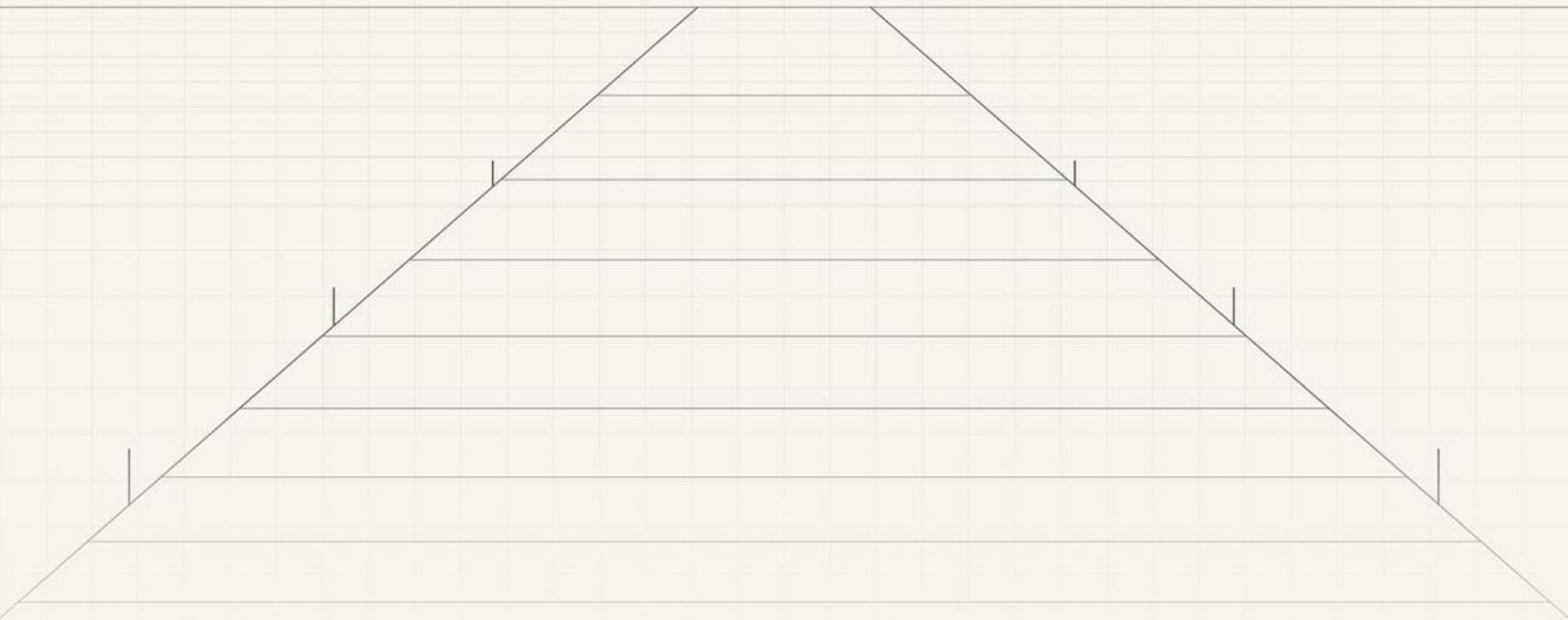


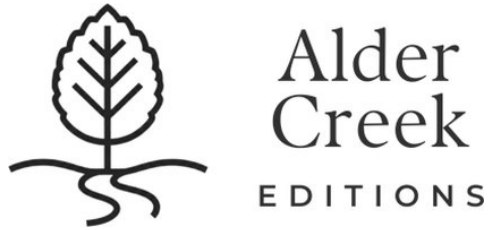
The Family Integrator's Handbook

Worksheets for Families Coordinating Care



A COMPANION TO THE OPERATIONAL RELIABILITY SERIES

Stephen Deason



THE FAMILY INTEGRATOR'S HANDBOOK

Worksheets for Families Coordinating Care

STEPHEN DEASON

A companion to The Operational Reliability Series

The Family Integrator's Handbook
Worksheets for Families Coordinating Care

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This book is a set of organizing tools. It is not legal, medical, financial, or tax advice, and using it does not create a professional relationship of any kind. Several worksheets identify decisions that require an attorney or a licensed clinician. Those notes appear because the decision is one for a professional, not as a formality.

Program rules for Medicare, Medicaid, and veterans benefits change, and licensure differs by state. Confirm anything you intend to rely on with someone who works with those rules where you live.

These worksheets are also available as free individual downloads, in standard and large print, at aldercreekeditions.com.

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First Edition

Why This Book Exists

Every organization involved in someone's care is built to solve one bounded problem. A doctor's office keeps a patient panel seen. An agency puts a trained person in a house on a schedule. An attorney answers who is allowed to decide what. Each of them is good at its job, and each of them stops.

What is left over when all of them have stopped is the part nobody was assigned. Whether the medication list is right. Whether the substitute knows about three o'clock. Whether recovery is actually happening. Whether the person at the center of all this is having a good life, most days, inside whatever they are now living with.

That leftover part has a name. In a few technical fields it is called a residual: whatever remains once a process has done everything it was built to do. In a family, it does not have a name. It has a person. Usually whoever was closest, showing up the most, noticing first.

This book will not make that job smaller. Nothing does. What it does is make the job visible, so that the person holding it is holding it on purpose rather than by exhaustion, and so that the rest of the family can see what they are holding.

Use what you need. Ignore the rest. Photocopy anything. Nothing in here has to be done in order, and no family has ever needed all of it at once. The pages most families use week after week appear several times, so there is room to keep going.

Start Here If

Nothing in this book has to be read in order. Find the row that sounds like your week and start there.

You just got a diagnosis and nobody told you what happens next

What a Good Day Looks Like, Family Care Notebook, Legal Readiness

They come home from the hospital tomorrow

Discharge Day, Medication Reconciliation, Emergency Information

You are about to call an agency for the first time

The First Phone Call, Hiring In-Home Help

A stranger is about to spend a day in the house

What a Good Day Looks Like, The Next-of-Kin Box

You are the one doing everything and nobody has said so out loud

Who Owns Continuity?, Dividing the Work, What This Is Costing You

The family is meeting and you do not want it to end in nothing

Dividing the Work, Family Meeting and Decision Log

You cannot remember whether this started three months ago or a year ago

Observation Log, Family Care Notebook

Someone said the word memory care and the room went quiet

Housing Decision Worksheet, Care Continuum at a Glance

You do not know what any of this is going to cost

Financial Readiness, Paying for Care

Nobody can find the power of attorney

Document Locator, Essential Documents, Legal Readiness

You have not had a day off in four months

Getting a Week Off, Primary Caregiver Backup Plan

They keep asking to go home, and they are home

When They Ask to Go Home

You want to know what you are actually dealing with

System Maps, Map Your Own Arrangement, What This Organization Owns

CONTENTS

START HERE

The Next-of-Kin Box	8
Emergency Information	10
Care Team Directory	11
Medications and Allergies (2 copies)	12
Medical History Summary	14
What a Good Day Looks Like	15
Document Locator	17
Discharge Day	18

THE FAMILY CARE NOTEBOOK

Family Care Notebook	21
Observation Log (6 copies)	22
Medication Reconciliation (3 copies)	28

WHO OWNS WHAT

Who Owns Continuity? (2 copies)	32
Dividing the Work (2 copies)	34
Family Communication Plan	36
Family Meeting and Decision Log (3 copies)	37
Primary Caregiver Backup Plan	40
Residual Outcome Worksheet (2 copies)	41
Operational Reliability Check-In (2 copies)	43
Care Coordination Grid (6 copies)	45

WORKING WITH ORGANIZATIONS

Care Continuum at a Glance	52
Five Questions for Any Provider	53
Appointment and Transition Prep	54
What This Organization Owns (3 copies)	56
Hiring In-Home Help	62
Care Agreement Terms	64
The First Phone Call	65

MONEY, LEGAL, AND INSURANCE

Financial Readiness	68
Paying for Care	69
Legal Readiness	70

CONTENTS

Insurance and Benefits Inventory	71
Essential Documents	72
HOME SAFETY AND GETTING AROUND	
Home Safety Walkthrough	74
Transportation Plan	75
Housing Decision Worksheet	76
THE CAREGIVER	
What This Is Costing You (3 copies)	78
Getting a Week Off	81
LATER STAGES	
When They Ask to Go Home	83
Goals of Care	85
What Happens After	86
SEEING THE SYSTEM	
System Maps	88
Map Your Own Arrangement (2 copies)	95

01

Start Here

The essential facts and contacts that make a first response less overwhelming.

