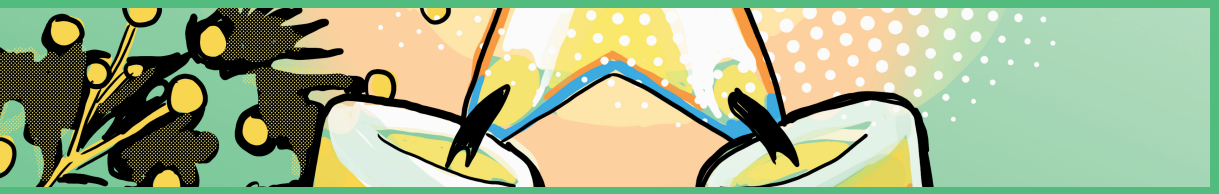
Chapter 4

Treatment considerations in sexually active patients living with schizophrenia

Explore Chapter **4**

This chapter explores how treatment may affect sexual well-being, intimacy, and relationships. It emphasizes the importance of identifying possible side effects, discussing personal priorities openly, and making treatment decisions collaboratively so that care supports both clinical stability and quality of life.



Mini-Glossary

Sexual functioning
A broad concept that includes desire, arousal, satisfaction, and emotional engagement in intimate relationships.

Prolactin
A hormone involved in reproductive and sexual functioning. Elevated levels may influence libido, menstrual cycles, and overall sexual well-being.

Hyperprolactinemia
A condition in which the level of prolactin in the blood is above the expected range, potentially affecting sexual function, fertility, and hormonal balance.

Treatment adherence
The extent to which a person follows the agreed treatment plan. It is closely linked to trust, communication, and perceived tolerability of treatment.

Side effects
Unintended effects of treatment that may influence physical, emotional, or sexual well-being.

Shared decision-making
A collaborative process in which clinicians and patients make treatment decisions together, based on medical evidence and personal preferences.

Therapeutic alliance
The relationship of trust and collaboration between a patient and clinician, which supports engagement and long-term outcomes.

Autonomy
The patient's right to make informed decisions about their own care, based on understanding and personal values.

Welcome to podcast #4

Treatment considerations in sexually active patients living with schizophrenia

*with **Elena Maurer,** Health Journalist, and*
***Dr. Lukas Stein**, Psychiatrist and Researcher*

Elena:

Welcome back to Living, Loving, Recovering.

In the previous chapter, we explored how body image and physical well-being shape confidence, relationships, and closeness.

Today, we take the next step, looking at something that often becomes part of that experience: treatment.

How does treatment influence intimacy, and how can these decisions be made in a way that respects both clinical needs and personal priorities?

Dr. Stein:

Thank you, Elena. These topics can be discussed openly, and in many cases concerns can be assessed and addressed.

Elena:

Many families may find it reassuring to know that these concerns can be discussed and addressed rather than simply accepted.

4.1 Why is sexual well-being part of recovery?

“When we address sexual well-being, we are not shifting attention away from symptom control. We are strengthening recovery.”

Elena:

Let me start with a very direct question. Some people might say,

“When someone has schizophrenia, shouldn’t we focus on symptom control first? Isn’t sexuality secondary?”

Dr. Stein:

Sexual functioning is not an optional add-on to recovery. It is closely connected to quality of life, identity, self-esteem, partnership stability, and long-term treatment engagement.

When we talk about recovery in schizophrenia, we no longer mean only “reducing hallucinations or delusions.” Modern psychiatric care also looks at:

- social functioning
- emotional well-being
- relational stability
- autonomy
- life satisfaction

Sexual well-being sits at the intersection of all of these. And because of that, it’s often one of the hardest things to talk about. In practice, this is often where patients struggle quietly. Some say, “*Everything is more stable, but I don’t feel like myself in my relationship anymore.*” Others say it more hesitantly:

“I didn’t want to complain… because in many ways things are better.”

Research consistently shows that sexual difficulties are common among people living with schizophrenia. These difficulties can include reduced desire, problems with arousal, difficulties with orgasm, or emotional detachment during intimacy. **When these concerns are ignored, they can lead to frustration, lowered self-confidence, relationship strain, and sometimes silent non-adherence to medication.**

From a clinical perspective, we also see very clearly how much this matters in everyday life.

When sexual well-being is affected, it often shows up in different ways, such as how satisfied someone feels overall, how stable a relationship feels, and even how motivated someone is to continue treatment.

We also know that individuals who feel their intimate life is respected and supported are more likely to remain engaged in care and communicate openly with clinicians.

So no, sexuality is not secondary. It is part of whole-person care.

When we address sexual well-being, we are not shifting attention away from symptom control. We are strengthening recovery.

Because recovery is not only about reducing symptoms, it is about restoring a meaningful life.

