delivery, supplies, and the first follow-up visit are confirmed - not merely mentioned.
☐ Unresolved needs are written down with one owner, one next action, and one date.

2 CORE DISCHARGE SCRIPT

SAY THIS CLEARLY

“I want to participate in the discharge plan. The unresolved home-care gaps are: _____. The available caregiver can safely do: _____. They cannot safely do: _____. Please document these gaps, tell us who owns each next step, and explain what review or appeal route applies.”

3 WHEN DISCHARGE FEELS TOO SOON

Ask for the discharge planner or case manager, the responsible clinician, and patient relations. Request a reassessment of the unresolved needs and a written explanation of the plan. If Medicare or another health plan applies, ask for the written notice that explains review or appeal rights and its deadline; follow that notice exactly. This page does not determine whether an appeal is available or likely to succeed.

EMERGENCY AND HOSPICE BOUNDARY

Call 911 for immediate danger, severe distress, trouble breathing, stroke signs, serious injury, violence, or inability to wake. When a person is enrolled in hospice, follow the hospice plan and use the 24/7 hospice number for expected changes; call 911 when the plan directs it or there is immediate danger.

Cross-reference: How Fast Should We Get Help?, Calm Escalation Scripts, Papers That Protect Choices, Memory Loss and Dementia, What Matters to Me Right Now, Serious Illness, Hospice, and T4. Official discharge and appeal information should be confirmed directly.

H2 Is the Home Ready?

Check the physical home, basic household needs, communication, transportation, and rural realities.

1 ARRIVAL AND FIRST NIGHT

Where is the person going? _____
Who will meet them? _____
Who will stay or check in first night? _____
Backup person and phone _____

SAFE PLACE TO SLEEP Bed, bedding, safe transfers, room for equipment, and a clear path. Ask before moving heavy furniture or changing prescribed positioning.	**BATHROOM AND FALL SAFETY** Usable toilet, lighting, clear floors, footwear, grab/support equipment if prescribed, and a plan for nighttime needs.
FOOD, WATER, AND MEDICINES Food that matches instructions, drinking water, prescriptions picked up, refrigeration if needed, and a plan for the first doses.	**PHONE, POWER, AND CLIMATE** Working phone, charger, lighting, heat or cooling, and a clinician/vendor-approved backup plan for prescribed powered equipment.
TRANSPORTATION AND ACCESS Vehicle and helper for follow-up, safe entry steps or ramp, pharmacy access, fuel, and backup transportation.	**RURAL AND DISTANCE CHECK** Road and weather conditions, travel time, pharmacy closing time, cell coverage, delivery limits, and the nearest appropriate emergency care.

2 HOUSEHOLD NEEDS AND DELIVERIES

Need	Who is getting it?	Confirmed / date
Bed / bedding	_____	_____
Dishes / food storage	_____	_____
Chair / safe seating	_____	_____
Curtains / privacy	_____	_____
Blankets / clothing / hygiene	_____	_____
Other: _____	_____	_____

DONATION AND EQUIPMENT SAFETY
Ask before bringing items. Deliver only clean, working, accepted goods and keep exits and equipment paths clear. Do not use a donated walker, wheelchair, hospital bed, oxygen device, lift, or other medical equipment unless the clinician, therapist, or supplier confirms that it fits, works, and has been set up safely.

H3 Medicines, Equipment, and Follow-Up

A referral is not the same as an accepted service, and an order is not the same as a delivered item.

1 MEDICATION REVIEW - USE TEACH-BACK

Ask the nurse, pharmacist, or clinician to review every medicine. Then explain the plan back in your own words and ask them to correct you.

Medicine / purpose	Start, stop, continue, or change?	First dose / refill / pharmacy
_____	_____	_____
_____	_____	_____
_____	_____	_____
_____	_____	_____

MEDICATION SCRIPT

"Please show us what to start, stop, continue, and change; when the next doses are due; what side effects require a call; and which pharmacy has the prescriptions. Please listen while I explain the plan back."

