

The Long Goodbye

When Your Spouse Has Few Months to Live at 60+

A 4-Phase Framework for the Final Chapter of Marriage



SANJAY SHARMA

Author, Businessman & Coach

Book 10 of The Care Collection

Introduction: The Marriage Nobody Plans For

I have not been where you are.

But I have been close. I have sat across the table from someone who has. I have held her hand while she tried to explain. I have watched her look at her own hands the way people look at hands that have just been told to stop doing what they have always done.

I have also been the one who stayed behind.

This book is for the person who has just heard the words. The ones the doctor says carefully, the way doctors say them when they have said them many times before. "It's terminal." "A few months." "We should think about comfort now." "Have you thought about hospice." "There is no further treatment that would help."

This book is for the person who is about to live inside a different kind of marriage than the one they thought they were in. A marriage with a clock in the room. A marriage where the small things suddenly become unbearable, and the unbearable things become ordinary. A marriage where the two of you are closer than you have ever been and farther than you can stand, sometimes in the same hour.

I want to be careful with this book. I want to be useful to you without being sentimental, honest without being grim. I want to be the friend who has seen a few of these marriages through, who knows the things that matter and the things that don't, who can tell you what people wish they had done and what they wish they hadn't.

I have written this book because I have learned, slowly and against my will, that the end of a marriage is not a single event. It is a long season. It is a thousand small moments that you will not remember individually but that you will carry as a whole for the rest of your life. The way you handle this season will become part of who you are. The marriage you had at the end — the one you had when you knew it was ending — is the last marriage you will have. It deserves your attention.

I lost my wife to cancer after many years of marriage. I was her primary caregiver through the long middle. I sat with her in the quiet at the end. I held

her hand when the last breath came. I have lived the first hours and the first year and the first decade of the after. I know the road you are about to walk.

I do not have all the answers. Some of the things that happen in the last months of a marriage cannot be answered. They can only be witnessed.

But I have learned a few things. I have collected them from my own marriage, from other marriages I have watched, from the people I have talked to in the years since, and from the research that exists about end of life, palliative care, anticipatory grief, and widowhood.

I want to share what I have learned.

What This Book Is

This book is a practical guide to the final months of a marriage. It is not a religious book. It is not a self-help book. It is a guidebook — the kind of book a friend might write for you if your friend had been through this and you had not.

It has four parts, one for each of the four phases of this season:

- Part I: The Day They Tell You** — the diagnosis, the first days, the first decisions
- Part II: The Long Middle** — the weeks and months of treatment, daily life, and marriage under stress
- Part III: The Quiet** — the acceptance, the final weeks, the saying goodbye
- Part IV: The Goodbye** — the last days, the last breath, the first days alone

It also has a short Epilogue for the after — the year that follows — and five bonus toolkits you can use at any stage. The toolkits are practical. They have worksheets. You do not have to use them in order. Use what you need when you need it.

What This Book Is Not

This book is not going to tell you how to feel. Grief is not a problem to be solved. Love is not a strategy. Death is not a lesson.

This book is not going to give you the right words. There are no right words. There are only the words that come out of your mouth on the day you need them, and they will be enough.

This book is not going to tell you to be strong, or to be positive, or to make every moment count. Some moments you will not want to count. Some moments you will be too tired to count. Some moments you will be too angry

to count. That is normal. That is allowed.

A Note on the Word "Spouse"

I have used "spouse" throughout this book, not "husband" or "wife." The person reading this book might be the one who is dying or the one who is staying behind. The marriage at end of life does not have a gender. The work of caring does not have a gender. The grief that follows does not have a gender. The book is for both of you.

I have used "they" for the dying spouse in case studies for the same reason. In a few of the stories, you will see a name. That name is a person. That person is also you, if your spouse is named that. That person is also not you. These are real stories, lightly fictionalized, but the feelings are universal.

A Note on Timing

This book was written for a spouse who has been told there are "a few months." That can be one month. That can be three months. That can be six months. That can be a year. The framework here works for all of those timeframes.

If you have just been told, this book is for you. If you have been in this for a while, this book is for you. If you are reading this in the after, this book is for you too — the parts that don't apply, skip. The parts that do, sit with them.

A Note on Reading

You do not have to read this book in order. You do not have to read it at all if you do not want to. You do not have to finish any chapter you start. You are allowed to put the book down. You are allowed to come back to it. You are allowed to read only the parts that help and leave the rest.

You are in charge.

The marriage is still yours.

A Final Note

I want to say one thing before we begin.

You are not failing.

Whatever you are doing right now — whatever you are not doing — you are not failing. There is no right way to do this. There are people who will tell you there is. They are wrong. The right way to do this is the way that lets you and your spouse still recognize each other at the end.

If you are reading this book, you are trying. That is enough.

Let us begin.

Part I: The Day They Tell You

Chapter 1: The Word That Changes Everything

There is a moment. You will know it when it comes. The doctor says something, or you read something in a chart, or you see a scan, and the world becomes two versions of itself. The version that was true until that moment, and the version that is true after. The line between the two is the moment. It is the moment the marriage you had becomes the marriage you have.

For some of you, this moment is sudden. An accident. A stroke. A heart attack that doesn't end the way the movies do. For most of you, this moment is slow. A scan that has been showing something for a while. A biopsy that came back. A conversation with a doctor that started about one thing and ended about another.

Either way, the moment is the same. The doctor — or the test, or the body itself — has said: there is a clock. The clock has a number. The number is "a few months." Or "a year." Or less. The number is a guess, but it is a guess with gravity.

This chapter is about that moment. About what happens in the hours and days after. About how the marriage changes instantly, and about what the two of you can do in the first 72 hours to set the tone for what comes next.

Chapter at a Glance

- The 5 Things to Do in the First 72 Hours (Scorecard)
- The 3 Things Couples Get Wrong in the First 24 Hours
- Why the Second Conversation Matters More Than the First
- The 5 Things to Say — and 5 Things Not to Say — to Each Other
- The Scorecard: How Are We Doing So Far?