Sexual well-being is part of recovery

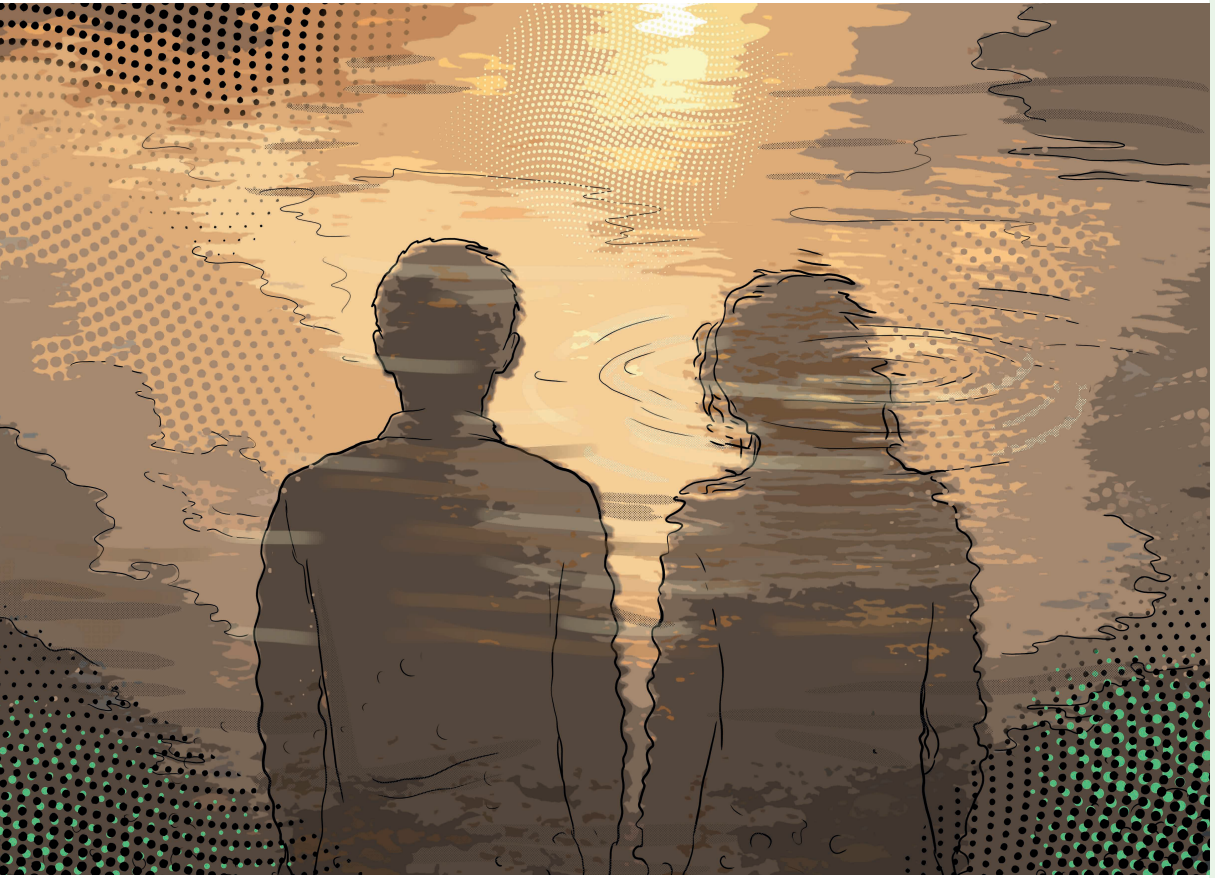
Sexual functioning is linked to:

- *quality of life*
- *self-esteem*
- *emotional connection*
- *relationship stability*
- *treatment adherence*

✓ Addressing it supports recovery

✗ Ignoring it may weaken engagement in care

4.2 Can treatment affect intimacy and relationships?



"The most important point is that treatments are not identical in how they influence sexual functioning."

Elena:

Families often ask, "*Does treatment affect sexuality?*" What should they understand?

Dr. Stein:

The most important point is that **treatments are not identical in how they influence sexual functioning**.

Some antipsychotic medications can increase prolactin, a hormone that plays a role in sexual desire, reproductive physiology, and menstrual cycles. When prolactin rises significantly, it can contribute to reduced libido, changes in sexual response, menstrual irregularities, or breast-related symptoms.

Other antipsychotic options have minimal or no impact on prolactin levels.

Large comparative analyses show that prolactin response varies considerably between treatments and even by dose. So, if a patient experiences changes in intimacy, there may be options.

Elena:

This isn't something patients simply have to accept?

Dr. Stein:

No. **It's something to discuss. Most treatment-related sexual changes are manageable.**

Elena:

Dr. Stein, if changes in intimacy can be related to treatment, how can families or patients recognize when something is happening?

Dr. Stein:

That's an important question, because these changes are often subtle at first.

Someone might feel less interested in closeness or notice that emotional or physical responses feel different. Many people don't connect it to treatment.

They may think, "Maybe it's just me... maybe something has changed in the relationship."

Others begin to avoid intimacy or feel less confident in their relationships without fully understanding why.

These signs are not always immediately linked to treatment. They can easily be misunderstood as emotional distance or relationship difficulties. And that uncertainty can make it harder to bring up.

Elena:

The risk may therefore be misinterpreting the situation?

Dr. Stein:

What matters is not to jump to conclusions, but to stay attentive and open.

A helpful approach is to notice patterns over time rather than focusing on a single moment.

Elena:

And how should this be discussed?

Dr. Stein:

Gently and without pressure.