2 EQUIPMENT AND SKILLED SERVICES

Need	Exact status	Owner / number	Date / backup
Equipment or supplies	Ordered / accepted / delivered	_____	_____
Home health	Referral sent / agency accepted	_____	_____
Therapy	Ordered / accepted / scheduled	_____	_____
Hospice or palliative care	Referred / enrolled / first visit	_____	_____
Follow-up appointment	Scheduled / transport confirmed	_____	_____

3 THREE CONFIRMATION SCRIPTS

EQUIPMENT "Who ordered it, which supplier accepted the order, when will it arrive, who sets it up, and what do we do if delivery is late?"	**HOME HEALTH** "Was the referral accepted by a named agency? What is the first-visit date? What care is and is not covered before that visit?"
FOLLOW-UP "Who must be seen, by when, where, what records or labs are needed, and who will arrange transportation?"	**CHANGE IN CONDITION** "This is different from their normal condition. Who will assess it now? What signs mean call the clinic, hospice, nurse line, or 911?"

HOME HEALTH IS NOT ROUND-THE-CLOCK PERSONAL CARE

Home health usually provides ordered skilled or intermittent services. It should not be assumed to cover continuous supervision, all personal care, or every hour the family needs. Ask exactly what the agency will provide, how often, when it starts, and what remains uncovered.

H4 First 72 Hours and Temporary Care

Family and community help can bridge a gap; it must not be treated as a substitute for ordered or skilled care.

1 CAREGIVER CAPACITY COMES BEFORE THE SCHEDULE

Main coordinator _____
Backup coordinator _____
Person who can make medical decisions, if any _____
24/7 clinical or agency number _____

CAPACITY STATEMENT
"I can safely help with: _____. I am available: _____. I cannot safely provide: _____. I need training, equipment, another person, or professional support for: _____." A relative may say no to tasks they cannot safely perform.

2 WHAT HELPERS MAY DO - AND WHAT NEEDS A QUALIFIED PERSON

Usually practical help	Needs training, authorization, or professional direction
Meals, dishes, laundry, errands	Medication setup or administration when not authorized
Rides and appointment companionship	Wound care, injections, tube care, or oxygen changes
Phone calls, notes, pickups, deliveries	Complex lifting, transfers, or equipment operation
Sitting, visiting, reading, cultural presence	Assessing symptoms or changing the clinical plan
Household setup and accepted donations	Any task the person or helper does not understand or cannot do safely

3 FIRST 72 HOURS SCHEDULE

Time	Day 1	Day 2	Day 3 / backup
Morning	_____	_____	_____
Afternoon	_____	_____	_____
Evening	_____	_____	_____
Overnight	_____	_____	_____

NO SAFE PERSON AVAILABLE
Do not hide an uncovered shift or unsafe task. Tell the discharge planner, clinician, agency, or supervisor exactly what is uncovered and ask for a new plan. If the person is already home and safety is failing, call the responsible clinical service, APS when abuse/neglect/self-neglect may be involved, or 911 for immediate danger.

H5 Replace “Pending” With an Exact Status

Every service needs a name, owner, next step, and date.

1 STATUS LADDER

Status	What it means	What to ask next
Mentioned	Someone suggested the service	Who will make the request?
Requested / applied	A request or application was started	Date, office, receipt, and missing documents?
Ordered / referral sent	A clinician or office sent an order/referral	Which agency received it?
Accepted / approved	The service or benefit accepted the case	What is authorized and for how long?
Scheduled	A date and responsible person exist	What happens until then?
Started	The first visit, shift, or service occurred	Is the actual help enough and correct?

2 DO NOT CONFUSE THE SYSTEMS

IHS / TRIBAL HEALTH
Indian Health Service or a tribal/Native health pathway provides or coordinates health care. It is not the same as California paid in-home personal care. Ask what medical service can act now and what must be referred elsewhere.

CALIFORNIA IHSS
In-Home Supportive Services is a county-administered program for eligible aged, blind, or disabled people who need help to remain safely at home. Application, assessment, certification, authorization, and provider enrollment can take separate steps.

HOME HEALTH
An ordered agency service for skilled nursing, therapy, and related intermittent care when eligibility and coverage requirements are met. Ask what visits are accepted and what personal-care hours remain uncovered.

