OpenNotes: A patient perspective

Liz Salmi
I am a patient
What mattered to me at 25

✓ Nice website
✓ Make appointments
✓ Email doctor
✓ View test results
✓ Order prescription refills

@TheLizArmy
My 29th birthday

July 18, 2008
My 29th birthday

July 25, 2008
Astrocytoma
My blog → TheLizArmy.com

@TheLizArmy
Salmi, L. Medical record. (2008-2016)

@TheLizArmy
When my husband and I learned our health insurance would be changing from Kaiser (HMO) to a PPO (plan to remain anonymous), we had just one concern: How would we manage our care?

We had three priorities:
1. Have access to top-notch neuro-oncologists at health systems connected to advanced treatments and clinical trials.
2. Have affordable payments for MRI scans, which are the only accurate screening tool for brain tumors.
3. To not go bankrupt in case my tumor decides to grow and I end up back in active treatment (which may include another (cns) biopsy, radiation, chemotherapy, or clinical trial).

Choosing a neuro-oncologist

My first step in picking a new neuro-oncologist was to ask my Kaiser neuro-oncologist where I should go for care. I live in Sacramento, CA, so my local options included the UC Davis Health System and Sutter Health, which both have neuro-oncology programs. I could also consider Dignity Health, but they do not specialize in neuro-oncology. With the PPO plan, I could also choose from UCSF and Stanford, which are both known for having world class neuro-oncology teams.

According to our records, you’re no longer a Kaiser Permanente member and aren’t eligible to use our site’s secure features. You can still browse our health encyclopedia and other health information.

Call us at 1-800-556-7677, available 24 hours a day, 7 days a week, except on major holidays. Have your Kaiser Permanente Health/Medical Record number ready.

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Rights under HIPAA

✓ See a copy of your medical record
✓ Get a copy of your medical record
✓ Change incorrect information
✓ Find out who has seen your health information
Printed record = $725.40

Digital record = $45 for 3 DVDs
4,836-page medical record

- Emails
- Lab results
- Surgical reports
- Pathology reports and biomarkers
- Clinical notes
Follow-up Patient Evaluation

Elizabeth Salmi is a 37-year-old female who is seen today for follow-up of low-grade astrocytoma WHO grade II. She has been on observation and we have been checking MRI scans every 6 months. She reports normal activities without any restrictions. She exercises regularly and has problems with strenuous physical activity. She has good compliance with medications. She takes her anti-convulsants consistently and has not had any breakthrough seizures.

Oncologic History:

She was diagnosed on July 25, 2008, after presenting with a generalized tonic-clonic seizure. She underwent a resection of the lesion on September 17, 2008, by Dr. at UC Davis in Sacramento. Pathological examination revealed a low-grade astrocytoma WHO grade II with gemistocytic features. Surveillance MRI 3 months later showed enhancement in the resection cavity and she underwent a second resection on February 6, 2009. The pathology was the same which was confirmed with a second opinion at UCSF. Due to the presumed progression, she was offered adjuvant therapy and was advised to have temozolomide. She received temozolomide 150 mg/m² 2/3/3 for 24 cycles from 2/2009 to 4/2011.

Active Ambulatory Problems

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Date Noted</th>
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<tbody>
<tr>
<td>PARTIAL EPILEPSY</td>
<td>10/09/2008</td>
</tr>
<tr>
<td>ASTROCYTOMA, BRAIN GRADE 2</td>
<td>10/22/2008</td>
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<tr>
<td>LEFT SENSORYNEURAL HEARING LOSS.</td>
<td>02/05/2009</td>
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<tr>
<td>ANXIETY DISORDER DUE TO ANOTHER MEDICAL CONDITION</td>
<td>02/11/2009</td>
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<tr>
<td>ECZEMA</td>
<td>11/01/2010</td>
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<tr>
<td>CONGENITAL KERATOSIS PILARIS</td>
<td>01/11/2011</td>
</tr>
<tr>
<td>HX OF CHEMOTHERAPY</td>
<td>07/27/2011</td>
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<tr>
<td>HX OF CRANIOTOMY</td>
<td>07/27/2011</td>
</tr>
<tr>
<td>GENETIC CANCER RISK EVALUATION</td>
<td>11/17/2015</td>
</tr>
</tbody>
</table>

I have confirmed with the patient and/or the medical record the presence of the above diagnoses, and the diagnoses are followed or will be followed by his or her PCP or appropriate specialist.