One container, in one fixed place, holding what a paramedic, a substitute caregiver, or a relative arriving from out of town would need in the first ten minutes. Responders in many areas are trained to check the refrigerator, so that is the convention worth following. Put a card on the fridge and one on the inside of the front door saying the information is there.

Everything in this box is knowledge that otherwise lives in one person's head. The box exists for the day that person is not there to be asked.

DOCUMENTS

- ☐ Copy of the healthcare power of attorney
- ☐ Copy of the advance directive or living will
- ☐ Copy of a signed HIPAA authorization
- ☐ Copy of the durable power of attorney for finances
- ☐ A note saying where the originals are kept and who holds copies
- ☐ Insurance cards: health, Medicare or Medicaid, supplement or Advantage
- ☐ A recent photograph, dated on the back

MEDICAL

- ☐ Current medication list with doses and times, dated
- ☐ Allergies, and what reaction each one causes
- ☐ Ongoing conditions, and roughly when each was diagnosed
- ☐ Implanted devices: pacemaker, defibrillator, stent, joint replacement
- ☐ Recent hospitalizations, and what changed as a result
- ☐ Primary care doctor, specialists, and pharmacy, with numbers
- ☐ Preferred hospital

PEOPLE

- ☐ Next-of-kin call list in order, with relationships and numbers
- ☐ Which person on that list is the healthcare agent
- ☐ Who has keys to the house, and where a spare is kept
- ☐ A neighbor who can get in
- ☐ Who to call about the pets

THE PART MOST BOXES LEAVE OUT

A responder can read a medication list. What they cannot do is guess any of this.

- ☐ Can this person reliably answer questions about themselves? Say so plainly.
- ☐ How they communicate if they cannot
- ☐ What settles them when they are frightened
- ☐ Anyone who depends on this person and cannot be left alone, including a spouse
- ☐ Pets in the house, and what they need
- ☐ Where the full Family Care Notebook lives

WHERE THE BOX LIVES, AND WHO KNOWS

Duplicate kept in:

Contents last reviewed on:

Review it whenever a medication changes, after any hospitalization, and twice a year regardless. A box nobody has opened in three years is worse than no box, because somebody will trust it.

Emergency Information

The one page a paramedic, a substitute caregiver, or a relative arriving from out of town should be able to find without asking. Keep it on the refrigerator and a photograph of it on every phone that matters.

Full legal name	
Date of birth	
Home address	
Primary phone	
Blood type, if known	
Preferred hospital	
Primary care doctor and phone	
Pharmacy and phone	
Health insurance and member number	
Medicare or Medicaid number	

CALL FIRST, IN THIS ORDER

	Name	Relationship	Phone
1			
2			
3			

CRITICAL TO KNOW IMMEDIATELY

Allergies, conditions a first responder must know about, and where the advance directive is kept.

Every organization involved, what it owns, and one name inside it who answers the phone. The second column matters more than it looks. An organization you cannot describe is one you will ask for the wrong thing.

Organization or person	Role, and what they own	Contact	Best number

Medications and Allergies

The short version, for the refrigerator and the glove compartment. The long version, with prescribers and changes over time, belongs on the Medication Reconciliation Worksheet.

ALLERGIES AND REACTIONS

Allergy or sensitivity	What happens

CURRENT MEDICATIONS

Medication and dose	What it is for	When taken

Last updated:



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ALLERGIES AND REACTIONS

Allergy or sensitivity	What happens

CURRENT MEDICATIONS

Medication and dose	What it is for	When taken

Last updated:

Medical History Summary

What a new provider needs in the first two minutes. A family that can hand this over is not relying on remembering it correctly under pressure, in order, at the end of a long day.

ONGOING CONDITIONS

Condition	Diagnosed when	Treated by

SURGERIES AND HOSPITALIZATIONS

What and when	What changed as a result

ANYTHING A NEW PROVIDER SHOULD KNOW THAT IS NOT IN A CHART

What a Good Day Looks Like

Diane's first question was not what happened. It was tell me about Elaine, asked before anything had gone wrong. This page is that question, written down.

Everything on it is knowledge that lives in one person's head until somebody writes it out. A substitute who has this page has most of what a regular caregiver spends months learning.

Who they were before any of this. Work, church, hobbies, what they were known for.

What a good day looks like, in their own words if you can get them.

Routines that matter. What time, in what order, and what happens if it slips.

The wrong question to ask, and the right way to offer instead.

Food and drink. How they take it, what they will not eat, what they will always accept.

What settles them when they are agitated.

What sets them off.

Names, relationships, and stories they return to.

ANYTHING ELSE A NEW PERSON WOULD NEED TO KNOW ON THE FIRST MORNING

Not the documents. Where the documents are, and who can get to them. A signed power of attorney nobody can find at eleven at night is not doing the job it was signed for.

TALK TO AN ATTORNEY ABOUT THIS

If any row on this page is blank, that document either does not exist or nobody can find it. Both are problems an elder law attorney can fix in a single meeting, and both get much harder to fix once the person it concerns can no longer sign.

Document	Where it is kept	Who has a copy	Who to call about it
Durable power of attorney			
Healthcare power of attorney			
Advance directive			
HIPAA authorization			
Will			
Trust documents			
Insurance policies			
Deed and title documents			
Bank and investment accounts			
Military discharge papers			
Safe or lockbox, and the key			

A hospital is built to stabilize a crisis and arrange a safe handoff. Discharge is the edge of what it was ever built to cover. Everything after the door is yours, and it starts faster than most families expect.

BEFORE YOU LEAVE THE ROOM

1. What changed, medically, that was not true before this admission?

2. What are we watching for in the first forty-eight hours, and what means call somebody?

3. Which medications are new, which stopped, and which changed dose? Ask for the list to be read aloud against the one you brought.

4. What does this discharge plan assume we already have at home?

5. Who do we call if something goes wrong tonight, and is that number staffed?

6. What follow-up is scheduled, and who made the appointment?

BEFORE THE CAR PULLS IN

- ☐ Prescriptions filled, not just written. Check that the pharmacy has them.
- ☐ A bed on the ground floor if stairs are now a problem.
- ☐ Someone present for the first night, by name.
- ☐ Food in the house that matches any new restriction.
- ☐ Equipment delivered and someone who knows how to use it.
- ☐ A clear path from the car to the bed, with nothing to trip on.

THE FIRST FORTY-EIGHT HOURS

This is the window where families are most tired and most alone. Write down what you see, not what you conclude from it.

Day and time	What we saw	What we did	Who we told

TALK TO AN ATTORNEY ABOUT THIS

If the person coming home cannot make their own medical or financial decisions, and no power of attorney exists, this is the moment that becomes urgent. A hospital social worker can tell you what the facility requires. Only an attorney can tell you what your state requires, and guardianship, if it becomes necessary, takes weeks rather than days.

WHAT IS STILL UNANSWERED

02

The Family Care Notebook

Keep a single, current record that can travel with the family through change.

One notebook, physical or digital, kept in one place, that anyone stepping in could pick up and understand without you there to explain it. That is the whole test for whether it is working.

Set up these nine sections. Note where each one lives and who keeps it current.

Section	What goes in it	Who keeps it current
Medication list	Every medication being taken, and who prescribed it	
Provider list	Name, role, and phone for everyone involved	
Timeline	Diagnoses, hospitalizations, big changes, in order	
Observation log	Specific, dated entries (see the Observation Log sheet)	
Questions	A running list for the next appointment	
Hospitalizations	Dates, reasons, and what changed as a result	
Emergency contacts	Who is called first, in order, and what each can do	
Insurance	Policy numbers, coverage basics, billing contact	
Legal	Where the documents are kept and who has copies	

Notebook lives here:

NOTES

Write down what you saw rather than what you concluded from it. Observations can be checked against what happens next. Conclusions cannot, which is what makes an observation useful to a doctor, to a new aide, or to you in three months trying to remember when this started.

Instead of “She seemed off today,” write: Left half her lunch, which is new. Usually finishes the plate. No fever, no complaints when asked directly.

[illegible]

Observation Log

Write down what you saw rather than what you concluded from it. Observations can be checked against what happens next. Conclusions cannot, which is what makes an observation useful to a doctor, to a new aide, or to you in three months trying to remember when this started.

INSTEAD OF THIS, WRITE THIS

Instead of "Mom is getting worse," write: Asked the same question three times between breakfast and lunch.

Instead of "He had a bad night," write: Awake and asking to go home four times between 1 and 4 a.m. Settled once the hallway light was left on.

Instead of "She seemed off today," write: Left half her lunch, which is new. Usually finishes the plate. No fever, no complaints when asked directly.

Date and time	What happened	Different from usual	Who else saw it



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Medication Reconciliation

One line per medication, filled in once and corrected whenever something changes. This is the single worksheet most likely to help prevent a dangerous mistake, because medication lists are where different providers' information most often stops matching.