HOSPICE / PALLIATIVE CARE
Comfort-focused or serious-illness support with its own plan, eligibility, team, and after-hours route. Cross-reference: When Hospice Has Been Called; keep the hospice number visible.

3 SERVICE TRACKER

Service	Current status	Owner / number	Next date
IHS / tribal health	_____	_____	_____
IHSS / county in-home care	_____	_____	_____
Home health / therapy	_____	_____	_____
Meals / transport / aging service	_____	_____	_____
VA / Veteran caregiver support	_____	_____	_____

4 SCRIPTS FOR PENDING SERVICES

IHSS: “Has the application been submitted to the county? Has the health-care certification been requested or received? What step remains before assessment or authorization, and who follows up?”

IHS / tribal health: “We need help connecting medical care, transportation, and family support. Which service can act now, and which request must go to another office?”

H6 Community Help Without Losing Privacy

Use one coordinator, one private care sheet, and one public needs list.

1 SEPARATE THE RECORDS

Private care sheet - limited access	Public needs list - share only with permission
Diagnosis, medicines, intimate care, behavior, finances, legal authority	Household items, meals, rides, errands, and volunteer time blocks
Exact address, entry instructions, times the person is alone	Coordinator contact and general delivery instructions
Clinical instructions and agency records	Only the minimum information needed to offer practical help

PERMISSION BEFORE POSTING

Ask the person receiving care, or the lawful decision-maker when applicable, before using their name, photograph, diagnosis, story, or home information. A provider may be able to share care-relevant information with a person involved in care in permitted circumstances, but a public social-media post is different: use consent and minimum necessary detail.

2 COMMUNITY NEEDS AND SHIFT LIST

Need / time block	Person offering	Confirmed by coordinator	Complete
_____	_____	_____	☐
_____	_____	_____	☐
_____	_____	_____	☐
_____	_____	_____	☐
_____	_____	_____	☐

3 PUBLIC REQUEST SCRIPT

COPY AND ADAPT

“With permission, we are coordinating practical help for a relative returning home after a hospital stay. Current needs are: _____. Helpful time blocks are: _____. Please contact _____ directly so the list stays current. Please do not post or request private health details.”

4 VOLUNTEER COMMITMENT SCRIPT

“I can provide _____ on _____ from _____ to _____. I cannot provide medical care, medication help, or lifting unless the coordinator and qualified care team have confirmed that I am trained and authorized. Please confirm the assignment before I arrive.”

MONEY AND GOODS

Use one accountable coordinator for purchases or cash, keep receipts, document what was received and delivered, and avoid publishing financial or benefits information. Cross-reference: Money Safety.

H7 Scripts for the Hard Calls

Clear, respectful words create an answerable request and a usable record.

SAFE DISCHARGE	“I do not understand how this discharge is safe with these unresolved needs: _____. Please explain the plan in writing and identify who is responsible for each gap.”
CAREGIVER CAPACITY	“Please do not record me as available for tasks I have not agreed to or cannot perform safely. I can do _____. I cannot do _____. What is the alternative plan?”
MEDICATIONS	“Please review every medicine and then listen while I explain the plan back. Which medicines stop, start, change, or continue, and when are the next doses?”
EQUIPMENT	“Is the equipment ordered, accepted by the supplier, delivered, fitted, and taught? Who do we call if any step fails?”
HOME HEALTH / HOSPICE	“Which agency accepted the referral? What is the first visit date and after-hours number? What needs remain the family’s responsibility before service starts?”
WARM HANDOFF	“If your office is not responsible, which office is? Please give the number, transfer me if possible, and document the referral.”
NO CALLBACK	“The promised callback time passed. Who owns the next step now, and what new time can we rely on?”
PRIVACY / PERMISSION	“What information can be shared with me because I am involved in care, what permission or authority is still needed, and how can the person record their choice?”

CULTURAL AND FAMILY WAY

“The person’s priorities include comfort, family presence, language, foods, prayer, ceremony, songs, or other practices: _____. Who will place these preferences in the care plan, and what limits must be explained?” Distinguish cultural and family standing from legal authority to make medical or financial decisions.