Physical Exam:

BP 127/76 mmHg | Pulse 59 | Temp(Oral) 97.9°F (36.6°C) | Wt 156 lb (70.761 kg)

Constitutional: Appears well, no distress

Mental Status: Alert, oriented X 3, able to name and repeat, good fund of knowledge, normal comprehension

Gait: Normal.

Second Review of Imaging:

MRI brain 12/12/16, 7/24/16, 4/28/13 are reviewed. There is a left parietal lobe resection cavity with small areas of FLAIR hyperintensity around it (residual tumor). There is no enhancement. The scans are stable and there is no evidence of growth.

Pathology:

Diffuse Fibrillary Astrocytoma WHO grade II

IDH mutant

ATRX mutant

MGMT methylated

Clinical Summary:

Elizabeth Salmi is a 37-year-old woman with a left parietal low-grade astrocytoma WHO grade II with gemistocytic features. She had two resections (9/2008 and 2/2009) and 24 cycles of temozolomide 150 mg/m² completed in April 2011. She is currently stable without any evidence of disease progression clinically and radiographically. She is being followed closely with clinical examinations and MRI scans. We will continue observation and surveillance MRI scans.

We will maintain current doses of anti-seizure medication and continue to observe.

Assessment:

- Neuro-Oncology: low-grade astrocytoma, WHO grade II, left parietal lobe, stable
- KPS: 90
- Epilepsy, localization related, good control

Plan is as follows:

- Neuro-Oncology therapy: continue surveillance MRIs, no active treatment indicated at this time.
- MRI: 6 months
- Salvars: continued levodopa, 1500 mg BID, topiramate 200 mg BID
- Symptom management: None
- Social issues: none
- Psychological: no significant problems
- Advance directives status: completed
- Follow-up: 6 months

The total visit time face to face with the patient was over 30 minutes. Time spent in counseling and discussion with the patient was over 25 minutes. Topics discussed: diagnosis, imaging findings, prognosis and follow-up plan.
INTERVAL HISTORY:
The patient was last evaluated in the neuro-oncology clinic in October 2008. Since that time, her main issue has been related to difficult seizure management. She has had increasing frequency with a changing characteristic to the seizures over the past few months. The last seizure occurred on Jan. 14th and was a partial seizure. Her aura is now "feeling a little out of it... Things aren't clear... Then something more happens... I'll take ativan... And then afterwards get dizzy, can feel my eyes twitching". It starts in the right hand, stating "it doesn't really feel like it belongs to me" and then may progress up the arm or over the chest. This often causes more anxiety. She notes on Dec 21 had an episode where her chest was "pulsating" and Bret noted "her abdomen was quivering." He had to call 911 at that time.
Patients like me are created every day
Of the 40,000 Google searches made every second, 2,000 are health-related.
Published research

Annals of Internal Medicine
Journal of the American Medical Association
New England Journal of Medicine
American Journal of Medicine
Journal of American Health Information Management Association
British Medical Journal of Quality and Safety
Journal of the American Medical Informatics Association
Academy of Medicine
Journal of General Internal Medicine
BMJ (British Medical Journal)
Journal of Medical Care
Journal of Medical and Internet Research
The Joint Commission Journal on Quality and Patient Safety
Journal of the International Association of Providers of AIDS Care
American Medical Informatics Association
Journal of the American College of Radiology
Journal of Hospital Medicine
Health Expectations
New England Journal of Medicine Catalyst
BMC Medical Informatics and Decision Making
Society of General Internal Medicine Forum

opennotes.org/case-for-opennotes

@TheLizArmy
Patients who read notes...

- Have a **better understanding** of their health and medical conditions
- Better recall and follow their care plan
- Feel more **in control** of their health
- Take better care of themselves
- **Do a better job taking medications** as prescribed
- Can identify inaccuracies in the record and **play a role in the safety** of care
- **Feel comfortable** sharing notes with care partners and others involved in their care
- **Can communicate more clearly**, helping to strengthen the partnership between themselves and their health care team

People are capable of amazing things
You can make it easier for patients to be engaged.
Transparency is logical & ethical
17+ million people have access to clinical notes

OpenNotes available at all U.S. Department of Veterans Affairs Medical Centers nationwide.

More than one organization
One organization
VA only

opennotes.org/join/map
5% of U.S. population
Larry Weed, MD

“A doctor has to be a guidance system. He is not an oracle that knows answers. And once he accepts the concept of being a guidance system … the record suddenly becomes an unbelievably important document in education, in care, and in research … The new knowledge we need now is how to use knowledge.”

Internal Medicine Grand Rounds, 1971

Are you a patient?
Share your notes
Patients & Doctors on the Same Page
Thank you

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