Simple, open questions can be very effective, such as:

- "Have you noticed any changes in how you feel emotionally or physically?"
- "Do you feel comfortable with how things are in your relationship?"

These questions create space without creating discomfort.

Elena:

The aim is to open a conversation, not to assume that there is a problem.

Dr. Stein:

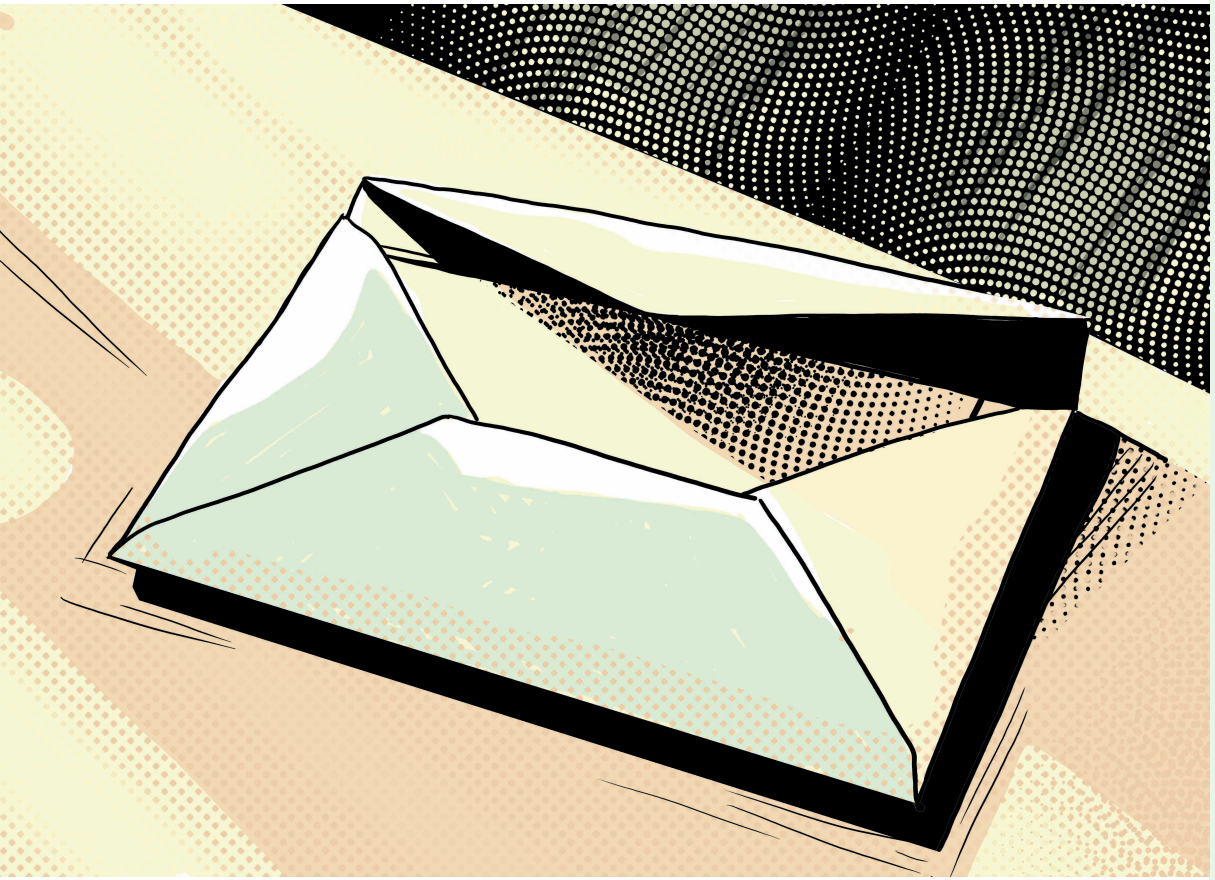
When changes in intimacy are recognized early and discussed openly:

- misunderstandings can be avoided
- treatment can be reviewed if appropriate
- communication and trust can be supported

Recognizing changes early is not about searching for problems.

It is about **protecting communication, trust, and well-being**.

4.3 Why are intimacy-related side effects often not discussed?



“You don’t have to explain everything right now. I’m here, and I’m not going anywhere.”

Elena:

If sexual well-being is so important, why is it still so rarely discussed in consultations?

Dr. Stein:

There isn’t just one reason. In practice, it’s usually a combination of very human factors.

For many people, sexuality is a sensitive topic. It can feel uncomfortable to bring it up, especially in a psychiatric setting. Some people worry that they will not be taken seriously or fear being judged. Others simply don’t know how to start the conversation, or whether it’s appropriate to bring it up at all.

Elena:

Even when a concern is important, a person may find it difficult to raise.

Dr. Stein:

And sometimes it’s not only about the patient. **If the topic isn’t asked about directly, it can easily remain in the background.** People may assume it’s not something they’re supposed to talk about here.

Elena:

The concern can remain invisible in the consultation.

Dr. Stein:

And there’s another layer as well. Some people are not sure where the changes are coming from. They may think, “Maybe this is just part of the illness,” and not realize that treatment could also play a role.

When there isn’t a clear explanation, silence can feel like the easier option. Some people think,
“Maybe I should just accept it,” even when it affects them more than they expected.