H8 Close the Loop

Check whether the promised help actually arrived and whether the person is safer, heard, and supported.

1 UNRESOLVED NEEDS AND OWNERSHIP

Need / risk	Owner	Next action and date	Done
_____	_____	_____	☐
_____	_____	_____	☐
_____	_____	_____	☐
_____	_____	_____	☐

2 CALL LOG

Date / time	Office / person	What was promised	Follow-up
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____
_____	_____	_____	_____

3 24 HOURS, 72 HOURS, AND TWO WEEKS

☐ Is the person medically stable compared with the discharge baseline? New or sudden confusion is not automatically “just dementia.”
☐ Were medicines, equipment, food, transportation, and first visits actually received?
☐ Are all shifts and skilled tasks covered without forcing an unsafe burden onto one person?
☐ Does the person feel heard, safe, comfortable, and able to practice their family, cultural, or spiritual way?
☐ Did “pending” services move to a new exact status? What is still stuck?
☐ Is the temporary plan sustainable, or must the care setting, service level, or staffing plan change?

4 EMERGENCY AND BACKUP PLAN

Clinical / hospice / nurse line _____
Nearest emergency care _____
Backup transportation _____
Backup overnight person _____
Power / equipment backup contact _____

CROSS-REFERENCES IN THE FAMILY CARE NAVIGATION PACKET
Use Document a Concern; Calm Escalation Scripts; Money Safety; the Care Binder and authority papers; Memory Loss and Dementia; Veteran care; Care Team + Caregiver Capacity; What Matters to Me Right Now; Beliefs, Dignity, and Family Way; Caregiver / Advocate Self-Check; Serious Illness; Hospice; and After a Death.

KEEP CASE RECORDS WITH THE FAMILY
The Long Return Institute provides a public organization tool. It does not receive, store, or manage a family’s private medical, legal, financial, or benefits records. Report outdated contacts or confusing language without sending personal case details.

Status: integrated in Public v2.2 after benchmark-and-scope review. The packet remains a navigation tool; current services and individual instructions must be confirmed directly.

PART VI Keep the Human Center

Care must protect dignity, family presence, memory, meaningful choice, caregiver limits, and what makes life worth living.

Use these pages as working sheets. Fill only what helps; keep private case details with the family, not with the Institute.

INCLUDED IN THIS PART

CORE RULE

Safety matters, but maximum safety is not automatically the person's only goal. Make risks and trade-offs visible, preserve the person's priorities, and do not transfer unlimited duty onto one caregiver.

26 What Matters to Me Right Now

A reusable card for discharge, a move, a new diagnosis, serious illness, hospice, or any major change.

START WITH THE PERSON

Care should not reduce someone to a diagnosis, bed, risk score, or benefits file. Ask what makes life meaningful now and carry those priorities into the care plan. If the person cannot currently communicate, use known prior wishes and the legally authorized decision-maker as appropriate; do not invent preferences.

1 WHAT I WANT TO KEEP

What do I most want to keep doing, experiencing, or being part of?

_____

_____

2 WHAT MATTERS MOST RIGHT NOW

☐ Being at home	☐ Being with particular people	☐ Staying mentally clear
☐ Comfort / pain relief	☐ Mobility / getting outside	☐ Privacy / quiet
☐ Prayer / ceremony / spiritual care	☐ Language / songs / stories / foods	☐ Independence in certain activities
☐ An important event or responsibility	☐ Time with family / community	☐ Other: _____

3 WORRIES, LIMITS, AND TRADE-OFFS

What am I most worried about? _____

What outcome or burden would be especially hard for me? _____

What am I willing to go through for the possibility of improvement or more time? _____

What am I not willing to go through, if I can avoid it? _____

4 WHO SHOULD BE INCLUDED

People I want included in conversations: _____

Health-care agent / authorized decision-maker, if any: _____

USE THIS SCRIPT

“These are the things that matter most to me right now. Given these priorities, what options fit best, what trade-offs should I understand, and what do you recommend?”