Bring this to every appointment where medication might change. A prescriber who can see the full list, including what other prescribers have ordered, is one of the more effective ways to catch an interaction before it happens.

Medication	Purpose	Prescriber	Start	Changes	Questions
Lisinopril 10mg	Blood pressure	Dr. Patel	March	Dose increased in June	Any interaction with new prescription?

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03

Who Owns What

Make commitments, communication, and the family's continuity role visible before a gap becomes urgent.



Who Owns Continuity?

Nine tasks, one line each. Most families filling this out for the first time find several blank rows. That is the worksheet doing its job. A blank row is a task nobody has claimed, and finding it here is better than finding it during a crisis.

Task	Who owns this now	Backup
Scheduling appointments		
Updating extended family		
Attending appointments		
Paying bills		
Talking to caregivers day to day		
Maintaining the Family Care Notebook		
Reviewing medications		
Making legal and medical decisions		
Being the first call in an emergency		



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Reviewing medications		
Making legal and medical decisions		
Being the first call in an emergency		

Dividing the Work

The Wednesday at Ben and Emily's kitchen table ended with one question hanging in the room, and nobody answered it. This page is that question, answered in writing, by each person for themselves.

Two columns do the real work here. NOBODY YET is where every job goes that no one claimed. TOTAL is what the family has actually committed, added up. Fill both in before anyone leaves the table.

Commitment	Person 1	Person 2	Person 3	NOBODY YET	TOTAL
Name					
Hours each week					
Money toward paid help, monthly					
Jobs I am taking					
Jobs I cannot take					
What this costs me					
When I need to revisit this					

Hours the week actually needs:

If the total is smaller than that number, the difference is not going away. Somebody is absorbing it, or it is not getting done.

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Hours the week actually needs:

If the total is smaller than that number, the difference is not going away. Somebody is absorbing it, or it is not getting done.

Five decisions, made once, so they do not have to be renegotiated every time something comes up.

Weekly check-in. Who is on it, and when it happens.

Shared notebook access. Who can see it, and who can add to it.

Shared calendar. Appointments visible to everyone who needs to see them, not only to whoever booked them.

Emergency escalation order. Who gets called first, second, and third, decided ahead of time so nobody is improvising in the moment.

Decision rules. Which decisions need everyone's input, and which do not. Gather information from everyone who has some. Keep the deciding narrow.

NOTES

Family Meeting and Decision Log

Gather information from everyone who has some. Keep the deciding narrow. This page records both halves, so that a decision made in June is still a decision in October and nobody has to reconstruct who agreed to what.

Date	Who was there	What was decided	Who owns it	Revisit when

STILL UNANSWERED

The most useful line on this page. Write down what the meeting did not settle, before everyone leaves and it becomes nobody's.

Family Meeting and Decision Log

Gather information from everyone who has some. Keep the deciding narrow. This page records both halves, so that a decision made in June is still a decision in October and nobody has to reconstruct who agreed to what.

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Primary Caregiver Backup Plan

One of the easiest questions to postpone, because it is the one nobody wants to imagine answering. Answer it before you need the answer.

Who steps in, immediately, for the next 48 hours?

Does that person know where the Family Care Notebook is?

Do they have the same information the primary caregiver has, or only the general idea?

Has this person agreed to this role, or is it something everyone assumes?

CONFIRMED WITH

Name and date this plan was discussed with the person named above.

NOTES



Residual Outcome Worksheet

A residual is whatever remains once a process has done everything it was built to do. For any major event, ask three questions in order: What outcome was this organization responsible for? What outcome still remains, once they have done that well? Who owns that remaining outcome now?

Worked example, a hospital discharge. The hospital was responsible for stabilizing the crisis and arranging a safe discharge. What remains is whether recovery actually happens once your loved one is home. That outcome belongs to the family. It was never the hospital's to own past the door.

Event or organization	What they were responsible for	What still remains	Who owns it now

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Event or organization	What they were responsible for	What still remains	Who owns it now



Operational Reliability Check-In

An operational checklist, not a medical one. This is the kind of audit a reliable system runs on itself, adapted for a family running one. Work through it every few months, and after any change in the care arrangement.

1. Does everyone involved have the same, current medication list?
2. Who notices if something changes, and how would they tell anyone?
3. Who has authority to act on a decision, as opposed to an opinion about it?
4. What happens if the primary caregiver is hospitalized?
5. What happens if a hired caregiver does not show up?
6. Who updates family members who live far away, and how often?
7. Who reconciles it when two providers give conflicting advice?
8. What happens after hours, when no office is open?
9. What happens during a holiday or vacation, when the usual backup is not available?
10. When was any of this last tested, rather than assumed to work?

Date completed:

GAPS FOUND, AND WHO IS FIXING THEM



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Care Coordination Grid

Fill in a specific name, not “whoever is free,” in every cell that applies for the coming week. An empty cell is a task nobody has claimed yet. The point of the grid is to make that visible before it becomes a missed medication or a missed appointment.

The last column is the one job none of the professionals in this family's life were doing: watching the whole week rather than one piece of it. Someone has to own that column on purpose, in writing, every week. If no name is in that box, that is the most urgent gap on the page.

Day	Morning	Midday	Evening	Meds	Appts	WHO KNOWS
Monday						
Tuesday						
Wednesday						
Thursday						
Friday						
Saturday						
Sunday						

BEFORE THE WEEK STARTS

- ☐ Is there a name in every cell that needs one?
- ☐ Is there a name in the WHO KNOWS box? If not, that is this week's most important open task.
- ☐ If that person is unavailable for a day, who is the backup, and do they know they are the backup?



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Care Coordination Grid

Fill in a specific name, not “whoever is free,” in every cell that applies for the coming week. An empty cell is a task nobody has claimed yet. The point of the grid is to make that visible before it becomes a missed medication or a missed appointment.

The last column is the one job none of the professionals in this family's life were doing: watching the whole week rather than one piece of it. Someone has to own that column on purpose, in writing, every week. If no name is in that box, that is the most urgent gap on the page.

Day	Morning	Midday	Evening	Meds	Appts	WHO KNOWS
Monday						
Tuesday						
Wednesday						
Thursday						
Friday						
Saturday						
Sunday						

BEFORE THE WEEK STARTS

- ☐ Is there a name in every cell that needs one?
- ☐ Is there a name in the WHO KNOWS box? If not, that is this week's most important open task.
- ☐ If that person is unavailable for a day, who is the backup, and do they know they are the backup?



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04

Working With Organizations

Questions and working tools for appointments, transitions, in-home help, and the organizations involved in care.

The levels of housing and care, in the rough order most families move through them, so it is easier to see where you are now and what tends to come next. Costs are relative rather than absolute and vary widely by market.

Level	What it is	Common reason	Cost
Independent Living	Private housing with little or no built-in care, often with community amenities.	Isolation, or a home that has become hard to maintain alone.	Low to moderate
Home Care / Home Health	Support delivered in your own home, non-medical or medical.	Daily tasks or medical needs outpacing what family alone can cover.	Moderate
Assisted Living	Housing plus daily support with meals, medication, and personal care.	Needing help with daily activities more consistently than home care covers.	Moderate to high
Memory Care	Assisted living with a secured setting and dementia-specific staff training.	Wandering risk, or needs specific to dementia.	High
Skilled Nursing	Licensed medical staff on site, for short-term rehab or long-term nursing.	A medical need beyond what any residential setting can provide.	Highest
Hospice / Palliative	Comfort-focused care, at any stage for palliative, and after curative treatment stops for hospice.	A change in the goal of care rather than a change in setting.	Often covered separately

Which services a provider can legally offer is set by state regulation and differs from state to state. Use this to learn what to ask, then confirm locally.

Five Questions for Any Provider

These five work no matter who you are talking to: a doctor's office, an agency, a community, an attorney, a case manager. Ask them at the first meeting, before you have committed to anything.

Provider and date:

1. What do you need from us to do this job well?

2. What is the one thing that goes wrong most often with families like ours?

3. If this were not going well, how would we find out?

4. What do you wish families asked, and usually don't?

5. Who is your backup if you are not available?

ANYTHING ELSE WORTH WRITING DOWN

Three short lists, meant to be used in the moment: in the car, in the waiting room, on the drive home. None of them will do much good read once and set aside.

BEFORE EVERY APPOINTMENT

Answer these together beforehand, out loud, so the visit itself is not the first time anyone in your family has said them.

1. What changed since the last appointment?

2. What is concerning us right now?

3. What decision, if any, are we trying to make today?

4. What would make this particular visit a success?

AFTER EVERY APPOINTMENT

Answer these in the car, or that same evening, while the visit is still fresh enough to be exact about.

