AGORA CONFERENCE WORKSHOP

# From Fear to Confidence

## Managing Treatment Concerns in Rheumatic & Musculoskeletal Diseases

How can we help people move from fear and uncertainty to informed, confident treatment decisions?




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# Today’s workshop

## Our goal

To explore what creates treatment fear, what builds confidence, and what patient organisations can do about it.

### LISTEN

What are people actually afraid of?

### EXPLORE

What helps turn fear into useful questions?

### ACT

What can we do as patient organisations?

# One word: treatment

## When you think about your treatment, what is the FIRST word that comes to mind?

RELIEF

FEAR

HOPE

UNCERTAINTY

CONTROL

# What are people afraid of?

- Side effects and long-term safety
- Starting a treatment when you feel well
- The treatment not working — or stopping working
- Injections, infusions or daily medication
- Stories from friends, social media or online forums
- Interactions, missed doses, access or cost
- Losing control over decisions about your own body

**DISCUSSION**

Which of these concerns do you hear most often in your organisation?

**REMEMBER**

A concern is information — not an obstacle.

# Fear is not the problem

**The problem is when fear has no safe place to be discussed.**

**FEAR**

“What if something goes wrong?”

**UNCERTAINTY**

“I don't know what to believe.”

**AVOIDANCE**

“Maybe I should wait.”

# Fear vs. risk

**FEAR SAYS...**

“What if something goes wrong?”
“I heard this treatment is dangerous.”
“I don't want side effects.”

**CONFIDENCE ASKS...**

“How likely is it?”
“What does the evidence tell us?”
“What should I watch for?”
“What are my alternatives?”

# The information trap

## More information ≠ more confidence

- Google
- Social media
- Patient forums
- Friends' experiences
- Medicine leaflets
- Health websites
- Scientific papers

# Who is making the decision?

**HEALTHCARE PROFESSIONAL**

Medical knowledge
Evidence
Experience
Treatment options

**PERSON LIVING WITH RMD**

Goals
Experience
Concerns
Priorities
Lifestyle

**TOGETHER**

A decision that combines evidence with what matters to the person.

Shared decision-making does not mean the patient makes the medical decision alone — or the professional makes it alone.

# What matters to me?

**Complete the sentence:**

## “For me, successful treatment means…”

- Less pain or stiffness
- Better mobility or function
- Being able to work, travel or care for family
- Sleeping better and having more energy
- Preventing future damage
- Having a treatment that fits everyday life

# Turn fear into questions

**CONCERN**

“I'm scared of this medication.”

**QUESTION**

“What are the common side effects, the serious rare risks, and how will we monitor them?”

- How long before we know whether it is working?
- What are my alternatives?
- What happens if it doesn't work?
- What symptoms should make me contact you?
- What happens if I wait or choose not to start?

# The 5 questions I need answered

1. What are my options?
2. What are the benefits?
3. What are the risks?
4. What happens if I do nothing or wait?
5. Which option fits my life and priorities?

# The Fear Box

**Write privately:**

**“The treatment concern I don't usually say out loud is…”**

You do not need to share it.

# Role-play: Nefeli

**Nefeli has been offered a new biologic.**

“I don't want to start it. I have read so many scary things online. I'm worried about infections and what might happen after taking it for years.”

**PATIENT**

What am I afraid of?
What do I need to know?

**PATIENT ORGANISATION**

How can I support without telling Nefeli what to choose?

**HEALTHCARE PROFESSIONAL**

How can I explore concerns rather than dismiss them?

# What builds confidence?

- Clear, balanced information
- Time to ask questions
- Trust and respectful communication
- A real voice in decisions
- Understanding benefits and risks
- A monitoring plan
- A plan if treatment does not work
- Support from the healthcare team and patient organisations

# What can patient organisations do?

| | |
|---|---|
| **LISTEN** | Create spaces where treatment fears can be expressed without judgement. |
| **TRANSLATE** | Help people turn complex information into questions they can use. |
| **CONNECT** | Link people with trustworthy sources and appropriate support. |
| **EMPOWER** | Build skills for shared decision-making — without making the decision for them. |
| **AMPLIFY** | Bring patient experiences and priorities into healthcare conversations. |

# What can healthcare professionals do?

Instead of only asking:

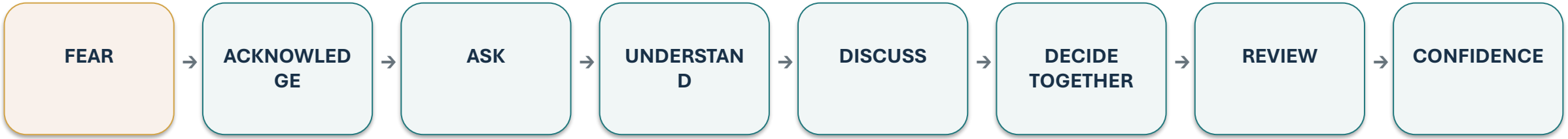
**“Do you have any questions?”**

Try asking:

**“What concerns you most about this treatment?”**

**A better question can open a better conversation.**

# From fear to confidence




**Confidence does not mean “I am not afraid anymore.”**

It means: “I understand my options, I know what matters to me, and I know what questions to ask.”

# Final challenge: What can WE do?

**In small groups, design 3 practical actions your patient organisation could take.**

**01**

ONE action to reduce fear

**02**

ONE action to improve trustworthy information

**03**

ONE action to strengthen shared decision-making

**Be specific: Who? What? When? What would success look like?**

# Take one thing with you

## What is ONE thing you will do differently at your next treatment discussion?

- I will ask about alternatives.
- I will say what I am really worried about.
- I will ask what happens if the treatment doesn't work.
- I will check the source before believing something online.
- I will ask for time to make a decision.

# Your concerns deserve a conversation

Your questions are not a challenge to your healthcare professional.

**They are part of good healthcare.**

**FEAR → QUESTIONS → UNDERSTANDING → SHARED DECISIONS → CONFIDENCE**