Elena:

But that silence can have consequences.

Dr. Stein:

It can.

In practice, these kinds of side effects are one of the reasons why people sometimes reduce or stop treatment without saying so. Not because they don't want help, but because something important in their life has changed and hasn't been addressed. And often, this happens quietly, without discussion, which makes it harder to understand what is really going on.

Elena:

What can make the difference?

Dr. Stein:

Often, it's something very simple.

When clinicians create space for these topics, even with a gentle question, people feel more able to speak.

A question like:
"How has treatment been affecting your energy, mood, or intimacy?"
can open the conversation in a natural way.

Elena:

A simple question may be enough to open the discussion?

Dr. Stein:

Very much so.

When intimacy is recognized as part of overall health, people feel seen. And when they feel seen, they are more likely to stay engaged, to talk openly, and to continue treatment.

Why patients may not talk about intimacy

Common reasons include:

- *embarrassment or shame*
- *fear of being misunderstood*
- *assumption that nothing can change*
- *not being asked directly*

✓ A simple question can open the conversation

✓ Open dialogue improves adherence

Why might someone hesitate to open up to their partner after diagnosis?

Elena:

Dr. Stein, we've talked about why people don't always report changes in intimacy or side effects.

But sometimes, the difficulty starts even earlier, right after diagnosis.

Some partners notice that their loved one becomes more open with family, but more distant or reserved with them. Why does that happen?

Dr. Stein:

That's a very important observation.

Receiving a diagnosis like schizophrenia can deeply affect how a person sees themselves, not only medically, but also personally and relationally.

Many people begin to wonder:

- *"Will I still be seen as the same partner?"*
- *"Am I still attractive, still trustworthy, still 'enough'?"* These thoughts are often not shared out loud, but they shape how someone behaves.

Elena:

The hesitation may reflect fear of how disclosure could affect the relationship, rather than a lack of trust.

Dr. Stein:

Exactly.

In clinical practice, we often see that people may feel safer sharing information with parents or family members first. These relationships are usually perceived as more stable, less dependent on intimacy, attraction, or future expectations.

With a partner, the stakes can feel higher. Especially when the relationship is important, the fear of losing it can become very strong.

Elena:

Holding back may function as a form of protection.

Dr. Stein:

Yes, emotional self-protection.

People may internalize fears of rejection, even when there is no actual rejection. This can lead to silence, distance, or partial sharing.

From the outside, it may look like withdrawal.
But internally, it is often:
"I don't want to lose you."

Elena:

That must be very confusing for partners.

Dr. Stein:

It is.

One partner may think:

"Why is he shutting me out?"

While the other is thinking:
"I'm afraid to let you see everything."

Elena:

What can help in that situation?

Dr. Stein:

Creating safety over time.

Not pushing for immediate openness, but showing:

- consistency
- acceptance
- and patience

Simple messages can help:
"You don't have to explain everything right now."
"I'm here, and I'm not going anywhere."

Over time, when fear decreases, openness usually follows.

What happens when desire is present, but circumstances don't allow expression?

Elena:

Dr. Stein, there is a topic that many people feel, but rarely talk about openly.

What happens when someone has sexual or emotional needs but cannot express them, for example, during hospitalization or when they are not in a relationship?

Dr. Stein:

That's a very important question, and one that deserves to be addressed with openness and respect.

First, it's important to say clearly:

Having sexual desire is a normal part of being human, including for people living with schizophrenia.

The illness does not remove the need for closeness, affection, or physical expression.

Elena:

But the situation may not always allow those needs to be fulfilled.

Dr. Stein:

There are periods when circumstances limit expression:

- during hospitalization
- during unstable phases of illness
- or simply when someone is not in a relationship

This can create frustration, loneliness and sometimes also confusion, "What am I supposed to do with these feelings?"

Some people may even feel that these needs are "inappropriate" or something they should suppress, which is not the case.

Elena:

The existence of the need is not itself a problem.

Dr. Stein:

Not at all. The key is how it is understood and managed. Not ignoring it, but also not feeling overwhelmed by it.

From a clinical perspective, we focus on **healthy, respectful, and safe ways of coping with these needs**.

This may include:

- understanding that desire can exist without immediate action
- finding other forms of connection, such as emotional closeness, conversation, or supportive relationships
- maintaining routines that support overall well-being, including physical activity and social interaction
- and, when appropriate, discussing concerns openly with a clinician

Elena:

So it's about acknowledging the need, but not feeling overwhelmed by it.

Dr. Stein:

Exactly.

When these needs are recognized as natural, they become easier to manage. When they are ignored or associated with shame, they can become more distressing.

Elena:

And does this change over time?

Dr. Stein:

Yes.

As stability improves, opportunities for relationships, intimacy, and personal expression often return.

So these phases are usually **temporary**, even if they feel difficult at the moment.

4.4 What does shared decision-making look like in practice?

"When treatment aligns with a person's values and life plans, it becomes much easier to continue."

Elena:

We hear the term *shared decision-making* quite often in modern psychiatry. But for families listening, it can sound a bit abstract. What does it actually look like in real life?

Dr. Stein:

You're right, it can sound theoretical. But in practice, it's actually quite simple.