1. What changed as a result of this appointment?

2. Who owns the next step?

3. What is still unresolved?

4. When do we follow up, and who makes sure that happens?

AT EVERY TRANSITION

Hospital to home. One caregiver to another. Home to memory care. Memory care back to a hospital. Every transition is where information most often gets lost, because the person handing off and the person receiving usually do not know each other and will not meet again.

1. What is the receiving party being told, and by whom?
2. What does the receiving party assume is already in place that might not be?
3. Who is the one person on each side who can be reached with a question?
4. What from the Family Care Notebook needs to travel with this transition?
5. What is different about this handoff compared to the last one?
6. Who confirms, within a day, that the transition went the way it was planned?

Hospital to home deserves extra attention. It gives you the least time to prepare, it usually happens while everyone involved is exhausted, and it is the one transition where a family is most likely to discover a gap only after they are already home.



What This Organization Owns

Fill one out for every organization you are relying on, before you rely on it. The third box is the one that matters. Whatever lands there is yours whether or not anyone said so.

ORGANIZATION

Owens. What it is built to deliver, and what it is good at.

Does not own. Where its job stops, and what it was never built to carry.

Left over. What remains when they have done their job well, and who is holding it.

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A staffing organization is built to put a trained person in the house on a schedule. That is a real thing and it is not nothing. What it cannot do is know your mother. These questions separate the two so you know what you are buying.

ASK THE AGENCY

1. What service categories does your license cover in this state, and which do you not?

 2. Will the same caregiver come consistently, or does the assignment rotate?

 3. What happens when our regular caregiver is sick, and how fast?

 4. What does the substitute know about our situation before walking in, and how does that get to them?

 5. Who supervises the caregiver, how often, and does a nurse ever visit?

 6. What gets written down after a shift, and can we see it?

 7. What is the minimum shift, the rate, and what triggers a higher rate?

 8. How do we raise a problem, and what happens after we do?

-



Elaine insisted on meeting Angela before anyone was hired. She was right to.

1. What kind of situations have you worked in before?

2. What do you need from us to do this well?

3. What would you want to know about someone before your first morning in their house?

4. What would make you tell us something rather than wait to be asked?

IMPRESSIONS, AND WHO ELSE WE SHOULD MEET

Whether you are hiring through an agency or paying a family member directly, write the terms down before the first shift. Most of what goes wrong later is something both sides assumed and neither said.

This is a worksheet for getting to terms, not a contract. If money is changing hands, particularly with a family member, have someone qualified review the arrangement for tax and employment implications before it starts.

TALK TO AN ATTORNEY ABOUT THIS

Paying a family member for care creates a legal relationship, not just an arrangement. Depending on how it is structured it can create employer obligations, payroll and tax reporting duties, and, if Medicaid is ever applied for, a transfer that looks like a gift unless a written personal care agreement exists first. Have an elder law attorney draft or review the agreement before the first payment. This worksheet gets you to the terms. It is not the agreement.

Term	What we agreed
Who is providing care	
Days and hours	
Rate, and how overtime works	
How and when payment happens	
What the job includes	
What the job does not include	
Notice required to cancel a shift	
What happens if they cannot come	
Who they call in an emergency	
What gets written down after each shift	
How we raise a problem	
When we revisit these terms	

Most families call an agency without knowing what an agency is, and end up asking for the wrong thing or agreeing to something larger than they meant. This page is what to say and what to listen for, on any first call.

SAY THIS FIRST

You do not have to know what you need. Saying so plainly gets you a better call than pretending otherwise.

"I am not sure yet what we need, or whether we need anything. Here is what is happening, and I would like to know what you would do."

HAVE THESE READY

- ☐ What changed, and roughly when
- ☐ What a bad day currently looks like
- ☐ Who is doing the work right now, and how many hours
- ☐ What you are trying to protect, in one sentence
- ☐ What you can spend, or that you do not know yet

LISTEN FOR

1. Do they ask about the person, or only about the schedule and the billing?
2. Do they say plainly what they do not do?
3. Will the same caregiver come, and what happens when that caregiver is out?
4. Who supervises, how often, and does a nurse ever visit?
5. What are they licensed for in this state, and what falls outside it?
6. If they are not the right fit, will they give you a name anyway?

That last one tells you most of what you need to know. An organization that will point you somewhere else when it cannot help you is one that has been doing this long enough to know the difference.

NOTES FROM THE CALL

05

Money, Legal, and Insurance

Planning tools to organize questions and documents before discussing decisions with the appropriate professional.

Five numbers, gathered in one place, revisited as things change. A financial planner still has a role here. This worksheet means that conversation starts from facts rather than guesses.

TALK TO AN ATTORNEY ABOUT THIS

Bring an elder law attorney into this before moving money, retitling anything, or adding a name to an account. Steps that look sensible in isolation can create a Medicaid penalty period later, and most of them cannot be undone once done.

Category	Current amount	Notes
Monthly care costs, current		
Available savings and investments		
Monthly income		
Insurance coverage: what is covered, what is not		
Expected future costs as needs increase		

Reviewed on:

Read this as a starting vocabulary, not as current rules. Coverage rules, income and asset limits, benefit amounts, and what counts as a qualifying stay all get revised, and much of it varies by state. Use it to learn what exists and what to ask about. Then get current answers from a benefits counselor, an elder law attorney, your State Health Insurance Assistance Program, or your local Area Agency on Aging. Ask when the information you are given was last updated.

TALK TO AN ATTORNEY ABOUT THIS

Two things on this page need a lawyer rather than a benefits counselor. First, anything involving Medicaid eligibility, asset transfers, or spend-down. Transfers made without advice can trigger a penalty period that delays coverage for months. Second, a reverse mortgage, which is a lien on the home and affects what heirs receive. Have both reviewed before signing anything.

Source	What it generally does	Applies to us?
Private pay	Paying directly. The most flexible option and usually the most expensive.	
Medicare	Medical care and short-term skilled care after a qualifying hospital stay. Has not historically covered long-term custodial care.	
Medicaid	Can cover long-term custodial care in many settings. Financial eligibility set state by state.	
VA benefits	Programs for veterans and some surviving spouses. Aid and Attendance is the one most families meet first.	
Long-term care insurance	Has to be bought before the need exists. Read what triggers an existing policy.	
Reverse mortgage	Converts home equity into usable funds while still living in the home.	
Life insurance provisions	Some policies allow early access through an accelerated death benefit or a viatical settlement.	
Family contribution	Direct money, shared costs, or unpaid care. Often the largest source and the hardest to see.	

Legal planning answers one question cleanly enough to survive a hospital hallway or a courtroom: who is allowed to make which decisions, and what happens if the person who is supposed to make them cannot. It does not feed anyone or sit with anyone on a Tuesday. Get it done anyway, early, while the person it concerns can still take part.

What these documents are called, what they can do, and how they must be signed and witnessed are set by state law and the rules change. Have an attorney licensed in your state prepare or review anything you intend to rely on.

TALK TO AN ATTORNEY ABOUT THIS

Every item on this list requires an attorney licensed in your state. Specifically: drafting or updating a power of attorney or advance directive, confirming that an out-of-state document will be honored where you live, deciding whether guardianship is necessary, and any question about Medicaid eligibility or asset planning. Do not rely on a template for any of it. If cost is the obstacle, ask your local Area Agency on Aging about legal aid for older adults.

- ☐ Is there a durable power of attorney for financial decisions, and has anyone read it recently?
- ☐ Is there a healthcare power of attorney, and does the named person know they are named?
- ☐ Is there an advance directive, and does the family know what it says?
- ☐ Is there a HIPAA authorization on file with each provider, not just signed and filed at home?
- ☐ Do beneficiary designations on accounts and policies still name the right people?
- ☐ Is there a power of attorney for the primary caregiver, not only for the person being cared for?
- ☐ Does anyone know where all of it is kept? See the Document Locator.
- ☐ What happens if we wait, and a crisis forces the decision instead?

QUESTIONS FOR THE ATTORNEY

Insurance and Benefits Inventory

Every policy, in one place, with the number you actually call. A coordinator can tell you what a plan will pay for. Which care is best is a different question, and a narrower one than most families expect.

Policy or program	Company	Policy or member number	Phone
Medicare			
Medicare supplement or Advantage			
Prescription drug coverage			
Medicaid			
Long-term care insurance			
Life insurance			
VA benefits			
Homeowner or renter			
Auto			
Other			

TALK TO AN ATTORNEY ABOUT THIS

A denied claim is not the end of the process. Appeal windows are short and they start on the date of the notice, not the date you understood it. If a denial involves long-term care coverage or a Medicare or Medicaid determination, an attorney or a benefits advocate can often reverse it, but only inside the window.

