CHCA Project ECHO Integrated Seniors Care

All Teach, All Learn

Bridging the Knowledge Gap in Home and Primary Health Care

Communication and Goals of Care in Serious Illness

Meet Evelyn

Background and Situation

Evelyn is an 83-year-old Jamaican-born retired librarian who moved to Ontario in her thirties. A keen reader who enjoys lively conversation, she has maintained close ties with relatives in Jamaica and a local Jamaican community group. She looks forward to unhurried lunches with her friend Nora and telephone calls with family. Choosing her own routine and having people visit have always mattered to her.

Evelyn lives alone in an accessible seniors' apartment. Nora, her neighbour and long-time friend whom she considers chosen family, visits daily and is staying temporarily following Evelyn's recent hospital discharge. Her daughter Claire, who is a physician, lives three hours away, calls regularly and joins care discussions by phone. Evelyn wants both women involved but wants decisions discussed with her directly.

She has lived with Parkinson's disease for 12 years, alongside heart failure and chronic kidney disease. Over six months, her progressing Parkinson's has brought increasing stiffness, freezing, fatigue and swallowing difficulties. She can no longer attend her community group, and her softer voice makes family calls tiring. Increasing dependence is frustrating: she wants help to keep doing things she enjoys, while retaining control over her daily life.

Medical History and Functional Status:

- Recently discharged after aspiration pneumonia, she uses a walker with assistance and needs help with bathing, dressing, medicines and meals. Modified food textures and supervised meals have been recommended. Parkinson's treatment continues.
- Her speech is soft and responses are slow; hearing loss adds difficulty. She speaks English and Jamaican Patois, preferring care discussions in English. There is no known dementia; given time, she expresses her wishes clearly.
- Her physician, neurologist and home care team recommend involving the support of a palliative care team alongside ongoing treatment to address her growing needs.

Current Concerns:

- When the nurse introduces a palliative approach, Evelyn becomes upset: "Palliative care means the end, doesn't it? I'm not ready." Her previous experience was during a friend's final days. She fears that accepting it means treatment will stop and others will give up on helping her live well.
- Others sometimes complete her answers before she has finished speaking. This is especially frustrating for someone who has always enjoyed conversation. She becomes quieter when explanations feel overwhelming. No one has explored what palliative care means to her or what she fears most.
- • The team has not linked the approach to what Evelyn hopes to preserve, such as enjoying meals and staying connected with family. Providers have not agreed on a consistent explanation. Discussion has stalled before her goals and preferences can guide a shared plan.

Caregiver Perspective:

- Claire understands that a palliative approach can begin well before the final months or days and can support quality of life throughout the remaining illness trajectory, alongside ongoing treatment. She sees opportunities for symptom relief, daily participation and planning, but her clinical explanations have not eased her mother's fears. She worries that pressing the point will damage trust.
- • Nora notices Evelyn withdrawing from conversations and missing the social contact she enjoys. She wants the team to listen before explaining more. As meals and personal care take longer, she also needs guidance and help to sustain her caregiving role.

Challenge for Discussion:

How can the team acknowledge Evelyn's fears, explain the palliative approach through what matters to her, and involve Claire and Nora in shared decisions while keeping Evelyn's voice central across care settings?

Canadian Home Care Association

Project ECHO

Project ECHO Integrated Seniors Care (ISC) is a transformative initiative to enhance primary and home care providers' skills, knowledge, and attitudes to deliver integrated, patient-centered care for seniors with complex chronic conditions. Project ECHO ISC offers collaborative, expert-led presentations and case-based learning to bridge these gaps.

The Canadian Home Care Association (CHCA) is a national non-profit association focused on strengthening integrated home-based care. Representing public and private organizations across the county the CHCA partners with members to address pan-Canadian priorities through advocacy, awareness, innovation, and knowledge exchange. CHCA Website / X / LinkedIn