A person’s preference does not create unlimited caregiving capacity in another person. Use page 24B to identify what family or caregivers can actually provide and what must be supplied by services, alternatives, or a different plan.

27

How to Care and Be Present

Advocacy is one kind of care. Presence, comfort, and ordinary time are also care.

Notice / offer	Examples
Body	Pain, hunger, thirst, warmth, breathing, skin, hygiene, mobility, hearing, vision, dentures, sleep
Mind and mood	Fear, confusion, calm, sadness, withdrawal, anger, relief, engagement
Environment	Noise, light, cleanliness, safety, privacy, needed items, call button, phone charger
Respect	Name used, explanations, consent, interpreter, family involvement, cultural or spiritual needs
Connection	Stories, music, language, prayer, food, nature, laughter, quiet, touch when welcomed
Next step	One concern to address, one comfort to bring, one person to call, one thing to leave alone

ASK THE PERSON

When possible: "What matters most today? What hurts? What would help? Who do you want here? What do you want us to stop doing?"

28

Family Schedule and Presence Plan

One person should not carry everything alone if others can help.

Role	Person	Phone	Notes
Main contact			
Backup contact			
Visits / calls			
Rides			
Supplies / laundry			
Paperwork / benefits			
Medical appointments			
Escalation helper			
Prayer / cultural support			
Respite / relief			

WEEKLY RHYTHM

Day	Who visits / calls	What to check / bring	Notes
Monday			
Tuesday			
Wednesday			
Thursday			
Friday			
Saturday			
Sunday			

SMALL SHIFTS COUNT

A ten-minute call, one ride, a meal, one load of laundry, or one visit a month can keep the person closest to the bed from burning out.

29

Beliefs, Dignity, and Family Way

Cultural, family, spiritual, and personal practices are part of care, not decorative extras.

What dignity means to this person _____
Preferred name / language / way of speaking _____
People who should be consulted _____
Prayer, ceremony, songs, stories, or spiritual support _____
Foods, objects, clothing, scents, or comfort practices _____
Touch, privacy, gender, or modesty preferences _____
What staff should understand about the family _____
What should never be ignored _____
What should happen near end of life _____
What should happen after death _____

PROTECTED KNOWLEDGE BOUNDARY

The packet should record only what the family chooses to share for care. Do not extract, publish, photograph, or circulate protected cultural knowledge merely because it may be relevant to comfort or ceremony.

30

Caregiver / Advocate Self-Check

You are a witness, helper, continuity person, and human being - not an unlimited resource.

☐ I know the one next step; I am not trying to solve the entire system tonight.
☐ I have eaten, had water, taken needed medication, and slept enough to drive or make decisions safely.
☐ Another person knows what is happening and can listen, visit, call, or take a shift.
☐ I have separated facts, fears, and assumptions before making the next call.
☐ I am protecting private information and not posting an active case publicly.
☐ I can be calm and still be serious; loving and still be firm.
☐ I know when to call emergency services, a professional, an advocate, or an attorney.
☐ I have made room for a visit that is not about paperwork.

What am I carrying today? _____

Who can take one task? _____

What is the next step only? _____

When will I rest? _____

Who can sit with me? _____

CAREGIVER SAFETY + CAPACITY

If exhaustion, despair, substance use, violence, suicidal thoughts, or inability to provide safe care is present, call or text 988 for 24/7 general crisis support - for the caregiver, the person receiving care, or someone worried about another person. Call 911 for immediate physical danger. Asking for relief is a safety action, not abandonment.

31 Serious Illness: What to Ask and Say

Help the person understand the road ahead and make the care plan answerable to what matters.

PURPOSE

This page helps organize a conversation; it does not choose treatment, predict prognosis, determine capacity, or replace the clinician's recommendation. Ask for plain language, write down the answer, and use page 26 to keep the person's priorities visible.