CLAIMS AND APPEALS

What has been filed, what was denied, and when the appeal window closes.

Nine documents are common starting points, though not all nine apply to every situation. Check which ones are relevant to yours.

What these documents are called, what they can do, and how they have to be signed and witnessed are set by state law, and the rules change. Use this list to know what to ask for. Have an attorney licensed in your state prepare or review anything you intend to rely on.

TALK TO AN ATTORNEY ABOUT THIS

Have an attorney licensed in your state prepare or review any document you intend to rely on. The four that most often go wrong without advice: a power of attorney too narrow to cover what is actually needed, an advance directive that conflicts with what the healthcare agent believes, beneficiary designations that contradict the will, and out-of-state documents a local institution refuses to honor. A template cannot catch any of these.

Document	What it does	In place?	Where it is kept
Durable power of attorney	Names who can make financial and legal decisions		
Healthcare power of attorney	Names who can make medical decisions		
Advance directive	States what treatment is wanted, and what is not		
HIPAA authorization	Lets providers share medical information with a named person		
Will	States how assets should be distributed		
Trust, if applicable	Manages assets outside the will process		
Beneficiary designations	Generally control who receives an account, whatever a will says		
Insurance policies	Health, long-term care, and life, gathered in one place		
Military discharge papers	DD-214, needed to access VA benefits		

06

Home Safety and Getting Around

Make the home, transportation, and housing questions more concrete.

Walk the whole house, room by room, the way Frank walks the whole dock rather than the boards that gave him trouble last time. Mark what is a problem now and what will be a problem in a year.

Area	Now	Soon	What needs doing
Stairs, inside and out. Railings on both sides.			
Bathroom. Grab bars, shower entry, toilet height.			
Floors. Rugs, cords, thresholds, uneven spots.			
Lighting. Hallways, stairs, the path to the bathroom at night.			
Kitchen. Stove safety, reachable storage, sharp items.			
Bedroom. Bed height, path to the door, phone within reach.			
Entry. Steps, threshold, whether a walker fits through.			
Smoke and carbon monoxide alarms. Tested when?			
Medications. Stored where, and can they be double-dosed?			
Getting help. Phone, alert system, who is nearby.			
Driving. Is it still safe, and who will say so?			

A transportation service owns getting someone from one place to another safely. It does not own what happens once they arrive. That gap is usually where a ride arrangement fails, and it fails quietly, at the far end, with nobody watching.

WHAT WE NEED RIDES FOR

Where	How often	Who drives now	Backup

QUESTIONS FOR ANY RIDE SERVICE

1. Is this door to door, or do we need someone at both ends?
2. How far ahead does a ride have to be scheduled?
3. What happens if an appointment runs long?
4. Can a caregiver ride along?
5. What does it cost, and is any of it covered?

IF DRIVING IS ENDING

Who is having that conversation, when, and what replaces the car the week after.

Before touring anything, answer Diane's question. When people say they want to keep someone home, the first answer is rarely the real one. Ask why, then ask again, until somebody says what they are actually trying to protect.

What are we optimizing for? Say it plainly.

What would have to be true for the current arrangement to keep working?

What would tell us it has stopped working, and who is watching for that?

COMPARING OPTIONS

TALK TO AN ATTORNEY ABOUT THIS

Before signing with any community, have an attorney read the residency agreement. The clauses that matter most are the ones covering what triggers a required move to a higher level of care, what happens to money already paid if that happens, how much notice either side must give, and what the community can change without your consent.

Option	What it costs	What it solves	What it does not solve

07

The Caregiver

Tools for making the caregiver's load visible and planning room to rest.

What This Is Costing You

Every invoice in this story measures something. What never appears on any of them is everything that happened around them: the calls made on a lunch break, the meeting not taken, the night spent awake running through what a substitute might not know.

A cost with no formal place to go is invisible to everyone except the person carrying it. That is what makes it easy for a family to underestimate what one member is absorbing, including their own.

This month	Hours	What it displaced
Phone calls and paperwork		
Appointments attended		
Hands-on care		
Coordinating between providers		
Nights interrupted		
Money out of pocket		

What have you stopped doing since this started?

Who else in the family knows any of this?

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Money out of pocket		

What have you stopped doing since this started?

Who else in the family knows any of this?

Whoever ends up as the hands-on person burns out on a predictable schedule, because nobody budgets for the person who is not the one who is sick. This page is the budget.

What week are you taking, and what is the date?

Who covers each day, and have they said yes out loud?

What do they need from you in writing before you leave? Start with the Family Care Notebook and What a Good Day Looks Like.

What paid help fills the gaps the family cannot, and is it booked?

Who is the one person to call if something changes, and does everyone have that number?

A week you have not put on a calendar is not a plan. Put a date on this page before you set it down.

08

Later Stages

Prompts for hard conversations and the practical work that follows a major change.

They are home, and they want to go home. Arguing about the address does not work, because the address is not what they are asking about. What they are saying is that something here feels wrong and they want to be somewhere safe.

RULE THIS OUT FIRST

A sudden change in behavior is a medical question before it is a behavioral one. New confusion, agitation, or a sharp decline over hours or days can be an infection, pain, dehydration, or a medication problem, and all of those are treatable. Call the doctor before you conclude this is the disease progressing.

WHAT TENDS TO WORK

- ☐ Answer the feeling rather than the fact. “You want to go home” before anything else.
- ☐ Ask about the home they mean. Often it is a childhood house, and the question becomes a conversation.
- ☐ Change the room, the light, or the activity. Movement resolves more than reasoning does.
- ☐ Offer food or a drink. Hunger and thirst show up as agitation more often than anyone expects.
- ☐ Check the clock. Late afternoon is a common time for this, and it will pass.
- ☐ Agree to go later, then move on. A promise you will not keep is kinder than an argument you will lose.

WHAT TENDS NOT TO WORK

- ☐ Correcting them. Being told you are wrong about where you live is frightening, not clarifying.
- ☐ Explaining the diagnosis. It will not be remembered and it lands as an accusation.
- ☐ Reasoning from evidence. Photographs and documents rarely persuade and often escalate.
- ☐ Raising your voice, which they will read as danger even when the words are calm.

WHAT WE SAW, AND WHAT WORKED

Every family finds a few things that work for their person and nobody else's. Write them down, because the next person in this house will not know them.

Date and time	What set it off, if we know	What we tried	Did it help?

WHAT WE NOW KNOW SETTLES THEM

Copy this onto the What a Good Day Looks Like sheet so a substitute has it.

At some point the goal of care changes, and the change is a decision rather than a decline in setting. Families who have talked about it before that day arrives are not making the decision in a hospital hallway at two in the morning.

This is a conversation worksheet, not a legal document. What is written here has no authority on its own. Put the decisions into an advance directive with an attorney licensed in your state.

TALK TO AN ATTORNEY ABOUT THIS

Nothing written on this page has any legal force. To make these wishes binding, they have to go into an advance directive and a healthcare power of attorney prepared under your state's law. Bring this page to that appointment. It is the hard part, and most people arrive without it.

In their own words, what makes a life worth living to them right now?

What would they not want, under any circumstances?

Who speaks for them if they cannot, and does that person know what is written above?

What have we not asked because it was too hard to bring up?

WHO KNOWS THIS

Naming everyone who has heard this directly, not everyone who could guess.

Hospice care ends. The family's does not. What is left over after the last professional goes home is grief with nowhere to file itself, and a list of practical things nobody was assigned.

TALK TO AN ATTORNEY ABOUT THIS

An attorney is worth a call early if there is a will to probate, real property to transfer, a trust to administer, an estate with debts, or any disagreement among heirs. Waiting rarely makes any of those simpler, and in some states there are filing deadlines that start running immediately.

PRACTICAL, IN THE FIRST TWO WEEKS

- ☐ Who notifies family, friends, and the people who were part of daily life?
- ☐ Who contacts Social Security, pensions, and the VA?
- ☐ Who handles insurance claims and final medical bills?
- ☐ Who returns or disposes of medical equipment and unused medication?
- ☐ Who has the will, and who is the executor?
- ☐ Who cancels services, accounts, and subscriptions?

THE OTHER PART

The grief in this kind of loss often started long before the day it ended, and the ending does not close it. If the person who carried the most is now the person with nothing to carry, that is worth saying out loud to someone.