- Key Terms: Terminal, Palliative, Hospice, Prognosis, End-of-Life Care
- Reflection Questions for the Two of You
- Action for This Week: The First Conversation

The 5 Things to Do in the First 72 Hours

When the word lands, the first 72 hours are not a time for big decisions. They are a time for small things that set the tone. The decisions will come. The research will come. The second opinions will come. The next three to six months will come. But in the first 72 hours, the most important things are these:

- 1. Be together.** Not on the phone with family, not in the doctor's office with the specialist, not on the internet looking for the cure. Together. In the same room. The first 24 hours are not for action. They are for being in the same room with each other while the news becomes real.
- 2. Sleep.** Not plan. Not research. Not "have the conversation." Sleep. The news will still be there tomorrow. The clarity will be better with sleep. Many couples report that the night of the diagnosis is the night they cannot sleep, and that the day after is the day they cannot think. The way to push back on this is to take a sleeping pill if you need to. Or to ask the doctor for one. Or to just commit to going to bed even if you do not think you will sleep. The body needs rest. The mind needs rest.
- 3. Tell one person.** Not everyone. Not yet. One person. The one you trust most. The one who will not panic. The one who will not immediately start looking for cures. The one who will sit with you and not need to fix anything. Tell that person. Let them help you figure out who else to tell and when. Many couples in this position make the mistake of telling everyone in the first 48 hours, and they spend the next two weeks managing other people's grief instead of their own.
- 4. Write down what the doctor said.** Not your feelings about what the doctor said. What the doctor said. The words. The number. The timeline. The recommended next steps. The names of the medications. The names of the specialists. The date of the next appointment. You will not remember this clearly tomorrow. You will remember it less clearly in a week. Write it down. Take a notebook to the appointment. Or use the voice memo on your phone. Or have your spouse write while you listen. The point is that this information is now part of your life and you will need to refer back to it.

- 5. Have one small ordinary moment.** Eat a meal. Take a walk around the block. Watch a show you both like. Hold hands. Make the bed. Do one small thing that is part of your ordinary life. This is not about distraction. This is about reminding yourselves, in the middle of the worst moment, that the marriage is still here. The marriage is the ordinary. The marriage is the meal, the walk, the show, the bed. The illness is something that is happening to the marriage. The marriage is still the marriage.

The 3 Things Couples Get Wrong in the First 24 Hours

In my conversations with people who have lived through this, three patterns come up again and again. The first 24 hours are a vulnerable time. Couples make these mistakes not because they are weak, but because they are in shock. Knowing about them in advance can help you avoid them.

- Mistake 1: Trying to be strong for the other person.** This is the most common mistake. One spouse tries to hide the grief from the other. They think they are protecting the other person. They are not. They are putting a wall between the two of you at the exact moment when you need to be on the same side of the wall. The diagnosis is happening to both of you. The grief is happening to both of you. Hiding it doesn't protect them — it just means they are alone with theirs. Be weak together. Cry together. Be afraid together. You have time to be strong later. In the first 24 hours, be honest.

- Mistake 2: Going to war with the disease immediately.** Many spouses, especially the well one, respond to the diagnosis by becoming a general. They will research. They will get second opinions. They will find clinical trials. They will look for the cure. They will fight. The instinct is right — to do something. But the timing is wrong. In the first 24 hours, before the well spouse has fully processed the news, the spouse who is dying often feels like a project, not a person. The fighter is trying to save them. The one being saved feels like they have already been written off. Slow down. There is time. The first 24 hours are for being together, not for waging war.

- Mistake 3: Trying to have the big conversation right away.** Couples in this position often feel pressure to "have the conversation" — about what to do, about what the dying spouse wants, about how the rest of the time will be spent. That conversation matters. But it does not have to happen in the first 24 hours. In fact, it usually cannot happen in the first 24 hours, because both of you are still in shock. The big conversation will be better on day four or day

five, when the news has settled into your bones. In the first 24 hours, you do not have to have the conversation. You only have to be in the same room.

Why the Second Conversation Matters More Than the First

There will be many conversations about what comes next. There will be the conversation about treatment, the conversation about hospice, the conversation about who to tell, the conversation about money, the conversation about the funeral you do not want to plan yet, the conversation about what the dying spouse wants to do with the time they have left.

The first conversation — the one you have in the first day or two — is usually not the most important. It is the one that happens in shock. It is the one where the well spouse is fighting and the dying spouse is processing. It is the one where neither of you really knows what you want yet.

The second conversation, a few days later, is the one that matters. By then, the news has settled. By then, the first wave of grief has passed through. By then, you have had one or two good nights of sleep (or at least rested). By then, you have talked to a few people and have started to hear yourselves think.

The second conversation is the one where you actually decide. Not in a final way. Not in a complete way. But in a real way. The second conversation is when you say: this is what we are going to do next. This is what we want for the time we have. This is how we are going to be with each other.

Plan for the second conversation. Do not try to have it in the first 24 hours. Do not try to have it in the first 72 hours. Have it when you can both sit with each other and know that you are not deciding everything, just deciding the next thing.

The 5 Things to Say — and 5 Things Not to Say — to Each Other

The instinct in the first 24 hours is to say the big things. The things you have been meaning to say. The things you have not said in 30 years of marriage. The things you thought you would have more time to say.

Some of those big things are right to say. Many of them are wrong to say in the first 24 hours, because the first 24 hours are not a time for big things. They are a time for small honest things.

The 5 Things to Say in the First 72 Hours

- 1. "I am here."** Not "I am here for you" — that is for the caregiver, not the spouse. Just "I am here." Three words. They mean: I am not going anywhere. They mean: you are not alone. They mean: we are in this together.
- 2. "I don't know what to say."** This is honest. It is what you are feeling. And it gives the other person permission to also not know what to say. So many couples in this position feel pressure to have the right words. The right words are: "I don't know what to say." That is the right words.
- 3. "I love you."** Not the big version. The small one. The one you say without thinking. The one that is true. Say it. Even if you have said it a thousand times. Say it again. It is the most important sentence in your marriage right now.
- 4. "What do you need right now?"** Not "what do you need" in the abstract. "What do you need right now" in this hour, this afternoon, this evening. Do you need to be alone? Do you need to be held? Do you need to be distracted? Do you need to talk? Do you need to cry? The question is small. The question is specific. The answer is usually small too.
- 5. "We will figure this out."** Not "I will fix this." Not "We will beat this." Just "we will figure this out." It is honest. You don't know yet what figuring it out will look like. But you will figure it out. You have figured out other things in your marriage. You will figure this out too.

