

LIVED EXPERIENCE SERIES

GETTING A DIAGNOSIS OF ARTHRITIS

WEBINAR PANEL

On November 19, 2025, CAPA hosted the Lived Experience Webinar as part of the Annual General Meeting (AGM). This session explored the challenges, emotions, and lessons learned through the process of being diagnosed, offering valuable insights for both people living with arthritis and those supporting them.

Panelists shared their experiences of recognizing early signs, navigating the healthcare system, and coping with the emotional and physical impact of their diagnosis.

“Thank you for making the invisible visible” – Jenny

PANELISTS:




- From Calgary; officially living with RA since 2022, unofficially probably longer
- Proud CAPA board member, patient partner and strong advocate for newcomer experiences & health equity

LUCY KOVALOVA-WOODS
CAPA Board Member

NAZRET R.
Full-time Caregiver

- From Edmonton; diagnosed 10+ years ago
- Multiple family members also affected
- Joined CAPA to help expose and address systemic barriers to diagnosis and equitable care




- Edmonton-based OT with 30 years' experience
- Has worked with rheumatic disease populations since 2001
- Husband and caregiver to a person living with RA

DR. RASHID KASHANI
Occupational Therapist

KIM TREMBLAY
Lived Experience Advocate

- From Montréal; diagnosed just over a year ago
- Joined CAPA to push for better alignment with the Francophone community
- Passionate about meaningful French-language resources



MODERATOR:

JENNIFER LORCA
CAPA Board Member



WHAT HAS YOUR EXPERIENCE BEEN WITH GETTING A DIAGNOSIS?

KIM

- Initially **thought symptoms were carpal tunnel**; family doctor ordered tests and referred her promptly, but she was **waitlisted**
- Called the waitlist line and secured a specialist within two months
- **“Don’t be shy to pick up the phone and call and that’ll help you greatly”**

LUCY

- Early symptoms in Ukraine led to extensive testing but were initially **dismissed as “anxiety”**
- After moving to Canada, pain became more regular and a supportive **family doctor quickly recognized RA**, started treatment, and referred her to rheumatology
- Discusses witnessed **newcomer challenges**: discrimination, language barriers, dismissal due to accent or not knowing terminology

NAZRET

- Diagnosed only after **insisting on imaging** for persistent **back pain** but was initially dismissed
- Never referred to a specialist; **treatment access** for her family has been extremely **limited**.
- Points out **systemic barriers**: delayed diagnosis and treatment for Black patients and lack of pathways to prevent severe outcomes.

RASHID

- From a **clinician’s perspective**, diagnosis is **often rushed** and overly **focused on checklists**
- Uses a narrative-based approach, asking patients: **“What matters most to you? What can’t you do right now that you need to do?”**

WHAT HAVE YOUR EXPERIENCES BEEN WITH HEALTHCARE PROFESSIONALS?

LUCY

- Only her **4th family doctor** validated her pain and asked direct and empathetic questions
- Notes how **discouraging** it is when clinicians don't **engage** with basic concerns, leaving patients to manage symptoms alone

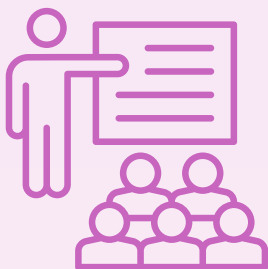
NAZRET

- Felt consistently **unheard** by providers and struggled even to get assessed
- Was **dismissed** after diagnosis: *"Don't worry about it, everybody's got that"*

WHAT RESOURCES WERE HELPFUL FOR YOU TO LEARN TO TALK ABOUT YOUR LIVED EXPERIENCE WITH YOUR CLINICIANS?

KIM

- Her specialist focuses on how arthritis affects **daily functioning**
 - Kim adapted her **corporate knowledge** to be **assertive, communicate**, make a **presentation**
 - Likes to come **prepared** to meetings with her specialist, tracks what she can't do



NAZRET

- Is a member of the **patient and family advisory group** with Alberta Health Services, attended training on **engaging with the healthcare system**
 - Feels it should be the **other way around** rather than to *"put the burden on me as a patient and caregiver"*

RASHID

- Emphasizes **truly listening to patients' stories**, not just focusing on checklists or assessments
 - Recognizes that **patients often feel unheard**
- Strives to **address** both immediate **concerns and broader questions** in limited appointment time, ensuring patients have their needs acknowledged



HOW HAS RECEIVING A DIAGNOSIS IMPACTED YOUR EXPERIENCE OF LIVING WITH ARTHRITIS?