1 ASK THE CLINICIAN

☐ What do you expect from here? What are the best realistic outcomes, and what difficult possibilities should we prepare for?
☐ What is this treatment, procedure, or hospital stay meant to accomplish now?
☐ What burdens, side effects, loss of function, or change in care setting are reasonably possible?
☐ What happens if we do not do this, or if we try a less burdensome option?
☐ What decision might we face next, and how soon might we need to decide?
☐ Could palliative care help with symptoms, support, and goals alongside the current treatment?
☐ If hospice may become relevant, when should we ask for an information visit so we understand the option before a crisis?
☐ Given what matters most to this person, what do you recommend?

2 ASK THE PERSON, WHEN POSSIBLE

What are you hoping for? _____	**What are you most afraid of?** _____
What makes a good day now? _____	**What would be too much to go through?** _____

3 CLOSE THE LOOP

Teach-back: "I want to make sure I understand. What I heard is: _____. The next decision or action is: _____. The person responsible is: _____. We should revisit this by: _____."

PALLIATIVE CARE AND HOSPICE ARE NOT THE SAME THING

Palliative care can support quality of life and symptom relief alongside other treatment. Hospice has its own eligibility, plan of care, and after-hours route. Ask the care team which service fits the person's situation; do not assume one automatically means the other.

32 When Hospice Has Been Called

Hospice is a shift toward comfort, support, dignity, and family - not the end of asking questions.

FIRST-WEEK QUESTIONS

☐ Who is the nurse, social worker, aide, chaplain or spiritual-care contact, physician, and after-hours number?
☐ What symptoms should trigger an immediate call? What should trigger 911?
☐ Which medications and equipment will be delivered, stopped, or changed?
☐ What is the plan for pain, breathlessness, agitation, nausea, constipation, wounds, falls, and nighttime crises?
☐ What help is available for bathing, respite, caregiver training, supplies, and transportation?
☐ How will cultural, tribal, spiritual, language, family, and after-death practices be documented and honored?
☐ What happens if the family changes its mind or the person needs hospital care?
☐ What support is available to the family after death?

WRITE THE HOSPICE CONTACTS

Agency / team _____
24-hour number _____
Primary nurse _____
Social worker _____
Aide schedule _____
Spiritual / cultural contact _____
Pharmacy / equipment _____
Funeral home / after-death plan _____

COMFORT AND CONSENT
Ask before touching, moving, bathing, medicating, photographing, or bringing visitors whenever possible. A person approaching death still has preferences, relationships, and dignity.

33

After a Death: The First Days

Slow down. Follow the care setting's instructions, protect family time, and write down the next steps.

Situation	First step
Death on hospice	Call the hospice number first unless there is danger or the team instructed otherwise. Hospice confirms and coordinates the next steps.
Expected death in facility / hospital	Ask the nurse what happens next, how long family may stay, how belongings are handled, and who contacts the funeral home.
Unexpected death at home	Call 911. Do not move the body or disturb the scene unless emergency responders instruct you.
Cultural / family time	Tell staff promptly about prayer, songs, washing, clothing, family arrival, sacred items, photography limits, and other practices; legal and facility requirements still apply.
Veteran	Ask about burial flag, cemetery eligibility, marker, burial allowance, survivor benefits, and accredited claims help.
Documents and notifications	Death certificates, funeral home, Social Security, VA, employer or pension, insurance, banks, utilities, landlord, benefits, and estate representative.

FAMILY NOTES

Who was notified _____
Funeral home / mortuary _____
Death certificates ordered _____
Person handling property / estate _____
Ceremony and burial contacts _____
Benefits / survivor helper _____
Items and documents secured _____

PROTECT GRIEVING FAMILIES
Do not rush into contracts, asset transfers, debt payments, benefit decisions, or public announcements under pressure. Get copies, ask prices in writing, and involve the authorized person.

34 Love and Care Time

Do not let the system take all the time.

- Some visits are for paperwork.
- Some visits are for advocacy.
- Some visits are for prayer, stories, songs, language, food, memory, laughter, nature, or quiet.
- Some visits are simply for love.

What brings comfort _____
Favorite stories, songs, prayers, or places _____
People they like hearing from _____
Foods / drinks / scents / textures they enjoy _____
Things to bring next time _____
Things to avoid _____
A visit that is not about administration _____
What we want to remember _____

> **PRESENCE IS NOT WASTED TIME**
> The packet exists to help the family recover time and attention from fragmented systems so that care can remain human.