The 5 Things NOT to Say in the First 72 Hours

- 1. Don't say "we will beat this" or "we will fight this" unless you mean it.** Most people say it because they don't know what else to say. The person who is dying often hears it as: I am not allowed to die. I am not allowed to give up. I have to fight. If you say it, mean it. If you don't, say something else.
- 2. Don't say "I can't live without you."** This is the most common thing spouses say in the first 24 hours. It is said with love. It is heard as pressure. The person who is dying now has to manage your grief in addition to their own. Many dying spouses report that the worst part of the first 24 hours was their spouse's grief, not their own. Save "I can't live without you" for a few days later, when the well spouse has more support.
- 3. Don't say "you have to be positive" or "you have to fight."** The dying spouse gets to feel whatever they feel. They get to be sad. They get to be scared. They get to be angry. They get to give up on a Tuesday and be hopeful on a Wednesday. Your job is not to manage their emotions. Your job is to be with them while they have their emotions.

- 4. Don't say "we don't have to talk about it right now."** This sounds kind. It usually means you cannot handle the conversation. But the dying spouse often wants to talk, and the spouse who says "we don't have to" is taking that away. If you can't handle it, say "I am not ready to talk about it right now, but I want to when I can." That is honest. It opens the door. It does not shut it.

- 5. Don't say "call me if you need anything" to other people and then be unavailable.** The first 72 hours is when other people will offer help. Take the help. Let someone bring dinner. Let someone take the dog. Let someone drive you to the appointment. This is not the time to be polite. This is the time to accept that you cannot do this alone.

The Scorecard: How Are We Doing So Far?

Use this in the first week. Both of you. Take turns answering. Be honest.

| Question | Score (1-5) |

|---|---|

| We are spending time together, not on phones or tasks | /5 |

| We are both sleeping at least a few hours | /5 |

| We have told one trusted person | /5 |

| We have written down what the doctor said | /5 |

| We have had one small ordinary moment | /5 |

| We have not tried to have the big conversation in the first 24 hours | /5 |

| We are not pretending to be strong for the other | /5 |

| We have said "I love you" at least once | /5 |

| We are not pressuring each other to feel a certain way | /5 |

| We have accepted one offer of help | /5 |

- Total:** /50

- Interpreting your score:**

- 40-50: You are doing the first 72 hours well. The marriage is intact.

- 30-39: You are doing okay. Some patterns to watch. Use the toolkits.

- 20-29: You are struggling. Reach out to a counselor, a chaplain, a friend, a family member.

- Under 20: You need help. The marriage is at risk. The first 72 hours are not a time to white-knuckle it.

Key Terms

These are the words the doctor will use in the first 72 hours. Knowing them in advance helps you not be overwhelmed by them.

- **Terminal**: The illness cannot be cured. Treatment is no longer aimed at cure. This is not the same as "immediate." Terminal often means months.
- **Palliative**: Treatment aimed at comfort, not cure. Pain management, symptom control, quality of life. Palliative care is not the same as end-of-life care — it can start much earlier.
- **Hospice**: A specific kind of palliative care, usually for the last 6 months of life. Hospice is a philosophy and often a service. It can be at home, in a facility, or in a hospital.
- **Prognosis**: The doctor's estimate of how the illness will progress. Often given in ranges (3-6 months, 6-12 months). Doctors are usually cautious — they tend to under-estimate.
- **End-of-Life Care**: The umbrella term for care when someone is dying. Includes palliative, hospice, and the medical and emotional support around it.

Reflection Questions for the Two of You

Take turns. Listen more than you speak. There are no right answers. There are only your answers.

1. What is one thing you are most afraid of right now?
2. What is one thing the other person has done in the last 24 hours that has helped?
3. What is one thing the other person has done in the last 24 hours that has not helped?
4. Is there anyone you both want to be with in the next 48 hours? Anyone you both do not want to be with?
5. Is there a small ordinary thing you want to do together in the next 48 hours? (Walk, meal, show, anything.)
6. What do you each need most right now — to be held, to be alone, to be distracted, to talk, to cry, to sleep?

Action for This Week: The First Conversation

Within the next 7 days, find a time when you are both rested and alone. Not in a doctor's office. Not with family around. Not in bed at night. A Saturday

morning, or an afternoon, or a quiet evening. Sit together. Make tea or coffee.

The first conversation has only one purpose. It is not to decide everything. It is to decide the next thing. Use these questions:

- What did the doctor say, in our own words?
- What is the next appointment, and what is it for?
- Who do we want to tell, and when?
- What do we want for the next week?
- What is one thing we want to do together in the next month?
- What do we each need from the other in the next week?

You do not have to answer all of these. You do not have to answer them in order. You do not have to write anything down unless you want to. The point is to be in the same room and start the next step.

The first conversation will be hard. It will be quiet. It will be the first of many. It is not the last conversation. It is the first one that is not the diagnosis itself.

After it, you will both feel a little lighter. Not happy — lighter. Like a small weight has been moved from one shoulder to a table. The weight is not gone. It is just somewhere you can both see it.

That is enough for the first week.

A Closing Word for This Chapter

The day they tell you is a day that splits your marriage in two. There is the marriage before the words and the marriage after the words. You will be tempted to try to live in the marriage before the words. You will want to pretend the words did not land. The words did land. The marriage after the words is the marriage you have now.

The good news is this: the marriage after the words is not worse than the marriage before. It is different. It is more honest. It is more present. It is the marriage you have been building your whole life without knowing it — the marriage that knows what matters.

In the chapters that follow, we will walk through the rest of this season. The long middle. The quiet. The goodbye. The after. You do not have to read them now. You can come back when you are ready. Or you can read them in the middle of the night, when sleep is not coming. The book will be here.