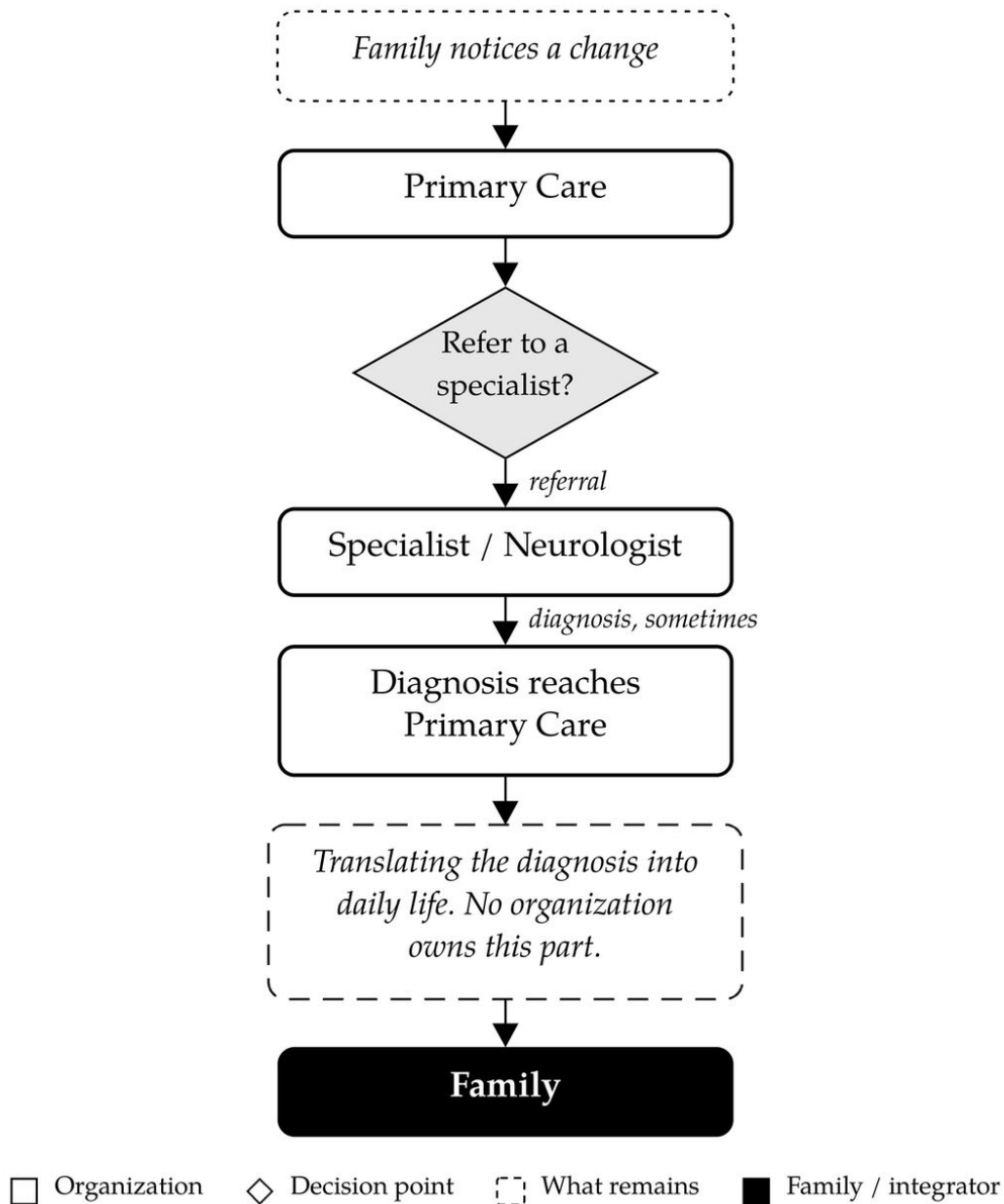
09

Seeing the System

Map the people, handoffs, and remaining responsibilities across a care journey.

