


Transition To Adulthood

An Inevitable Challenge



The Work Of Adolescence


- Independence
- Taking responsibility for decisions
- Taking responsibility for medical Care
- Understanding oneself
- The most difficult phase
- Just as hard on parents

Reflections On The Specialty

Pediatric Neurosurgery

- A specialty generated from a technologic advance (the shunt)
- New Opportunities/ New Challenges
- The Geographical Challenge
- The Economic Challenge for Neurosurgeons
- Reflections on Cardiac Surgery, orthopedics and Child Neurology



Unpleasant Economic Realities

- A New Shunt
 - Medicare payment for CPT code for new VP shunt
 - \$770
 - Average number of Physician-patient interactions 9
 - Global period for reimbursement 3 mo
 - Time in OR 60-90 m
 - Skin to skin 45-60 m
 - Likelihood of off-hours call nearly certain
- Lumbar microdisc
 - Medicare payment for lumbar microdisc-single level \$930-1170
 - Average number of Physician-patient interaction 4
 - Global period for reimbursement 3 mo
 - Time in OR: 60-90 m
 - Skin to skin 45-60 m
 - Almost never

Likely Transition Scenario



- Pediatric team
 - You
 - Parents
 - Neurosurgeon or team that knows your specific problems and specializes in the care of people with shunts
 - Frequent involvement of primary care
 - Other players
 - Pediatric facility
- Adult Team
 - ?
 - ?
 - ?

–You

– Neurosurgeon who wants to take good care of you but spends most of his or her time taking care of lumbar discs with only a few shunts in the practice

Adolescent Transition



- Child's team
 - Parents
 - Teachers
 - You
 - Home
 - School
- Adult's team
 - ?
 - ?
 - ?

–You

– Partner hopefully to share it with

Cruel Realities



- Shunt dependency is dangerous and how dangerous varies tremendously among individuals that have shunts
- On in five shunt dependent individuals will have a shunt failure episode that results in coma
- Risks of death may be as high as 1%/year
- There are other risks of shunt infection and blockage
- Timing of shunt failure is never predictable or convenient

Maximizing Safety Of Independent Life



- Understand the cause of your hydrocephalus
- Understand what happens to you when the shunt fails
- Understand what kind of shunt you have
- Be able to access critical information at times of shunt failure
- Have a plan to obtain care wherever you are
- Have a durable medical power of attorney who has the information and who will be contacted

Selection Of New Neurosurgeon In An Ideal World



- Look for a neurosurgeon who practices in a large general hospital with a children's unit
- He or she should be seeing both adult and pediatric patients
- Ideally the pediatric patients seen should be geographically linked somehow
- Should have respectful staff and be someone you are comfortable with

What You Cannot Expect



- He or she will not review a U-Haul truck of old CTs and MRIs
- He or she will not review large volumes of unorganized previous records. Old records are useful to have to compare what is happening now to what has happened in the past
- He or she is not likely to be willing to contact the previous caretakers for more information except to request records
- He or she will be expecting you to have yearly or sequential visits (contact me when your having problems)

Do Your Homework Getting Ready For The Consultation



- It is not ideal to meet your new neurosurgeon first in the emergency room
- Obtain consultation at a time things are going well to establish parameters to obtain care in emergency settings
- Be ready to explain the unique aspects of your hydrocephalus to the neurosurgeon and be able to access the information that is requested without wasting time
- Organize your stuff and your thoughts

<https://google.com/health>



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The Consultation

- Be charming
 - You don't want to be dreaded
- Be organized
- Be patient
- Avoid being overly critical or complimentary of former care settings

Do Your Homework It Is A Vital Process In Becoming An Adult



The Red Badge Of Courage

- As long as there is a shunt the headaches are always the shunt's fault
- The best treatment is no shunt
- If shunt cannot be removed at least the patient can be made normal biophysically and understand the problems
- Non-invasive ICP monitoring would be very valuable, save many thousands of dollars and many hours in ER

Following Imaging Study