For now, the first 72 hours. Be together. Sleep. Tell one person. Write it down. Have one small ordinary moment.

You are not failing. You are beginning.

Chapter 2: The First 48 Hours

The first 24 hours are about being together. The next 24 are about beginning. The first 48 hours together are the time when the news moves from being a thing that happened to you to being a thing you are doing something about. The diagnosis is in your body. Now you have to put it in your life.

This chapter is about the practical work of the first 48 hours. Not the emotional work — that will continue for months. The practical work. The phone calls. The questions to ask. The decisions to make and the decisions to defer. The people to tell and the people to wait on. The small acts of administration that, in the first 48 hours, are a way of caring for each other.

If Chapter 1 was about being, Chapter 2 is about doing. They are not in tension. The doing serves the being. The phone calls and the questions are not a way to avoid the feeling. They are a way of taking care of the person you are feeling with.

Chapter at a Glance

- The 6 Decisions to Make in the First 48 Hours (Scorecard)
- Who to Tell First, and When to Tell Them
- The 8 Questions to Ask the Doctor at the Next Appointment
- The Second Appointment: Getting a Second Opinion Without Losing a Week
- The 5 Things to Set Up in the First 48 Hours
- The 3 Things to Defer (You Don't Have to Decide Yet)
- The Scorecard: How Are We Doing on Day 2?
- Key Terms: Second Opinion, Palliative Care, Advance Directive, Healthcare Proxy
- Reflection Questions for the Two of You
- Action for This Week: The Three Lists

The 6 Decisions to Make in the First 48 Hours

The first 48 hours have six practical decisions. None of them are the big decisions. None of them are about treatment or hospice or how the rest of the time will be spent. They are the small decisions that make the next weeks possible.

- Decision 1: Who is the medical point person?*** In most marriages, one spouse has been the one who tracks the appointments, the medications, the test results. The other has trusted that person to handle it. With a terminal diagnosis, this changes. Both of you need to be able to talk to the medical team. Pick one of you to be the primary point person for appointments, but make sure the other has full access to the information. Most medical systems have a patient portal. Get the well spouse on it. Get the login. Know how to find the test results. This is a small act of love that will matter in the long middle.

- Decision 2: What is the next appointment, and what is it for?*** Within 48 hours, you should have clarity on what happens next. Is there a follow-up with the diagnosing doctor? Is there a referral to a specialist? Is there a test that needs to be scheduled? Write down the date, the time, the location, the doctor, and what it is for. Put it on the calendar. If the medical team does not have a follow-up scheduled, call and ask for one. You should not have to wait more than a week after the diagnosis to have a plan.

- Decision 3: What is the one question you need answered first?*** You will have a hundred questions. You will not be able to get them all answered in one appointment. Pick the one that is keeping you up at night. The one that is making the next day impossible. Write it down. Bring it to the next appointment. The doctor is there to answer your question, not to give you a survey of the disease. Your question. The most important one.

- Decision 4: Who is the one trusted person who will be there for the next 72 hours?*** You told someone in the first 24 hours. Now you need to ask that person for a specific thing. Not "let me know if you need anything." A specific thing. "Can you come over tomorrow afternoon for two hours so I can nap." "Can you take the dog for the weekend." "Can you come with us to the next appointment and take notes." "Can you call me every evening for the next week." The people who love you want to help. They need you to tell them how.

- Decision 5: What is the one small ordinary thing you are going to do together in the next 48 hours?*** You already did this in the first 24. Do it again. Eat a meal. Take a walk. Make the bed. Watch a show. Have tea. The illness is a thing that is happening. The marriage is a thing you are still doing. The ordinary is how you hold onto the marriage. Do one ordinary thing in the next

48 hours, even if it feels impossible.

- Decision 6: When are you going to tell the rest of the people who need to be told?*** You told one person. The rest will come. In the next week, the news will need to reach the children, the parents, the siblings, the close friends, the colleagues. You do not have to tell everyone in the first 48 hours. You do have to decide when you will. Make a list. Decide who tells whom. Pick a window — "we will tell the kids by Sunday" — and then tell them. The ambiguity of "we will tell people eventually" is worse than the act of telling.

Who to Tell First, and When to Tell Them

There is an order to telling people. The order is not always the order of your relationships. The order is: the people who can hold the news without needing to be held.

- Tell first:**
- The one person you trust most (already told in first 24 hours)
- The adult children (if you have them)
- The closest friend or sibling who is emotionally stable
- Tell second (within the first week):**
- Other family members
- Closer friends
- Anyone the dying spouse wants to know
- Tell third (within the first two weeks):**
- Extended family
- Work colleagues (only as needed for practical reasons)
- Wider friend network
- Tell much later (or not at all):**
- Acquaintances
- The "well-meaning" friends who will take the news harder than you
- The people who will want to fix it, advise you, or be angry

You are not obligated to tell everyone. You are not obligated to tell anyone except the people who need to know for practical reasons. The dying spouse gets to decide who they want to know and who they don't. The well spouse gets to decide who they want to lean on. The people you don't tell are not being left

out. They are being protected from a weight they didn't ask to carry.

The 8 Questions to Ask the Doctor at the Next Appointment

When you go to the next appointment — usually within a week of the diagnosis — bring these questions. Write down the answers. Don't trust yourself to remember.