It starts with a conversation. And sometimes that conversation feels uncertain at first, for both sides.

Instead of decisions being made only from a medical perspective, there is a dialogue. The clinician brings clinical knowledge, and the patient brings their own experience, priorities, and what matters most in their life. Both sides are important.

Elena:

It's more of a partnership than a one-sided decision.

Dr. Stein:

When people feel part of that process, something important happens. They feel more comfortable, more understood, and more willing to stay engaged with treatment over time.

Elena:

What does that conversation look like in practice?

Dr. Stein:

Often, it **begins with very simple questions**. There isn't always a clear answer immediately, and that's okay.

For example, a clinician might ask:
"What is most difficult for you right now?"
"What would feeling better actually look like in your daily life?"
"What matters most to you at this moment, your work, your relationships, your independence?"

And sometimes:
"How important is intimacy or closeness for you right now?"

Elena:

The focus remains on the person's life, not only the symptoms.

Dr. Stein:

Treatment doesn't exist in isolation. It has to fit into someone's life.

For one person, maintaining a relationship may be very important. For another, being able to concentrate at work may come first. These differences matter, and treatment should reflect them as much as possible.

Elena:

And what about caregivers? Where do they fit in?

Dr. Stein:

With the person's agreement, caregivers can play a very helpful role.

They can share what they observe, support follow-up, or help express concerns that might be difficult to put into words. But it's important that they support the conversation, not take it over.

Elena:

The person therefore remains at the centre of the decision.

Dr. Stein:

Always.

Shared decision-making is not about pressure or choosing between options quickly. It's about finding an approach that feels right, medically sound, and personally meaningful.

When treatment aligns with a person's values and life plans, it becomes much easier to continue. When it feels imposed, people may withdraw, sometimes quietly. Even if the intention is good, it can feel difficult to accept.

Elena:

This may influence more than communication; it may also affect engagement with care and outcomes.

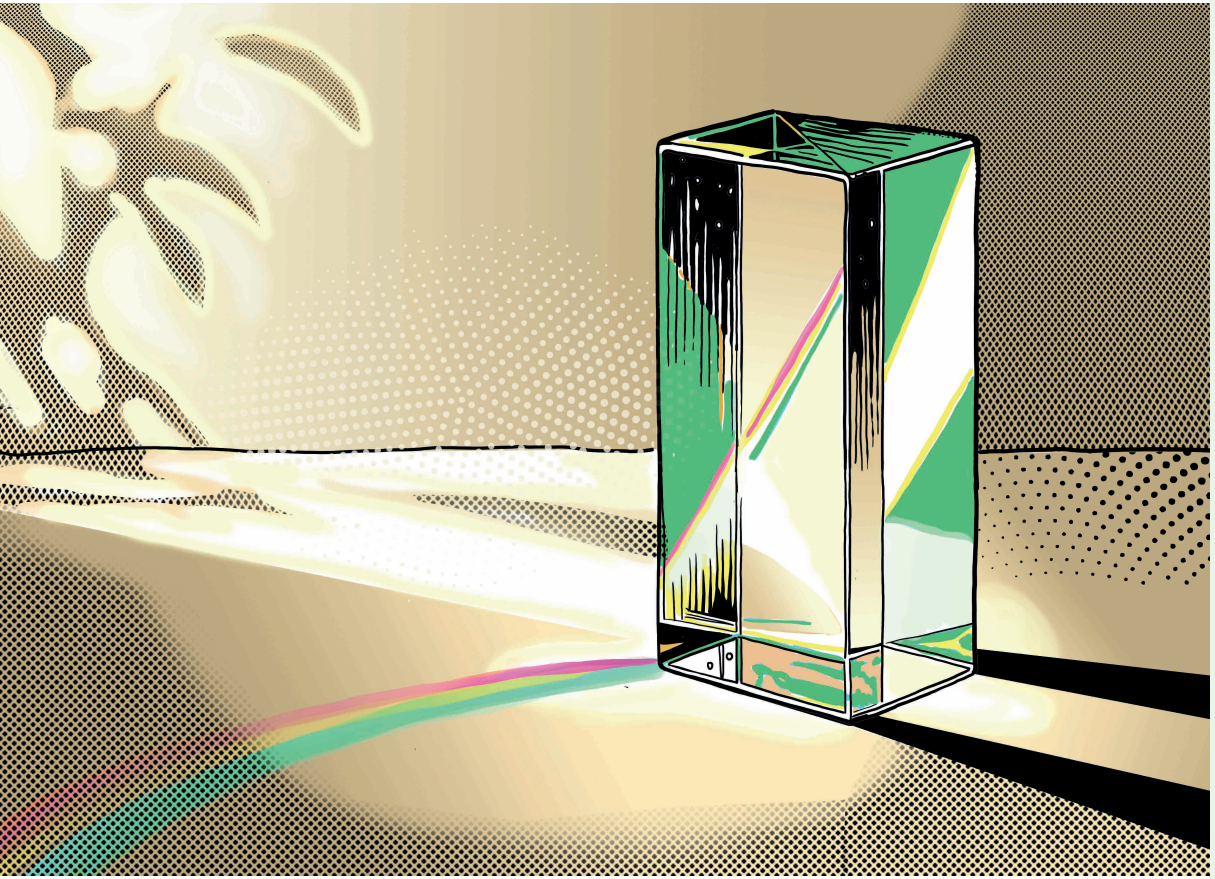
Dr. Stein:

Very much so.