35 Why This Packet Exists

A note to families and the people who help them.

This packet is dedicated to loved ones who have moved forward, and to families still sitting beside beds, making calls, asking questions, keeping notes, saying prayers, and trying to protect someone they love.

The deepest value of the packet is not the phone numbers. Phone numbers change. The deeper value is the stance:

Be loving, but not passive.
Be calm, but not silent.
Be organized, but not cold.
Be respectful, but do not disappear.
Ask for the next step, the responsible person, and the time it will happen.
Protect dignity, family authority, cultural practice, privacy, and room for love.

It is offered as a public bridge between families and the separate systems they must navigate: care institutions, legal advocates, public agencies, benefits systems, and policymakers. It does not replace those systems. It helps a family arrive organized, ask a clear question, and remain present.

> **THE LONG RETURN INSTITUTE**
> Institute-controlled, Native-centered public-service work. This packet speaks generally and does not represent the Pit River Tribe, any band, agency, clinic, family, or professional body.

36 Trusted Starting Points and QR Codes

Use official sources to verify numbers, programs, eligibility, and complaint routes.

CA OMBUDSMAN	CA APS	VA CONTACT
aging.ca.gov - Long-Term Care Ombudsman	cdss.ca.gov - Adult Protective Services	va.gov/contact-us
PIT RIVER HEALTH	**DEMENTIA HELP**	**THE LONG RETURN INSTITUTE**
pitriverhealthservice.org	alz.org - 24/7 Helpline	institute.thelongreturn.org/care - current controlled release

OTHER TRUSTED STARTING POINTS

Resource	Contact
California Aging Information Line	1-800-510-2020
Ombudsman CRISISline	1-800-231-4024
California APS routing	1-833-401-0832
Community Care Licensing	1-844-538-8766
CANHR	800-474-1116 / canhr.org
Medicare	1-800-MEDICARE / medicare.gov
Eldercare Locator	800-677-1116 / eldercare.acl.gov
Alzheimer's Association	800-272-3900 / alz.org
VA MyVA411	800-698-2411 / va.gov
988 Suicide & Crisis Lifeline	Call or text 988 / 988lifeline.org
Veterans Crisis Line	988 then press 1 / text 838255

DIGITAL PRIVACY

Do not put private health details, allegations, Social Security numbers, financial records, protected cultural information, or active family conflict into public websites or shared forms.

37 Distribution Partner Notes

For clinics, hospitals, elder programs, social services, libraries, advocates, and family helpers.

This is a family organization and navigation tool. It is designed for waiting rooms, discharge planning, caregiver meetings, tribal health and social services, senior centers, libraries, hospice teams, Veterans offices, and family meetings.

Partner	Appropriate use
Tribal social services / health / elder programs	Print copies; help families fill local contacts; explain available tribal services without promising eligibility.
Hospitals / clinics / discharge planners	Give the tear-outs early; use the contact, medication, authority, discharge, dementia, hospice, and VA pages as appropriate.
Ombudsman / APS / legal aid	Use as a family documentation and referral aid; do not treat it as an investigative finding.
Hospice / home health	Pair authority, dignity, hospital-to-home, serious-illness, hospice, and after-death pages with first visits and caregiver training.
Veterans service offices / accredited VSOs	Pair the Veteran pages with benefits screening and accredited claims help.
Libraries / senior centers / caregiver groups	Keep public copies, offer printing, and route users to official resources.
Funders / policymakers	Treat use and outcomes - not downloads alone - as the measure of value.

PARTNER SAFEGUARDS

☐ Confirm numbers before each print run.
☐ Do not collect more private information than the service requires.
☐ Do not imply that The Long Return Institute or the packet has investigated or verified an individual allegation.
☐ Do not remove the visible limits, emergency warning, version date, or correction invitation.
☐ Return corrections and user feedback to the packet maintainer.

38 Source Review and Version Record

Keep the packet honest, current, and answerable.