- 1. What is the diagnosis, in one sentence?*** If you are still not sure what the doctor said, ask. "What is the diagnosis, in one sentence." Don't leave without this.
- 2. What is the prognosis, in ranges?*** "How long do people with this condition typically live, with treatment." Doctors often won't give a specific number, but they will give a range. Get the range.
- 3. What are the treatment options, and what does each do?*** Not "what should we do" — "what are the options." The doctor may have a recommendation, but you are allowed to know all the options.
- 4. What does the treatment look like in daily life?*** "If we do this, what does our week look like." Some treatments are daily pills. Some are weekly infusions. Some are surgeries. Some are hospice. You need to know what you are signing up for.
- 5. What are the side effects, in real terms?*** "What will my spouse feel like." Nausea, fatigue, hair loss, pain, cognitive changes. Get the real list, not the medical list.
- 6. What is the one thing we should do this week?*** Not the one thing you should do this year. This week. The next step. The thing that is most urgent. The thing that will set the tone for the next weeks.
- 7. Is there a clinical trial or alternative therapy we should consider?*** Doctors have different comfort levels with this question. Ask it. Get the answer. If the answer is no, get the doctor's reasoning. If the answer is yes, get the details.
- 8. Who do we call if something happens in the middle of the night?*** This is the practical question. The one that matters at 2 a.m. on a Tuesday. Who do you call if there is a sudden change, a new symptom, an emergency. Get the name. Get the number. Put it on the fridge.

The Second Appointment: Getting a Second Opinion Without Losing a Week

The instinct after a terminal diagnosis is to get a second opinion. This is a good instinct. The question is how to do it without losing a week of the time you have.

In most major medical centers, getting a second opinion is fast. Many cancer centers have a "second opinion clinic" that can see you within days. The treating oncologist often encourages it. The insurance often pays for it.

A few principles for getting a second opinion without losing a week:

- **Ask your current doctor to recommend a second opinion.** They will have colleagues at other centers. They will know who to call. This is not a betrayal. This is good practice.
- **Bring everything.** Pathology slides, scans, the actual imaging files (not just the report), the doctor's notes, the list of medications. The second opinion is only as good as the materials you bring.
- **Ask specific questions.** "Is this the right diagnosis?" "Is this the right treatment plan?" "Are there other options we should consider?" "What would you do if this were your spouse / parent / child?"
- **Don't start treatment until you've had the second opinion, unless waiting is medically dangerous.** If the doctor says "we need to start this week or you will die," start. If they say "we can start in two weeks and that will not change anything," wait. Use the two weeks for the second opinion.
- **If the second opinion agrees, you have a plan.** If it disagrees, you have a third opinion to get. Most second opinions agree with the first. The point of the second opinion is not to find a different answer. The point is to feel confident in the answer you have.

The 5 Things to Set Up in the First 48 Hours

- 1. A shared calendar. Both of you need to know what is happening. Put the medical appointments, the daily rituals, the family visits, the "ordinary time" on a shared calendar. Google Calendar, a paper calendar on the fridge, whatever works.
- 2. A place to write things down. A notebook. A file on the computer. A specific place where you both know the questions, the answers, the medications, the symptoms, the things to ask the doctor, the things to

remember. One place. Both of you know where it is.

- 3. A communication system with the one trusted person.** A group text, a daily call, a "what we need today" email. The trusted person is on the team. They need to know what is happening without being asked every time.
- 4. A small emergency plan.** What to do if there is a fall, a sudden symptom, a new pain. Who to call. What number. Where the medications are. What the medications are for. The plan doesn't have to be perfect. It has to be written down somewhere.
- 5. A way to ask for help.** A shared note, a phone tree, a meal train, a "things we need this week" list. People will ask what they can do. The answer is usually "I don't know." The way to fix this is to have a list ready, and to have someone managing the list so you don't have to. The trusted person can be the list manager.

The 3 Things to Defer (You Don't Have to Decide Yet)

In the first 48 hours, you will be tempted to decide the big things. You will want to decide about treatment, about hospice, about the long-term plan. You don't have to decide these now. You have weeks to decide them. The first 48 hours are for the small things.

- Defer 1: The treatment decision.** Unless the doctor says "we need to start this week or you will die," you have time. The treatment plan can wait until you've had a second opinion, until you've processed the news, until you've had the second conversation with your spouse. Defer to day 5 or day 7. The treatment will still be there.
- Defer 2: The hospice decision.** Hospice is a decision you don't have to make now. Most hospice referrals are made weeks or months after the diagnosis, not days. The first 48 hours are not the time. When the time comes, you will know. You will be ready. Defer.
- Defer 3: The "what to do with the time" decision.** The dying spouse often wants to make a list. A bucket list. A "things I want to do before I die." This is healthy. It is also a decision that can wait. The list will be there. The dreams will be there. The trip to the place you always wanted to go can be planned in week 2, not in hour 48. For now, the only thing to do is to be in the same room.

The Scorecard: How Are We Doing on Day 2?

Use this on day 2 or day 3. Both of you. Take turns.

| Question | Score (1-5) |

|---|---|

| We have identified the next medical appointment | /5 |

| We have a list of questions to ask the doctor | /5 |

| We have identified our one trusted person for support | /5 |

| We have decided who to tell in the next week | /5 |

| We have a shared place to write things down | /5 |

| We have a small emergency plan written down | /5 |

| We are not trying to make big decisions yet | /5 |

| We have asked for and accepted one offer of help | /5 |

| We have slept at least 5 hours in the last 24 | /5 |

| We have had one small ordinary moment today | /5 |

- Total:** /50

- Interpreting your score:**

- 40-50: The first 48 hours are in good shape. The practical work is done.

- 30-39: Some patterns to watch. The toolkits will help.

- 20-29: You are behind on the practical work. Pick three of the items and do them today.

- Under 20: The first 48 hours are slipping. Get help from the trusted person today.

Key Terms

- **Second Opinion**: A second doctor reviewing the diagnosis and treatment plan. Standard practice. Not a sign of distrust. Most oncologists expect it.

- **Palliative Care**: Medical care focused on quality of life, not cure. Can begin at diagnosis and continue through treatment. Different from hospice.

- **Advance Directive**: A legal document stating what medical treatment the person wants if they cannot speak for themselves. Most people don't have one. The first 48 hours is a good time to think about this.

- **Healthcare Proxy**: A person designated to make medical decisions if the patient cannot. Usually the spouse. If not, named in the advance directive.

Reflection Questions for the Two of You

Take turns. Listen more than you speak.

1. What is one thing the medical team said that you want to understand better?
2. What is one person you want to tell in the next 48 hours?
3. What is one small ordinary thing you want to do in the next 48 hours?
4. What is one thing the trusted person could do to help that is specific?
5. What is one question you want to ask the doctor at the next appointment?
6. What is one thing you are most afraid of asking the doctor?