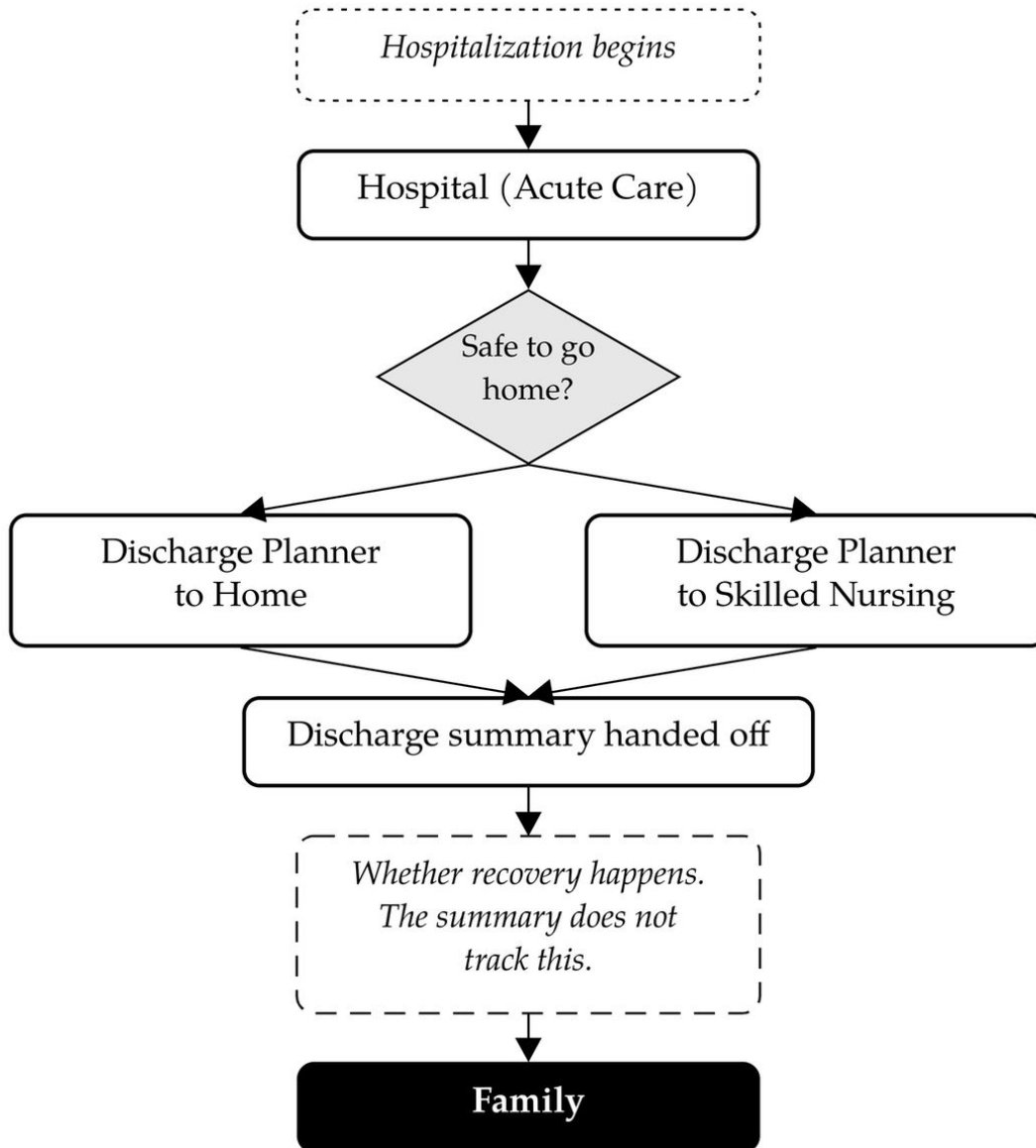
Diagnosis Journey

From a family noticing something to a diagnosis in hand



Hospital Discharge

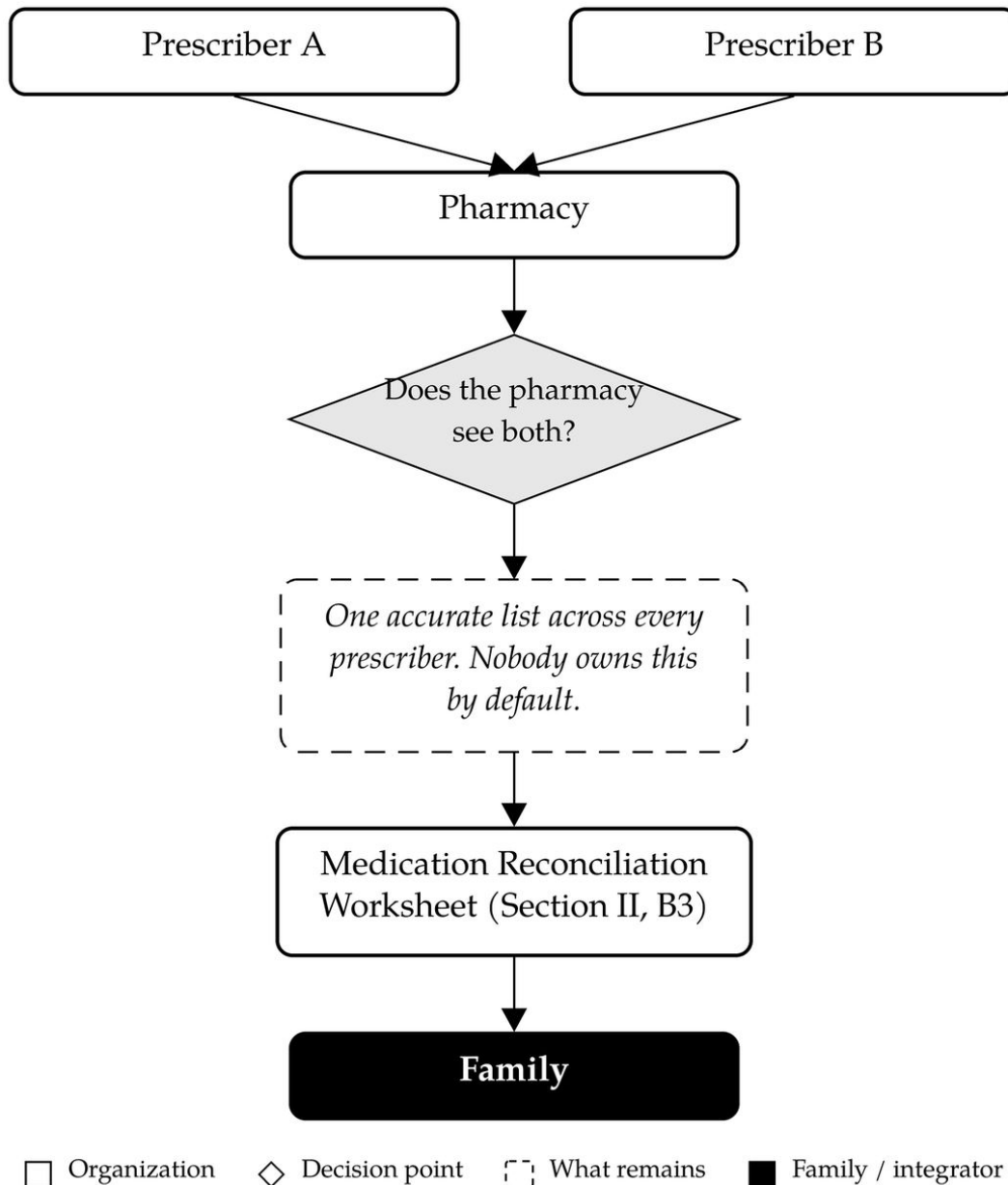
From a crisis stabilized to a family managing recovery



□ Organization ◇ Decision point [] What remains ■ Family / integrator

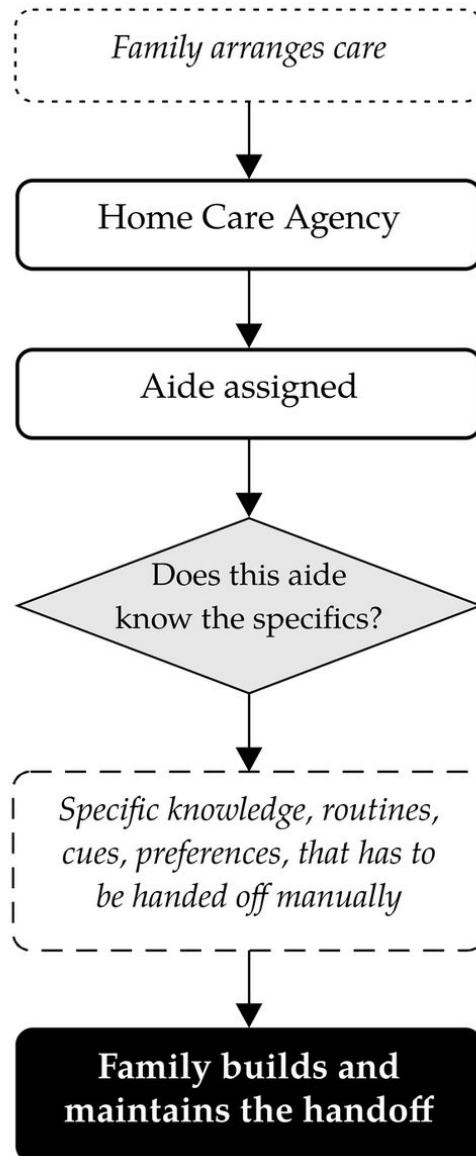
Medication Management

From several prescribers to one accurate list



Home Care

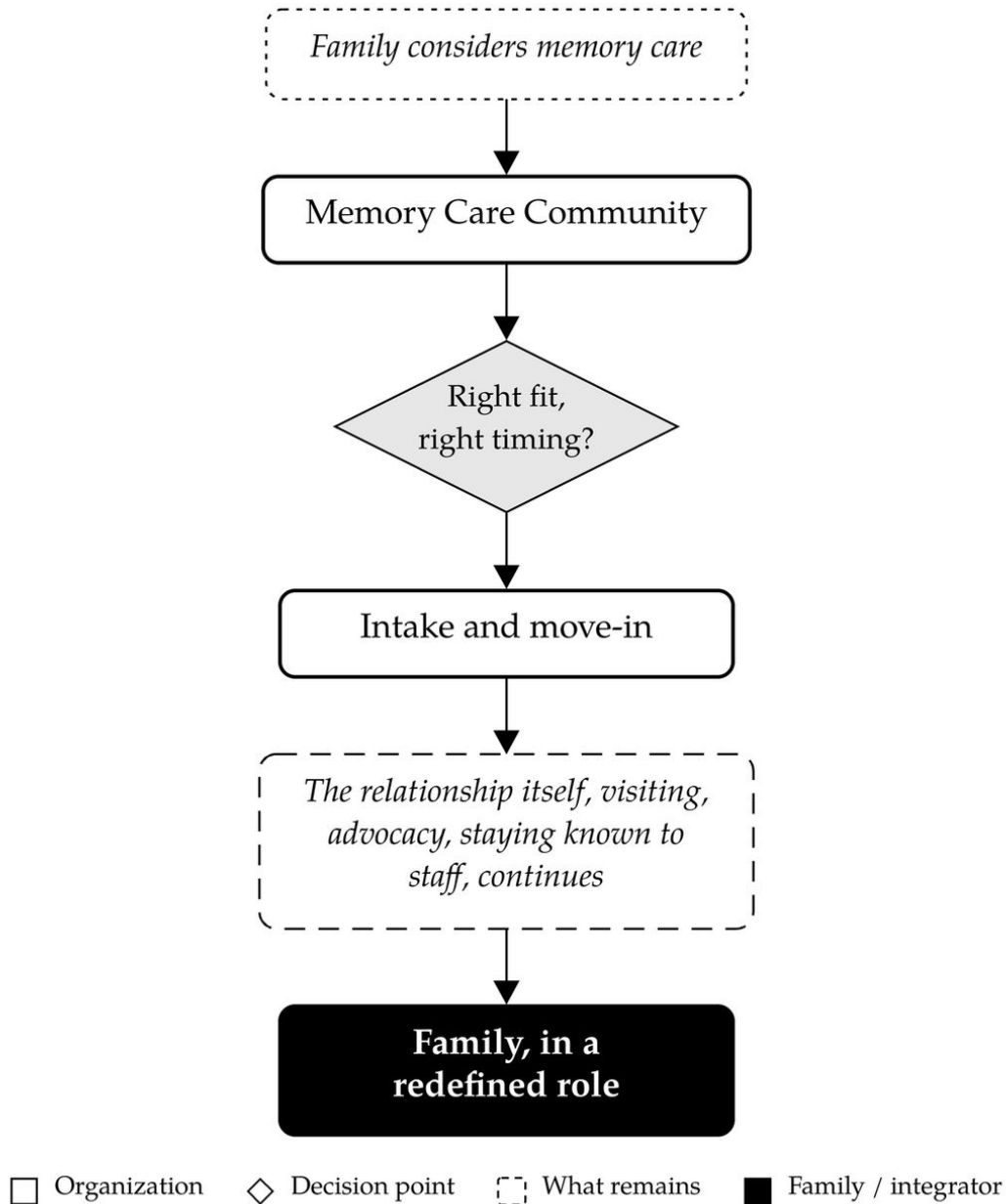
From an agency assignment to a trusted routine