In many ways, it helps protect long-term stability. When people feel heard and involved, they are more likely to stay engaged, to speak openly, and to continue treatment.

And **when topics like intimacy, relationships, or plans are part of that conversation, treatment becomes not only effective but also human**.

4.5 Why does treatment choice have ethical implications?



“Silence often creates uncertainty. Openness creates a sense of safety.”

Elena:

Earlier, you used the word *“ethical”* when talking about treatment choices. That sounds quite strong. Why do you see it that way?

Dr. Stein:

Because these decisions affect much more than symptoms.

Treatment doesn’t only influence hallucinations or mood. It can also affect how someone feels in their body, their energy, their emotions, and sometimes even how they experience closeness or intimacy.

Elena:

It touches very personal aspects of life.

Dr. Stein:

When something that personal is involved, it becomes important to talk about it openly. If we only focus on symptom control and ignore how a person feels in their relationships or in themselves, we’re only seeing part of the picture. This can happen unintentionally, not because anyone is ignoring it, but because it is not always easy to talk about.

Elena:

The ethical dimension includes considering the whole person, not symptoms alone.

Dr. Stein:

Yes.

People have the right to understand how treatment might affect different areas of their lives, including their intimate lives. **When they have that understanding, they can make decisions that feel right for them.**

Elena:

And what happens if these aspects are not discussed?

Dr. Stein:

Then important things can remain unspoken.

Sometimes a treatment is helping clinically, but at the same time, something feels different in a very personal way, and if that isn't acknowledged, it can affect confidence, relationships, and even willingness to continue treatment. **And that can create a difficult internal conflict.**

Elena:

So openness is key.

Dr. Stein:

Indeed.

This doesn't mean overwhelming people with information, but gently letting them know that these topics are valid and can be discussed.

Simple things matter:
letting someone know that changes are possible,
naturally asking about them,
and being ready to adjust if something becomes difficult.

Elena:

Discussing these effects openly can help build trust.

Dr. Stein:

When people feel they can speak openly, they feel respected. And when they feel respected, they are more likely to stay engaged in care.

Elena:

So raising the topic doesn't create anxiety; it can actually create security.

Dr. Stein:

Yes.

Silence often creates uncertainty. Openness creates a sense of safety.

When someone knows, *"If something changes, I can talk about it,"* it protects both the therapeutic relationship and the personal relationship.

Elena:

Ethical care involves not only what is chosen, but also how the decision is discussed.

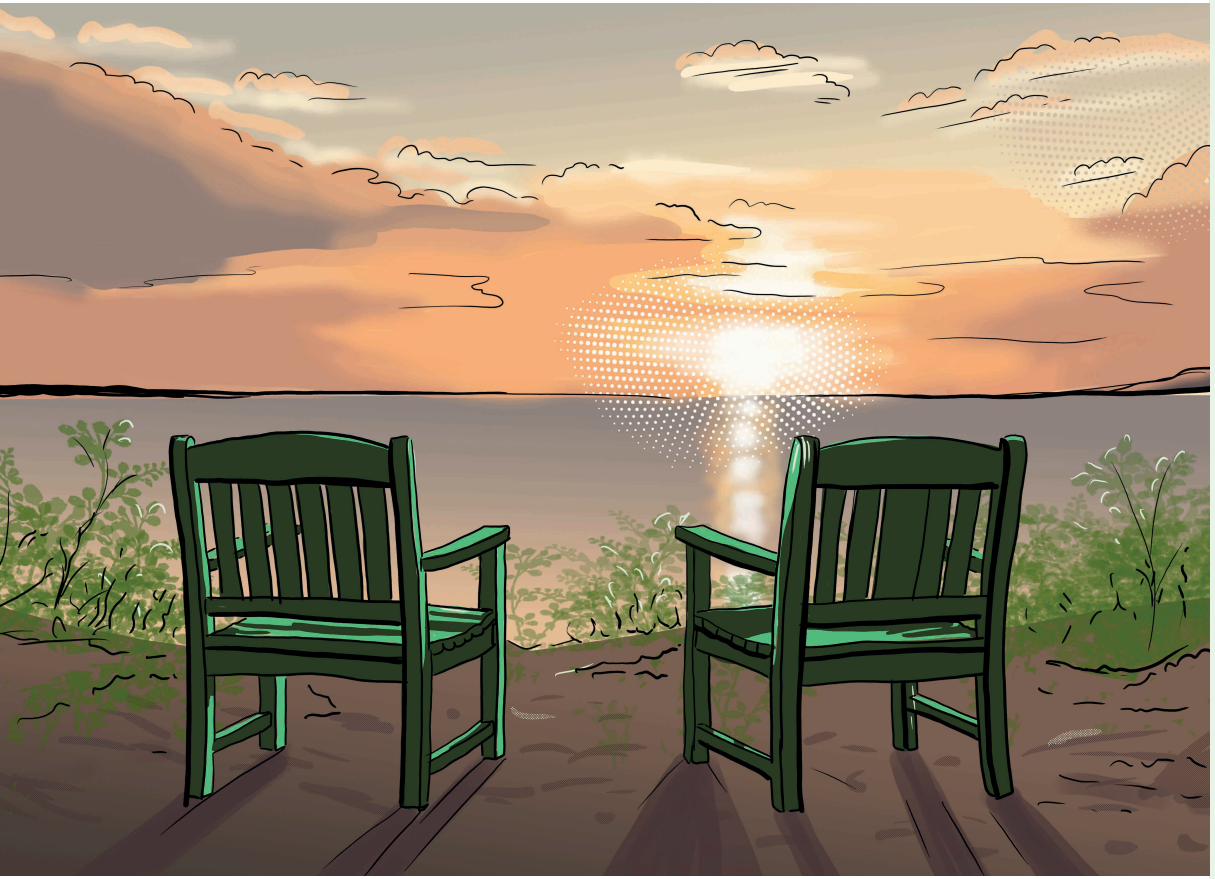
Dr. Stein:

