Roon: The Smartphone App for People Affected by Brain Tumors

Roon reimagines how people diagnosed with glioblastomas navigate health information related to this type of cancer.

August 21, 2023 By Adam Hayden

A simple google search for the word “glioblastoma” returns the following related searches—I’ve included these below and the response for this first return:

- What is the life expectancy for glioblastoma?

  Although the average life expectancy after a diagnosis with glioblastoma is between 14 and 16 months, patients with certain tumor genetics have a median survival time of 22 and 31 months.

- What was your first symptom of glioblastoma?

- Is glioblastoma usually fatal?

- How curable is glioblastoma?

- What is the longest survivor with glioblastoma?

- What is the deadliest brain tumor?

Search results when searching Google for the word “glioblastoma” (search executed on July 6, 2023)Courtesy of Adam Hayden

Imagine that you have little to no prior knowledge of the aggressive brain cancer called glioblastoma, beyond the diagnosis you recently heard in an exam room. How would these search returns affect your understanding of your new diagnosis?

“Life expectancy between 14 and 16 months,” “fatal,” “deadliest,” “aggressive,” “lethal,” “incurable”… these are many of the terms that patients and their loved ones encounter when turning to Google to learn about their brain cancer. Not to mention that image of a man in pain with a red mass depicted inside his brain like Superman beamed his x-ray vision into his skull.

Let me ask you to do this: Pause. Consider the search results. How might you feel if you knew nothing of the disease with which you were just diagnosed, and in addition to some big words your oncologist used, you were left to digest the information—alone—that information I’ve just presented to you?

The feeling that you may have is what tens of thousands of patients annually and their loved ones are left to wrestle with when they get home from the hospital or clinic after receiving a glioblastoma diagnosis. The emotional and psychological effects are compounded by the further realities that these newly diagnosed patients are likely recovering from an invasive brain surgery and are often prescribed steroids to control swelling following that surgery and anti-epileptic medications to mitigate the risk of seizures.

Fatigue from surgery, neurological effects from the damage to the brain by removal of the malignant brain tumor (at least swelling and fluid collection), and the mood-altering effects of steroids and seizure meds create a storm of distress and exhaustion for patients. Meanwhile, care partners and loved ones are quickly overwhelmed with processing and understanding this same information for the person they love, while balancing work, hospital stays, childcare, meal preparation, and all the other responsibilities of day-to-day activities. When patients and care

partners are at their most vulnerable, we pile on medical information that is not only grim, the jargon and medical terms are a foreign language to many: glioblastoma, gross total resection, temozolomide, dexamethasone, tumor treating fields, immunohistochemistry, histology, genomics, mutations… these are the common terms of any new glioblastoma diagnosis conversation. In a moment of life altering diagnosis, when everything is uncertain and fearful, for many it will be the first time they ever hear these words!

Images from the Roon smartphone appCourtesy of Adam Hayden

Enter: Roon. We knew we could do better for patients, but I needed a little convincing.

During my first Zoom with Roon co-founders Rohan and Vikram way back in 2021, they articulated a vision of this future service that existed only in their mind's eye. Rohan, an accomplished neurosurgeon, and Vikram, a veteran of the tech industry, peppered me with questions about my life with brain cancer and where I turned for support. We discussed support groups and patient blogs; social media and online discussion boards. They asked about my blog, and we discussed the talks that I had given and conferences I attended. They shared about their plans to reimagine the way patients receive medical information—currently cold and clinical, at best, or misinformed and inaccurate, at worst, when patients aren't sure where to turn other than Google and WebMd. Their vision was one of information delivery: empathetic, person-centered, and medically vetted.

I was resistant. That's the truth.

I was already involved in a thriving monthly Twitter chat (shout out the BTSM Chat), and my co-facilitator and I had recently migrated our virtual brain tumor support group to its new home with National Brain Tumor Society as the Brain Tumor Support Conversation. I was maintaining this blog, and I traveled often to give talks.

Owing mostly to capacity limitations, I thanked Rohan and Vikram for the outreach to recruit me into this new thing they were building, but I just couldn't commit. No hard feelings. I simply didn't have the bandwidth. I thanked them for sharing their vision, but my life was full for the next six months, and I'd have to pass.

Some time went by, and I got a follow up note in my inbox. Rohan and Vik were ready to take their idea from the drawing board to the production floor, and they invited me to another call. You can see where this is headed! Their idea was formed, and their pitch was tight. We were going to overcome those challenges that I shared at the top of the post, and we'd do it through a video format. We'd recruit experts from across the care continuum—surgeons, oncologists, mental health professionals, nurses, social workers, and yes, patients and care partners!

I was all in.

Several of the glioblastoma (GBM) experts contributing to RoonCourtesy of Adam Hayden

I tell this story because it's true! There are so many apps and tools, books, articles, explainers, YouTube channels, and Facebook groups. I needed convincing that this was something new; something needed. I needed to see something that I really thought would change the lived experience of people with brain cancer. The fact that I needed to be convinced is an important part of this story for me because in the end, I was convinced! We've built a tool that genuinely would have benefited me at the time of diagnosis.

Building Roon achieves the two goals I have in mind when I create, speak, or write anything: First, is this better than silence? I often ask myself this in meeting settings, but in applies here, is Roon better than not having Roon? Categorically yes! Second, does this thing I'm saying, doing, thinking, creating going to truly help people? Again, categorically yes! Roon brings world-leading clinicians and professionals to patient and care partners' smartphones. I've been in the advocacy space for seven years, and the names on this app are the very best in the care space.

The rural patient hundreds of miles from an academic center or the newly diagnosed patient whose rushed into surgery before catching their breath may never sit down with someone like Mitch Berger, Alice Chen, or Edjah Nduom, but these world class clinicians are on the app.

Newly diagnosed patients and care partners will find immediate benefit to opening the Roon app.

Roon is a living FAQ. We've created several "Guides" that categorize our short-form video content by topical areas. These include:

- GBM (glioblastoma) Basics
- Diagnosis
- Treatment
- Symptoms
- Recurrence
- Mental Health

- Life Hacks

- Precision Medicine, and more…

Our guides include videos that our experts think are must-know information from our lived experiences, but the real power is in the user questions. Patients and care partners submit questions, and our experts reply with 1-3 minute videos that then appear on the app. All of our content is medically vetted by our physicians and other clinicians, and we include multiple perspectives for most questions.

Wonder what the best advice is for someone who is newly diagnosed? We've sourced videos from physician, patient, and care partner perspectives to provide several responses from different points of view. We've also created two paths for Roon users to identify by either patient or care partner, and these content streams tailor the content to the pathway that aligns with you. We know that patients and care partners view the illness experience differently, with different pain points and different needs. Our paths respect the integrity of these shared, but unique experiences.

Our smartphone app is straightforward and easy to use, so you can effortlessly swipe through featured videos by popularity, videos by Guide (topic), use our advanced search feature to find particular topics, or simply follow our gentle guidance to discover, "Questions that people also ask."

Some of our Glioblastoma GBM Guides at RoonCourtesy of Adam Hayden

We are humans speaking to other humans, delivering medically vetted information in a human way! In a world of search engines and ChatGPT, our approach is rooted in our full humanity, speaking kindly, authentically, with empathy, from our own lived experience.

Scan the QR Code to download the app. We'd love to hear your feedback! Use the app, check out the videos and guides, then schedule a call to share your feedback! Think you're a good candidate to make some videos, we'd love to hear that, too!

Scan the QR Code to download the Roon app.Courtesy of Adam Hayden

I can’t wait to hear how Roon has been helpful to you! Drop a comment here to let me know!

Leave a comment

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