Action for This Week: The Three Lists

Within the next 7 days, sit down together — not at the doctor, not in crisis, just on a regular afternoon — and make three lists. Put them on paper. Put them on the fridge. Look at them again in a week.

- List 1: Questions for the Doctor**

Every question you can think of. Don't filter. Don't organize. Just write them as they come. Bring this list to every appointment. Cross off questions as they get answered. Add new ones.

- List 2: People to Tell in the Next Two Weeks**

Every person you think should know. Group them if it helps — family, close friends, work, etc. Beside each name, write who will tell them. Beside that, write when. The list is not a commitment. It is a plan. The plan can change. But having a plan is better than having no plan.

- List 3: Small Things We Want to Do in the Next 30 Days**

This is not a bucket list. It is the list of small ordinary things. The walk. The meal at the favorite restaurant. The phone call to the friend. The afternoon in the garden. The show you've been meaning to watch. The book on the bedside table. These are the things the marriage needs now — small, ordinary, present. They are not big. They are not expensive. They are the days.

A Closing Word for This Chapter

The first 48 hours are about setting the practical foundation. The medical plan. The communication. The trusted person. The lists. These are not the work of being married at end of life. They are the work of being married at end of life with some structure. The structure is what lets the rest of the marriage happen.

In the chapters that follow, we will move into the long middle — the weeks and months of treatment, of daily life, of the marriage under stress. We will talk about intimacy, about money, about the conversations that become harder as the illness goes on. We will talk about the things that couples wish they had done and the things they wish they had not.

But the foundation is here. The first 48 hours are done. The lists are made. The trusted person is in place. The next appointment is on the calendar. The marriage is still here.

You are not failing. You are beginning well.

Chapter 3: What the Doctors Won't Tell You

The medical team that gives you the diagnosis is, in most cases, the same medical team that will be with you through the next months. They are not villains. They are not heroes. They are people who have been trained to treat a disease, and they are now being asked to treat you. Both of those are hard.

This chapter is about the gap between what doctors know and what they say. It is not a complaint about doctors. It is a map of the things you can ask for that will make the medical part of this season more bearable. The doctors will do their best. Your job is to make sure the best is what you need.

Chapter at a Glance

- The 7 Things Doctors Know But Rarely Say Out Loud
- Why "A Few Months" Is a Range, Not a Number
- The Medical System's Blind Spots
- How to Read a Pathology Report in Plain English
- The 5 Questions to Ask If You Fear the Doctor Is Being Too Positive
- The 5 Questions to Ask If You Fear the Doctor Is Being Too Negative
- Case Study: Linda & James (ages 62/65)
- Scorecard: Are We Getting the Information We Need?
- Key Terms
- Reflection Questions

- Action for This Week: The 7-Day Medical Audit

The 7 Things Doctors Know But Rarely Say Out Loud

In the years I have spent around end-of-life care, I have heard the same seven statements from doctors, nurses, and hospice workers again and again. The statements are almost always true. The statements are almost never said. Here they are, plain:

- 1. "I have seen this before."** When the doctor tells you the diagnosis, they are telling you something they have seen many times. This is not comforting in the moment. It is, however, important. It means the doctor has a track record. It means they have watched people live with this for years, and they have watched people die of this in months. They know the range. They are not guessing. They have seen it before.
- 2. "I don't have a crystal ball."** When the doctor says "a few months," they are not making a precise prediction. They are giving you a range based on their experience with other patients. The range is useful. The specific number is not. Some people live longer than the doctor predicts. Some people die sooner. The doctor is rarely wrong about the general direction. They are often wrong about the specific number.
- 3. "There are things the treatment can do, and things it can't."** Doctors are trained to offer treatment. They are not trained to say "this treatment will not help." Most doctors will not say "stop treatment" until late in the game. They will offer options, and they will not always make clear which option has the best chance of helping. You have to ask. You have to ask specifically: "What does this treatment do? What does it not do? What are the chances it works? What does 'works' mean?"
- 4. "I am watching you more than I am telling you."** During the visits, the doctor is not just listening to your questions. They are watching how you walk, how you breathe, how you sit, how you answer. They are assessing your prognosis in real time. They will adjust their recommendations based on what they see. They do not always tell you this. They are not being deceptive. They are being clinical. But the conversations you have with them are not just about the words. They are about what they see.
- 5. "The numbers I quote are based on populations, not on you."** When the doctor says "the 5-year survival rate is X%," they are quoting a population statistic. The statistic is for 100 people like you. Some of those 100 will do

better. Some will do worse. The statistic is not a prediction about you. It is a description of a group. You are one person in the group, and the group is not you.

- 6. "There is a point where I will not be able to help."** This is the hardest one. Doctors are trained to treat. They are not always trained to recognize when treatment is no longer the answer. Some doctors see the end coming before others do. Some doctors will keep offering treatment even when they know it will not help. You may have to be the one to ask, gently, "Is there a point where we should consider stopping treatment?" The doctor will not be offended. They will, in many cases, be relieved that you asked.

- 7. "I am doing my best."** Most doctors, especially the ones who work in oncology, palliative care, and end-of-life medicine, are doing their best. They are also tired. They have been through this with other families. They have cried with other patients. They are not emotionless. They are also not able to be emotionally present with every family the way a friend can be. Your job is to find your emotional support outside the medical team. Your doctor's job is to give you the best medical care they can. Both of those jobs are real and both of those jobs are needed.

Why "A Few Months" Is a Range, Not a Number

When a doctor says "a few months," they are giving you a range. The range might be 1-3 months. It might be 3-6 months. It might be 6-12 months. The doctor is rarely making a precise prediction. They are giving you their best estimate based on their experience with patients like you.

This range is one of the hardest things to live with. The mind wants a number. "How long do I have?" is the most common question in this entire process, and the answer is almost always "we don't know exactly." The doctor will not lie to you. They will give you a range. They will give you their best guess. They will not be able to give you the specific number you want.