Exactly.

It's also about how we talk about it, how we listen, and how we adapt it to the person.

And when that happens, treatment becomes something people can trust, and that trust supports recovery.

4.6 What can caregivers do to support communication and trust?



“What helps most is staying calm, staying curious, and keeping the conversation open.”

Elena:

Let’s bring this into everyday life. Many caregivers listening might be thinking, *“This makes sense, but what do I actually say? How do I even start?”*

Dr. Stein:

That’s a very real question. **Many caregivers worry about saying the wrong thing. Often, it doesn’t start with finding the perfect words, but simply with creating a safe space to talk.**

Sometimes something as simple as saying,
“I care about how you feel. If something changes, it’s okay to talk about it. There may be ways to help,”
can already make a big difference.

Elena:

The tone may matter as much as the exact wording. Is that right?

Dr. Stein:

Yes, definitely.

When the conversation feels calm and without judgment, people are much more likely to open up. When it feels pressured or critical, they often withdraw, even if something is really bothering them.

Elena:

And what should caregivers be careful about?

Dr. Stein:

It helps to avoid reactions that might unintentionally add pressure.

For example, saying things like
“You’re not interested in me anymore,”
or
“You need to fix this.”
can make the situation feel heavier.

And **even when frustration is understandable, it’s important not to turn it into a conflict about treatment.**

Elena:

The goal is not to solve everything in one conversation.

Dr. Stein:

What helps most is staying calm, staying curious, and keeping the conversation open. Even though that is not always easy in emotionally charged moments.

Caregivers can also support in simple, practical ways, like encouraging follow-up appointments, noticing changes over time, or offering to come along to a consultation if that feels helpful.

Elena:

Support can therefore be both emotional and practical.

Dr. Stein:

Yes.

And there's one point that is very important to remember.

Changes in intimacy are very rarely about a loss of love or connection. But in the moment, it can feel that way. In many cases, they are linked to treatment or biological factors, and that means they can be discussed and, often, improved.

Elena:

Understanding that several factors may be involved can reduce blame and tension.

Dr. Stein:

Very much so.

A simple suggestion such as, "Would you like us to discuss this with your doctor?" can help move the concern from something stressful to something manageable.

Elena:

The caregiver's role is not to fix, but to support the conversation.

Dr. Stein:

That means listening, remaining present, and helping the person access professional advice if wanted.

Because in the end, the goal is not perfection in intimacy.
It's maintaining trust, both in the relationship and in the care process.

And that trust is one of the strongest supports for long-term stability and recovery.

What caregivers can do

Helpful approaches:

- *speak calmly and without pressure*
- *normalize discussion about intimacy*
- *encourage medical consultation*
- *support, but do not control decisions*

