The Horrifying Thought of Trying to Find a New Neurosurgeon

Harold L. Rekate MD
Congenital Neurosurgeon
Director: The Chiari Institute
Professor of Neurosurgery
Hofstra Northshore LIJ College of Medicine
Conflict of Interest

While I have a consultation contract with Codman Corporation I do not perceive any conflict of interest in this presentation.

Personal prejudice: I do not equate pediatric neurosurgery with neurosurgery in a children’s hospital.
Statement of the Problem

There are now fewer neurosurgeons who provide care to both children and adults.

Because of the distinct pathophysiology of hydrocephalus that begins in childhood the skill set and knowledge base of pediatric neurosurgeons may not be available to adults.

Somewhere between the ages of 18 and 25 almost all patients with hydrocephalus cared for in children’s hospitals will require adult centered care.
Thoughts on the Present and Future of Pediatric Neurosurgery

Essay for the 25 meeting of the International Society of Pediatric Neurosurgery
The Players

The patient and the family
The pediatric neurosurgical team
The general neurosurgical team
What We Know About the Significance of the Problem

Of Patients 20-45 years of age with a shunt
73% will have been shunted in the first year of life
40% of these (29% of total) have chronic daily headaches
20-25% have threateningly high intracranial pressure without increase in ventricular size at time of shunt failure
Transition From Patient Perspective

Independence and responsibility for healthcare is the most important goal.
Understand the condition and especially the unique nature of that condition in you.
Prepare a written document regarding challenges of healthcare.
Durable medical power of attorney.
Maintain records and studies (Follow Me™).

HA has an excellent template.
From the Perspective of the Pediatric Neurosurgeon

Practice in Children’s hospital
Are usually underwritten by those systems
Are being produced at less than 10/year in US
Are often hard to find
Over 80% have identified an adult neurosurgical practice to refer their transition patients to
Continued Involvement of the Pediatric Neurosurgeon

1 in 5 are willing to continue to see and care for their own patients now adults
Almost none are willing or able to take on new adult patients
40% are willing to give non face to face advice to old patients
Over 80% are willing to give advice to adult colleagues.
The Perspective of the General Neurosurgeon

Shunts are not interesting surgery
Reimbursement and payer mix are terrible in the treatment of hydrocephalus
Problems require thought which is not reimbursed
Problems occur inconveniently
What You Can Expect from the New Neurosurgeon

“Yes of course I will take care of you when your shunt fails. Come to the EW and have the resident call me.”

“You are too complicated, I cannot care for you”

From the front office staff “just go to the EW and the person on call will care for you”
What You Cannot Expect

That he or she will be willing to peruse moving boxes or thumb drives filled with records and scans
That he or she will believe that a shunt can fail without increase in the size of the ventricles
That he or she is likely to take orders from other neurosurgeons
What's the Answer
Where's the Hope
Be Prepared
What Does It Mean to Be Prepared?

Begin preparing today for the ultimate need for transition of care regardless of age.

Be involved and make certain you understand what is happening, why it is happening and what you have in your head.

Everyone is different and affected by hydrocephalus. It is essential to understand as much as possible how you are affected as an individual.
What You Must Know

What kind of shunt do you have and when was it last revised?
Name of shunt
?programmable, if so setting
Presence of device to retard siphoning
What were you told was the cause of the hydrocephalus in the first place
Probably the Most Important Question

If you have hydrocephalus that began in infancy “do your ventricles expand at the time of the failure of the shunt?”

If yes you may have trouble convincing the emergency physician or new neurosurgeon that this is so. I strongly recommend a statement from previous neurosurgeon and the use of a medic alert bracelet stating this
What Is Accomplished by Performing an ETV?
Be Prepared
Know Yourself
Know Your Issues
In deciding where you will get care make certain that they will do rapid sequence MRIs