KIM

- **"Totally changed my life"**
- *"From the disease itself to the medication side of things,"* it takes a lot of **time and energy "just to deal with it"**
- Struggled with **identity** and adjusting to limitations: *"Now, I'm not as active... I really have to manage my energy"*

LUCY

- *"The best part, to me, is knowing what I'm dealing with: the **cause**, the **consequence**, and the **treatment protocols**"*
- Felt **validated** and no longer "in the middle of nowhere"
 - *"Having that acknowledgement... gives you the direction where to dig in, where to read, and whom to reach out to"*

NAZRET

- *"Giving it a diagnosis **shocked me**. I didn't expect myself to be someone that would get arthritis"*
- She gained **understanding of her body and limits**, as well as felt the need to improve self-care and lifestyle choices
- **Built connections** with others with arthritis, such as with CAPA, and found herself relating more to people around her with arthritis

RASHID

- For his wife (living with arthritis):
 - **Relief from uncertainty** about other serious possible conditions
 - **Forces you to take a step back**, ask what is most important, and adapt roles within daily life and future plans
 - Required **open communication** and planning for changing routine as a caregiver: *"I can't be her OT and her spouse"*

HELPFUL RESOURCES AND LINKS FROM THE WEBINAR:

NHS: Living With RA Resources

<https://www.nhs.uk/conditions/rheumatoid-arthritis/living-with/>

This resource was shared as an overview of information on living with RA.

CAPA: "Talking with my Healthcare Provider" Web Resources

<https://arthritispatient.ca/en/talking-with-my-healthcare-provider/#understanding-treatment>

CAPA's "Talking with my Healthcare Provider" webpage includes resources like how to ask questions about biosimilars, blood test results (know your numbers), and more!

Voices Unheard: Canada's First National Health Survey of Black Women and Girls

<https://bwhealthinstitute.com/voices-unheard/>

This report was recommended in the webinar chat, it came out recently and is about Black Women and healthcare in Canada.

Paper: Rheumatoid Arthritis Care Experiences of Black People Living in Canada

<https://acrjournals.onlinelibrary.wiley.com/doi/10.1002/acr.25278>

CAPA's very own Therese Lane was involved in this paper! It's about better understanding experiences related to RA care and proposing service-level strategies to reduce and mitigate inequities for Black people living in Canada.

Giving Care: An approach to a better caregiving landscape in Canada

https://canadiancaregiving.org/wp-content/uploads/2022/11/CCCE_Giving-Care.pdf

This report was shared as a part of Dr Jasneet Parmar & Sharon Anderson's ongoing work on co-designing a caregiver-centered Care community of practice in healthcare.

The Alberta International Medical Graduate Association (AIMGA)

<https://www.newcomernavigation.ca/en/news/featured-org-aimga.aspx>

The AIMGA website has a health & language interpreter navigator program where patients & carers can request and receive a trained, health navigator to assist in communication, quality, and culturally appropriate access to health care.

The National Newcomer Navigation Network

<https://www.newcomernavigation.ca/en/index.aspx>

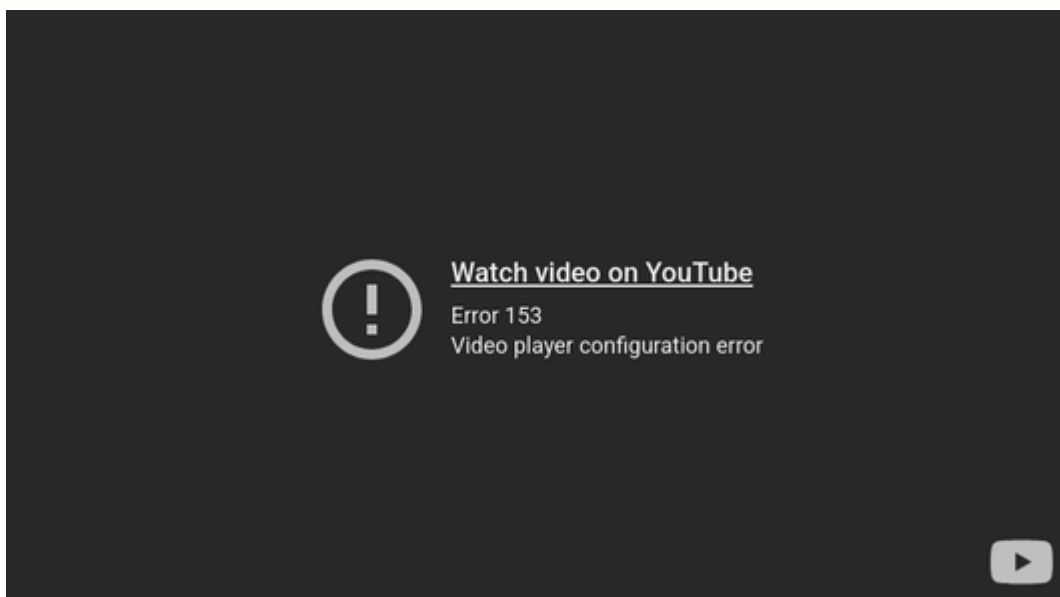
The Newcomer Navigation website is another great resource for equitable health care access. They have webinars, e-learning, tools, and many other excellent resources with the mission to create a national platform for newcomer serving professionals to connect, learn, and collaborate around newcomer navigation.

Amanda Parris' article on pregnancy and anti-black racism barriers in health care:

<https://www.cbc.ca/documentaries/i-made-a-documentary-about-the-black-maternal-health-crisis-then-i-experienced-it-1.7101607>

Canadian moderator, TV anchor, journalist Amanda Parris' *For The Culture* series on CBC & GEM was shared as a resource for Black Canadians going through pregnancies while facing ethnic barriers in health care.

WATCH THE PANEL HERE:



<https://www.youtube.com/watch?v=8zi4xFT5Wg&t=5s>