□ Organization ◇ Decision point [] What remains ■ Family / integrator

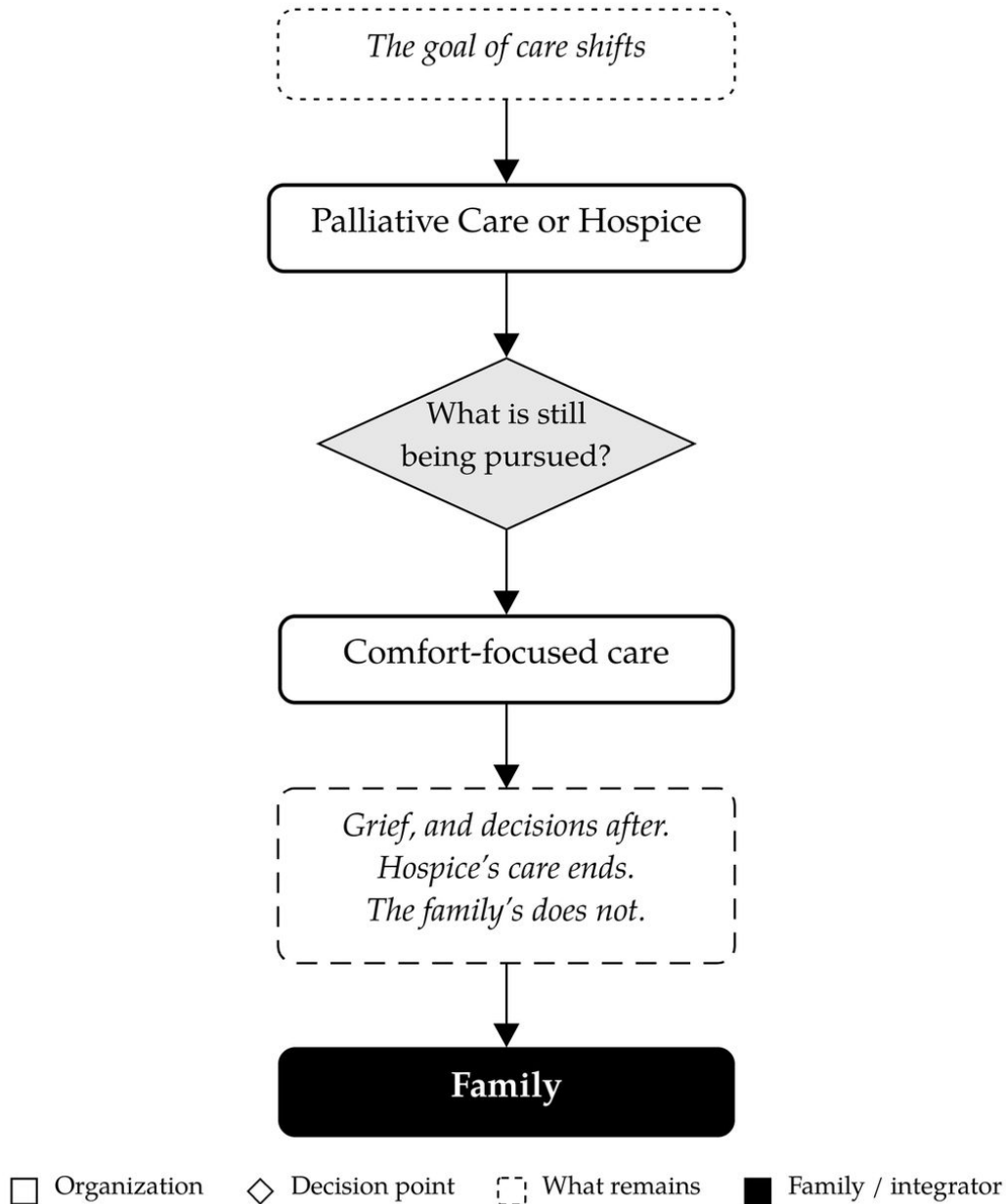
Memory Care

From a hard decision to a redefined family role



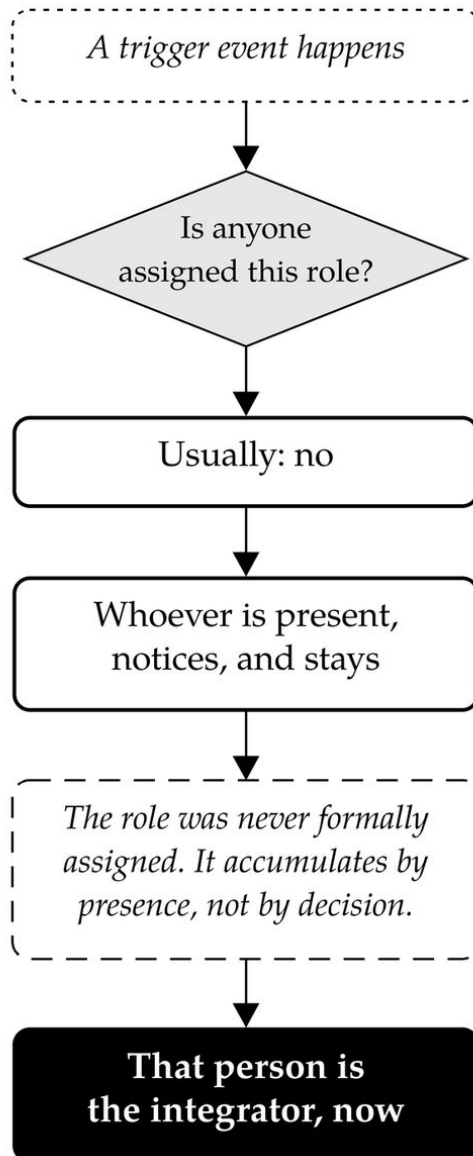
End-of-Life

From a shift in goals to grief that outlasts the care team



Becoming the Integrator

How the role gets filled, almost always without a decision



□ Organization ◇ Decision point [] What remains ■ Family / integrator

Map Your Own Arrangement

The maps in the book show seven common journeys. This page is for yours. List every organization currently involved, what each one hands off, and where it stops.

Organization	What it hands off	Where it stops

WHAT CONVERGES ON THE FAMILY

Everything above stops somewhere. Write down what is left standing after all of it, and whose name is on it.

THE ONE THING TO FIX FIRST

Map Your Own Arrangement

The maps in the book show seven common journeys. This page is for yours. List every organization currently involved, what each one hands off, and where it stops.

Organization	What it hands off	Where it stops

WHAT CONVERGES ON THE FAMILY

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THE ONE THING TO FIX FIRST

Index of Worksheets

The Next-of-Kin Box	8
Emergency Information	10
Care Team Directory	11
Medications and Allergies (2 copies)	12
Medical History Summary	14
What a Good Day Looks Like	15
Document Locator	17
Discharge Day	18
Family Care Notebook	21
Observation Log (6 copies)	22
Medication Reconciliation (3 copies)	28
Who Owns Continuity? (2 copies)	32
Dividing the Work (2 copies)	34
Family Communication Plan	36
Family Meeting and Decision Log (3 copies)	37
Primary Caregiver Backup Plan	40
Residual Outcome Worksheet (2 copies)	41
Operational Reliability Check-In (2 copies)	43
Care Coordination Grid (6 copies)	45
Care Continuum at a Glance	52
Five Questions for Any Provider	53
Appointment and Transition Prep	54
What This Organization Owns (3 copies)	56
Hiring In-Home Help	62
Care Agreement Terms	64
The First Phone Call	65
Financial Readiness	68
Paying for Care	69
Legal Readiness	70
Insurance and Benefits Inventory	71
Essential Documents	72
Home Safety Walkthrough	74
Transportation Plan	75
Housing Decision Worksheet	76
What This Is Costing You (3 copies)	78
Getting a Week Off	81

Index of Worksheets

When They Ask to Go Home	83
Goals of Care	85
What Happens After	86
System Maps	88
Map Your Own Arrangement (2 copies)	95

About the Series

The Operational Reliability Series is about a pattern that shows up wherever several organizations each do one bounded job well and something is still left over for whoever is standing there afterward.

The Weakest Link is a story about a family that nearly loses someone while every professional involved does their job correctly.

The Invisible Architecture is a story about senior care as a system, in three parts: a year in one family's life, a plain-language explanation of why the gap exists, and the handbook you are holding.

The Space Between: Institutional Architecture and Coordination Costs is a more formal treatment of the same argument, aimed at the people who design these systems.

Where These Worksheets Came From

Every page in this book was built for a real family, usually in the middle of a week that had already gone badly.

Stephen Deason owns OPA Home Care, a care coordination and skilled nursing company in the Atlanta area, licensed in Georgia as a Private Home Care Provider. The worksheets here are the ones his company kept rebuilding by hand, for one family and then another, until it made more sense to write them down properly.

If you are in Atlanta and want to talk through your situation, OPA is there. If they are not the right fit, they will tell you so and give you a name.

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