The reason this is hard is that the range is not actionable. "A few months" does not tell you what to do. It does not tell you whether to plan a trip, take a leave from work, sell the house, or have the conversation. It leaves you in the middle, unable to act, unable to wait, unable to know.

The way to live with this range is to commit to two things:

- First**, plan the next month. Not the next year. The next month. What do you want to do in the next 30 days? What conversations do you need to have in the next 30 days? What paperwork do you need to do in the next 30 days? What

small ordinary moments do you want to create in the next 30 days? Plan those. Do those. The next month is in the range. It is yours.

- Second**, revisit the plan every 30 days. If the range has shifted, the plan shifts. If the prognosis has changed, the plan changes. The plan is not a one-time thing. It is a rolling thing. Every 30 days, you ask: what is the next 30 days? And then you plan those 30 days.

This approach gives you a way to live with the uncertainty. The uncertainty does not go away. The way of being with the uncertainty is to plan only what you can plan and let the rest be.

The Medical System's Blind Spots

The medical system in most countries is built for acute care. It is built for the patient who has a problem, gets treatment, and goes home. It is not built for the patient who has a chronic, terminal illness and needs ongoing care for months or years.

The blind spots are real:

- The blind spot of time.** Doctors are usually given 15-20 minutes per appointment. In 15-20 minutes, they cannot answer all your questions, look at all your symptoms, do a full physical exam, and address your emotional state. They will prioritize what they can. The questions you don't ask are the questions they don't answer. Bring a list. Ask the most important questions first. Don't expect them to volunteer.

- The blind spot of home.** The doctor sees the patient in the office. The doctor does not see the patient at home. The doctor does not see what the dying spouse is like in the morning, or after a meal, or in the middle of the night. You, the well spouse, are the doctor's eyes at home. Tell the doctor what you see. The doctor will be able to adjust the treatment plan based on what you tell them.

- The blind spot of the family.** The doctor sees one patient. The doctor does not see the family. The doctor does not see the children, the siblings, the friends. The doctor does not know who is supporting the patient and who is not. You are the doctor's window into the family. Use it. Tell the doctor who is helping. Tell the doctor who is not. The doctor can help you find resources you don't know about.

- The blind spot of the long game.** The doctor thinks in appointments. The doctor thinks in test results. The doctor thinks in cycles of treatment. You are thinking in weeks and months. The doctor is not always able to zoom out and

see the long arc. You have to do that for them. You have to be the one who says, "We are tired. We are not sure we want to keep going to appointments. We want to know what you think." The doctor will be able to respond to that. They will not always bring it up themselves.

- The blind spot of grief.** The doctor is not trained to manage your grief. The doctor may be kind, may be sympathetic, may even cry with you. But the doctor's job is to treat the disease, not to treat your grief. Your grief needs to be treated by other people — by friends, by family, by a counselor, by a chaplain, by a hospice social worker. The medical system has these people. They are called different names. Ask for them. They are there.

How to Read a Pathology Report in Plain English

If your spouse has cancer, you will get a pathology report. The report will be in medical language. The report will look like a wall of words. You have a right to read it. You have a right to understand it. Here is what to look for:

- 1. The diagnosis.** Usually at the top. "Invasive ductal carcinoma" or "Stage IV pancreatic adenocarcinoma" or whatever the diagnosis is. Write it down. Look it up. Ask the doctor to explain it in plain English.
- 2. The grade.** How aggressive the cells are. Grade 1 is slow-growing. Grade 3 is fast-growing. The grade is a description, not a prediction.
- 3. The stage.** How far the disease has spread. Stage I is localized. Stage IV is metastatic. The stage is the most important number in the report. If you don't know the stage, ask.
- 4. The receptor status.** For some cancers (breast, prostate), the report will say things like ER+, PR+, HER2+. These are markers. They tell the doctor what treatments are likely to work. They are not good or bad in themselves. They are information.
- 5. The margins.** For surgical reports, the margins tell you whether all the cancer was removed. "Clear margins" means the surgeon got it all. "Positive margins" means some cancer cells are still at the edge of what was removed. The margins tell you if more surgery is needed.
- 6. The lymph nodes.** The report will often say how many lymph nodes were examined and how many had cancer cells. This is information about how far the disease has spread. The more nodes involved, the more serious the disease is likely to be.

You do not have to understand everything in the report. You have to know which questions to ask. Bring the report to the appointment. Point to the section. Ask: "What does this mean in plain English?"

The 5 Questions to Ask If You Fear the Doctor Is Being Too Positive

Sometimes the doctor is more optimistic than you are. The doctor may be hedging, or may be trying to give you hope, or may be clinically optimistic. Here are the questions to ask if you want to test the optimism:

1. "What is the worst-case scenario in your experience?" If the doctor cannot answer this, the doctor may be avoiding the truth.
2. "If this were your spouse, what would you be thinking right now?" A doctor will often answer this question more honestly than they will answer the direct question.
3. "What percentage of patients with this diagnosis are still alive in 1 year? In 5 years?" Numbers force honesty.
4. "What would tell you that the treatment is not working?" This question gives the doctor permission to talk about failure.
5. "Is there a point at which you would recommend stopping treatment?" If the doctor says no, ask: "Never?" The answer is usually "yes, at some point." The question is when.

The 5 Questions to Ask If You Fear the Doctor Is Being Too Negative

Sometimes the doctor is more pessimistic than you are. The doctor may be clinical, or may have seen the worst, or may be trying to prepare you. Here are the questions to ask if you want to test the pessimism:

1. "Are there patients with this diagnosis who have done better than the average? What did they have in common?" This question gives the doctor permission to talk about outliers.
2. "Is there anything I could do to improve the odds?" Diet, exercise, attitude, alternative therapies. The doctor may or may not have answers. The question opens the door.
3. "What is the best-case scenario in your experience?" If the doctor cannot answer this, the doctor may be avoiding hope.

4. "Are you familiar with the latest research? Has anything changed in the last 6-12 months?" This question checks whether the doctor is current.

5. "If you were in my position, would you get a second opinion?" The answer is almost always yes. The question gives you permission to do it.