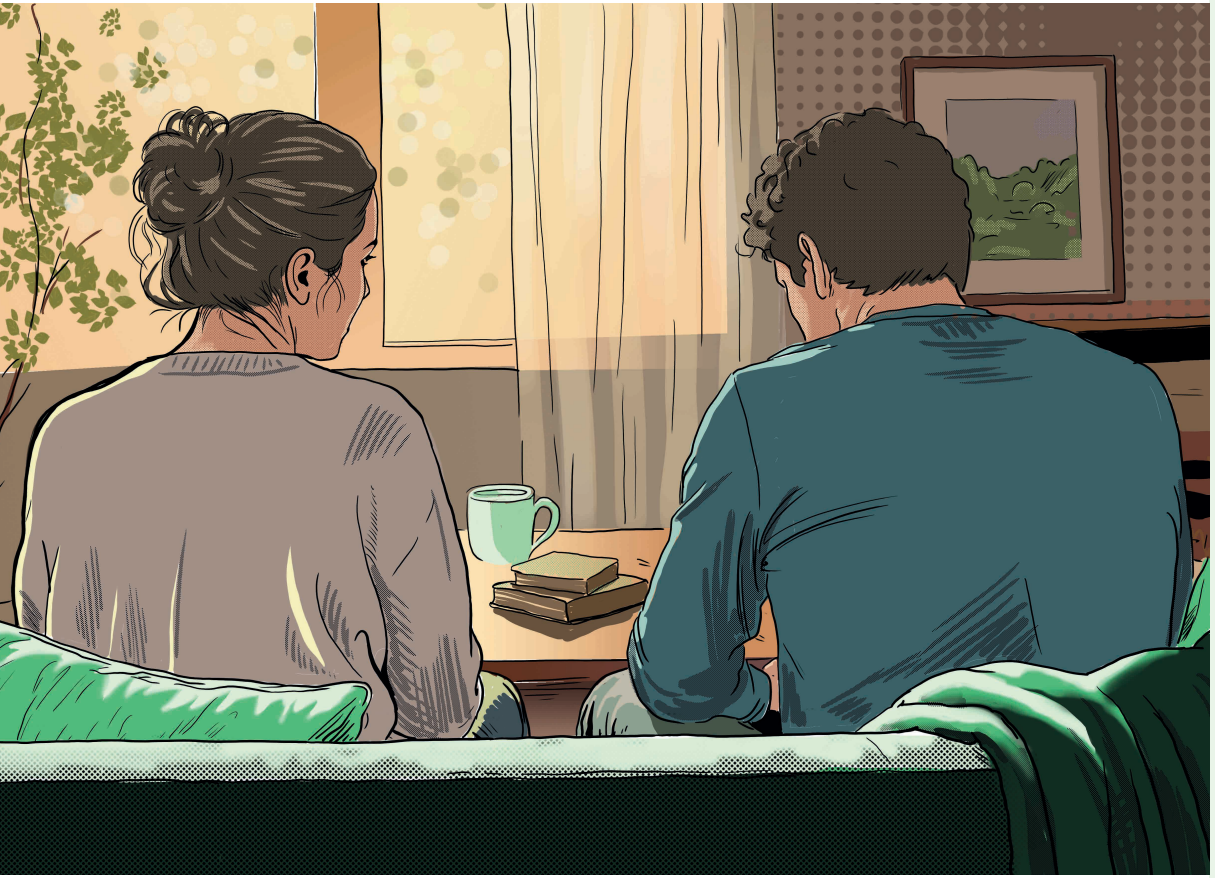
Avoid:

- *blame or accusations*
- *suggesting stopping treatment*
- *interpreting changes as loss of love*

The goal is communication, not correction

Clinical Story

"I didn't know if this was something I was allowed to talk about..."



Note: The clinical story in this chapter is created for educational purposes. Names and identifying details do not represent specific individuals.

Elena:

Before we close, Dr. Stein, could you share an example that brings all of this together?

Dr. Stein:

Of course.

I remember a man in his early thirties. His symptoms had improved significantly, and from a clinical perspective, everything seemed stable.

But during a follow-up visit, his partner mentioned that something had changed. He had become distant. Less affectionate. Less engaged.

At first, they both thought this was part of the illness.

But when we gently explored the topic, he admitted something he hadn't said before:

"I don't feel like myself anymore... not in that part of my life." He paused and then added quietly, "I didn't know if this was something I was allowed to talk about."

He had been experiencing changes in sexual functioning, but felt too uncomfortable to bring it up.

Elena:

The issue wasn't the relationship itself.

Dr. Stein:

It was a **treatment-related effect that had never been discussed**.

Once the conversation was opened, we reviewed options together. Adjustments were made carefully, and over time, both his confidence and the relationship improved.

Elena:

So the turning point was simply talking about it.

Dr. Stein:

Yes. Not a dramatic intervention. Just a **safe conversation**.

Sometimes, what appears to be emotional distance is actually **an unspoken, manageable issue**.

When patients, partners, and clinicians speak openly:

- trust improves
- adherence strengthens
- relationships recover.

Final reflection

Elena:

What I take from today is that treatment does more than reduce symptoms; it can also influence how people experience themselves, their relationships, and intimacy.

Dr. Stein:

Treatment is part of everyday life, not separate from it. When it fits well, it supports not only stability but also confidence, connection, and the ability to be present in relationships.

And when something doesn't feel right, especially in such a personal area as intimacy, it's important to know that this can be discussed, understood, and often adjusted.

Elena:

The goal is not to avoid treatment, but to stay engaged with it, and to talk openly about how it affects real life.

Dr. Stein:

When people feel heard, and when their personal experiences are part of the conversation, treatment becomes something they can live with, not something they have to endure. And often, it's these conversations, simple, honest, and sometimes difficult, that protect both relationships and recovery over time. **Not always comfortable, but often necessary.**

Elena:

And in many ways, this brings us to another important question that naturally follows.

If treatment, physical health, and intimacy are all connected, what happens when people begin to think about having children?

Dr. Stein:

That's a very important step.

Questions about fertility, reproductive health, and family planning often come at a time when people are beginning to feel more stable and are thinking about their future more seriously.

These decisions are deeply personal, but they are also closely connected to everything we've discussed: treatment, physical health, relationships, and confidence.

Elena:

Family planning is therefore not a separate topic, but a continuation of the same conversation.

Dr. Stein:

With the right information, planning, and support, these conversations can become not a source of uncertainty, but a way to build a future that feels both safe and meaningful.

Elena:

In our next chapter, we'll explore how fertility, reproductive health, and family planning can be approached in a thoughtful and informed way.

Until then, take care, and we look forward to continuing this conversation with you.

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