PRIMARY OFFICIAL SOURCES CARRIED FORWARD FROM v2.2.1 - CONTACTS LAST VERIFIED JULY 31, 2026

Source	Site / contact	Use
Pit River Tribe - Social Services	pitrivertribe.gov/socialservices/	Main office 530-335-5421; current page lists Social Services extension 2013.
Pit River Health Service	pitriverhealthservice.org	Burney 530-335-3651; XL 530-233-3223; transportation 530-335-0351.
California Department of Aging	aging.ca.gov	Ombudsman 1-800-231-4024; statewide aging line 1-800-510-2020.
California Dept. of Social Services	cdss.ca.gov	APS routing 1-833-401-0832; IHSS official program and county routing.
U.S. Department of Veterans Affairs	va.gov / caregiver.va.gov	MyVA411 800-698-2411; benefits 800-827-1000; caregiver support 855-260-3274.
Veterans Crisis Line	veteranscrisisline.net	988 then press 1; text 838255.
CMS discharge planning	cms.gov	Patient goals/preferences, caregiver participation, transfer of needed information.
National Institute on Aging	nia.nih.gov	Palliative care may be provided alongside current treatment.
Alzheimer's Association	alz.org	24/7 dementia helpline and caregiver resources.
988 Suicide & Crisis Lifeline	988lifeline.org	Call or text 988; free, confidential 24/7 support for anyone in crisis or emotional distress.
Shasta / Siskiyou APS	shastacounty.gov / co.siskiyou.ca.us	Shasta APS 530-225-5798 (24/7). Siskiyou APS / IHSS 530-841-4010 during posted business hours; statewide APS routing remains the 24/7 front door.
CDC / NIA / MedlinePlus	cdc.gov / nia.nih.gov / medlineplus.gov	Reviewed older-adult falls, head injury, sudden confusion, and dementia-sensitive emergency routing.

BENCHMARK SOURCES USED FOR COVERAGE AND DESIGN - NOT CURRENT AUTHORITY

Joy Loverde, The Complete Eldercare Planner (rev. ed., 2009); Virginia Morris, How to Care for Aging Parents, 3rd ed. (2014); Nancy L. Mace & Peter V. Rabins, The 36-Hour Day, 5th ed. (2011); Atul Gawande, Being Mortal (2014/2015). These sources were used to test coverage, transitions, caregiver burden, dementia sensitivity, and person-centered goals. Current rules, contacts, eligibility, and clinical/legal claims must be checked against official sources.

VERSION HISTORY

- v1.0 - first public family organization guide.
- v1.1 - production pass, tear-outs, dedication, maintenance and partner notes.
- v1.2 - county safety and hospice additions.
- v2.0 - canonical consolidation with money safety, authority papers, dementia, Veteran, hospice, and after-death pages.
- v2.1 - July 26, 2026: integrated Veteran Elder Care module; clarified naming; updated first-call routing and source review.
- v2.2 - July 31, 2026: benchmark-guided integration of hospital-to-home, caregiver capacity, documents locator, What Matters, serious-illness script, and related transition safeguards; superseded before public adoption after family-reader boundary review.
- v2.2.1 - July 31, 2026: bounded correction pass clarifying routing versus advice, warning signs versus findings, general 988 access, statewide APS routing, T1 simplification, one-time use, and public release control.
- v2.3.0 - August 19, 2026: Institute-control and identity successor; named adoption, maintainer, correction route, Institute identity, and predecessor status. Substantive care content unchanged; contacts last verified July 31, 2026.

CORRECTION INVITATION

Report outdated numbers, broken links, confusing language, missing local resources, accessibility problems, or harmful assumptions at institute.thelongreturn.org/corrections.
Identify the page, current wording, proposed correction, source, and date. Do not send private case records.

Issued by The Long Return Institute under LRI-PGM-001, Elder and Family Care Program. Adopted August 19, 2026 by Christopher Knorr as current program owner; maintained by Christopher Knorr until a successor owner is recorded. AI materially assisted research, drafting, layout, and quality control. This release creates no medical, legal, clinical, tribal, governmental, or external professional authority or approval.