Case Study: Linda & James (Ages 62/65)

Linda was 62. James was 65. They had been married for 38 years. Linda was a teacher. James was an engineer. They had two adult children, both out of state. They lived in a small house in the suburbs.

Linda was diagnosed with Stage IV pancreatic cancer in March. The doctor said "a few months." The doctor was right.

The first month was chaos. Linda and James told the children, told the siblings, told the friends. They went to four different doctors. They got four different opinions. They tried a clinical trial. The trial made Linda sick. James stopped working to be her full-time caregiver.

What Linda and James got right:

- They got a second opinion, and the second opinion agreed with the first.
- They asked the hard questions, and they got the hard answers.
- They accepted the truth of the diagnosis early, which gave them more time to use the time well.
- They used the time to say what needed to be said. They told their children what they meant to them. They forgave old wounds. They laughed a lot.

What Linda and James got wrong:

- They told too many people too quickly, and the managing of other people's grief became a second job.
- They didn't ask for help with the daily care until James was exhausted.
- They waited too long to talk to a hospice team. By the time they called, Linda was in her last 2 weeks.
- They didn't make the most of the "good months" early on because they were still trying to find a cure.

Linda died 7 months after the diagnosis. James describes the time as the hardest and the most meaningful of his life. He still lives in the small house in the suburbs. He has rebuilt a life. He is not the same. He is still married to Linda, in a different way.

Scorecard: Are We Getting the Information We Need?

| Question | Score (1-5) |

|---|---|

| Our doctor explains the diagnosis in plain English | /5 |

| Our doctor gives us a prognosis in ranges | /5 |

| We know the stage of the disease | /5 |

| We have asked about all treatment options | /5 |

| We have considered a second opinion | /5 |

| We know who to call in an emergency | /5 |

| Our doctor listens to our questions | /5 |

| Our doctor watches for the long game | /5 |

| We have asked about hospice / palliative care | /5 |

| We have a clear list of questions for the next appointment | /5 |

- Total:** /50

- Interpreting your score:**

- 40-50: You are getting good information. The medical team is working for you.

- 30-39: Some gaps. The questions in this chapter can help fill them.

- 20-29: You are missing key information. Use the 7-Day Medical Audit (below) to fill in the gaps.

- Under 20: The medical team is not giving you what you need. Consider switching doctors or getting a second opinion.

Key Terms

- **Oncologist**: Doctor who treats cancer

- **Pathology Report**: The lab report that describes the cells, the grade, the stage

- **Metastatic**: Cancer that has spread beyond the original site

- **Palliative Care**: Medical care for comfort and quality of life, not cure

- **Hospice**: Palliative care specifically for the end of life, usually the last 6 months

- ****Prognosis****: The doctor's estimate of the disease trajectory

Reflection Questions for the Two of You

1. What is one question you are afraid to ask the doctor?
2. What is one piece of information you have that the doctor does not have?
3. What is one thing the doctor has said that you want to understand better?
4. Do you trust the doctor to tell you the truth? Why or why not?
5. If you got bad news tomorrow, would you want to know right away or have time to prepare?

Action for This Week: The 7-Day Medical Audit

Over the next 7 days, do these 7 things:

- Day 1**: Get a copy of the most recent pathology report. Read it. Highlight the words you don't understand.
- Day 2**: Look up those words. Use the American Cancer Society, the National Cancer Institute (US), the NHS (UK), or any trusted source.
- Day 3**: Make a list of the top 3 questions you still have about the diagnosis.
- Day 4**: Call the doctor's office. Ask if the doctor can call you back to answer those 3 questions.
- Day 5**: Get the doctor's answer. Write it down.
- Day 6**: Make a list of all the medications the dying spouse is currently taking, including doses and times. Put it on the fridge. Bring a copy to every appointment.
- Day 7**: Decide if you want a second opinion. If yes, ask the doctor for a referral. If you are already getting treatment, ask if waiting for the second opinion is medically safe.

The 7-Day Medical Audit is the foundation. After it, you are not in the dark. You know what you know. You know what you don't know. You have a plan to find out.

A Closing Word

The medical system is not perfect. The doctors are not perfect. The information you get is not complete. You will have to do some of the work yourself. The good news is that you can. The 7-Day Medical Audit gives you a starting point. After it, the medical conversations are more focused. The questions are

sharper. The answers are clearer. The marriage is not in the dark.
You are not failing. You are getting informed.

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ABOUT THE AUTHOR

S. Shharma is the author of The Care Collection - books for couples in the second half of life, written by a man who lived the silence and survived it.

He lost his wife of many years to cancer. He was her primary caregiver through every stage of her illness. He held her hand in the hospital. He sat in the waiting room at 3 a.m. He learned the silence of a marriage the way you learn a language you never wanted to speak.

He is also a businessman, an M.Sc., an MBA, and an APSCM from the Indian Institute of Management (IIM) Calcutta, with thirty years in corporate management. But these are not credentials you need to trust him. The credentials that matter are the ones in the books.

The Care Collection is not about how to fix a marriage. The Care Collection is about how to live one - even when the marriage is quiet, even when one of you is sick, even when one of you is gone.

He lives in India. He writes from the perspective of someone who has been on every side of a marriage - the partner, the caregiver, and the one left behind.

THE CARE COLLECTION - 14 BOOKS BY S. SHHARMA

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Fade - Why friendships disappear in midlife and how to bring them back 14. Hum Ladte Nahi (Hinglish) - Shaadi ko wapas kholne ka 30-din ka plan (Indian edition)

CONNECT WITH S. SHHARMA

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ABOUT THE AUTHOR & THE 48-BOOK ECOSYSTEM

Navigating Human Pain across Health, Wealth, Relationships & Spirituality

About Sanjay Shharma (S. Sharma)

Sanjay Shharma is an author, entrepreneur, coach, and the founder of **Adorise Digital LLC**. Writing deeply compassionate, empathetic literature under the pen name **S. Sharma** for relationships and family care, and business architectures under **Sanjay Shharma**, his mission is to alleviate human pain across the four foundational pillars of life: Health, Wealth, Relationships, and Spirituality.

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