

HEALTH-CARE

TRANSITION GUIDE

FOR TEENS

AND

YOUNG ADULTS

WITH

HYDROCEPHALUS

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The Hydrocephalus Association is a national, 501(c)(3) nonprofit organization founded in 1983 to provide support, education and advocacy to families, individuals and professionals. Our goal is to provide comprehensive services that empower individuals and families to seek out the best medical care, programs and resources that meet their needs now and in the future.

Hydrocephalus is a chronic condition. With early detection, effective treatment and appropriate interventional services, the future for individuals with hydrocephalus is promising. We invite your inquiries.

Resources

About Hydrocephalus—A Book for Families (English or Spanish)

Hydrocephalus Diagnosed in Young and Middle-Aged Adults—A Book for Adults and Their Families

Prenatal Hydrocephalus—A Book for Parents

A Teacher's Guide to Hydrocephalus

Directory of Neurosurgeons

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Quarterly Newsletter

The Resource Guide

Fact and Information Sheets

Annual Educational Scholarships

Annual Neurosurgical Resident's Prize

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Dedication

WE ARE EXTREMELY GRATEFUL to the first generation of people shunted for hydrocephalus for being our mentors and our beacons; for blazing the trail into adulthood, oftentimes with fragmented services and limited options for continuing care. You have shared with us your successes and also your pain and frustrations. You are our heroes and our heroines.

We also express our gratitude to the men and women who have chosen to devote their medical practices to a specialty in pediatrics. Interest and expertise in the management of hydrocephalus has advanced and expanded hand in hand with the growth of pediatric neurosurgery. We are indebted to those pediatric neurosurgeons who have formed partnerships with us at the Association to provide support, services and resources to our unique community, recognizing the potential for a life of quality and dignity for every person with hydrocephalus.

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Introduction

HYDROCEPHALUS IS A CHRONIC MEDICAL CONDITION, meaning it is a lifelong condition that has no cure. In most cases, however, the symptoms of hydrocephalus are managed with a shunting device. The first generation of children successfully treated for hydrocephalus are now in their late 30s and early 40s. While there have been many advances in the diagnosis and treatment of hydrocephalus over the years, there remain many challenges—most notably, continuation of comprehensive medical services and care for teens and young adults after childhood. This booklet will discuss the process of making the transition from pediatric-centered to adult-centered medical care, and provide strategies, resources and encouragement to the second generation of children shunted for hydrocephalus and their families.

The goal of this Guide is to give teens, young adults and their families the tools they need to understand and implement the transition to adult-centered medical care. We will:

- Discuss the current climates of both pediatric and adult-centered care.
- Present techniques for evaluating your current health-care situation.
- Provide planning materials to assist you in preparing for transition.
- Share strategies that will support, empower and guide you.

We have made every attempt to keep the tone of the Guide conversational and nonjudgmental. It is addressed directly to *you*, a young person with hydrocephalus; this is our way of celebrating your potential and your journey to independence. Depending on your age, your parents or a friend may be reading this Guide with you, helping you get started with your transition planning. We also hope that it will be read by parents and medical professionals. An essential component of this process is self-determination (which we will discuss later in the Guide), and to this end we encourage your parents and members of your health-care team to help you start taking control of your life and your future *right now*.

Throughout the Guide, we use quotes from real-life experiences, and point you to further information in appendices to this booklet. At the end of the Guide is a series of worksheets to help you on your transition journey. We hope you will find them helpful and easy to use. Depending on your age and level of independence, you may want to work on some of them jointly with your parents, doctors and others on your team. You should redo them as you grow and mature—you can chart your progress as you complete certain tasks and obtain new skills and knowledge. Remember, these are *your* documents and they should tell *your* story.

The resources and references for this Guide have been many and varied. We tapped into 19 years of experiences here at the Association; we have researched and read many articles and journals, and we have spoken to many “experts”—those with lots of letters after their names and those with years of personal experience. We are indebted to all who have written on transition and we have made every effort to give credit where credit is due in the bibliography.

We hope this Guide will educate and empower you; we celebrate with you, and your family, as you journey toward adulthood and independence.

Why Transition?

IN RECENT YEARS, the majority of children with chronic medical conditions, including hydrocephalus, have been receiving their medical care in a pediatric-centered environment. Ideally, that care is family-centered, continuous, coordinated and compassionate. For children with hydrocephalus—like you—and their families, the neurosurgeon often becomes the health-care team leader, intimately involved in directing care from the time of initial diagnosis well into young adulthood.

It is not surprising, then, that you and your parents have come to expect that comprehensive, compassionate neurosurgical care will continue into young adulthood and beyond. For a few of you, that indeed has been the case, as some doctors and/or medical centers extend care into adulthood for their pediatric patients. Realistically, however, pediatric-focused medical care ends at either 18 or 21, and ready or not, the challenges can be considerable if transition plans have not been put into place.

The goal for all children, whether or not they have a chronic medical condition or a disability, should be to move progressively from dependence toward independence, gathering life skills that promote healthy self-esteem and self-sufficiency. All children need to be encouraged to develop attitudes, skills and knowledge that empower them to control, as much as possible, their own destiny.

As your parents encourage your move to independence, they must be willing to let go of their control, allowing you to make mistakes and encouraging you to use problem-solving skills to cope with challenges. Fostering opportunities, even at a very young age, to develop self-confidence, self-esteem, feelings of value by others, determination and a positive outlook will ease your way, preparing you for your transition to adulthood and a more independent lifestyle.

Successful transition in health care requires the cooperation and commitment of you, your parents, your current doctors and the new providers of adult health care. It should begin years before you age out of pediatric services. Successful transition requires communication and collaboration among primary-care specialists, subspecialists, you and your family.

 A study of adolescents age 11 to 14 done in the late 1980s revealed that 57% were unable to discuss or explain their disability and 50% of them who were taking medications could not name the medications or give the reason for which they were being taken.

What Is Transition?

“Transition is a process, not a single event.”

TRANSITION IN ADOLESCENCE is the movement from child-centered to adult-oriented activities. It is a process that depends on early education and coordination of effort by all involved persons. There are three major areas in transition:

1. From the school environment to the workplace.
2. From home to community living.
3. From child- and family-centered medical care to adult-oriented health care, which is the focus of this Guide.

It is important to understand that transition is a complex process that includes and incorporates competency and self-development in many areas. Health-care transition is a multifaceted, active process that can facilitate transition in other areas—such as work, community and school. It involves an increase in independent behavior, personal autonomy, competency and self-awareness.

“I don’t want to make the transition...I am very afraid.”

Transitions are part of normal, healthy development and they will occur across your life span. The goal is to maximize lifelong functioning and potential. To reach this goal you must be provided with high quality and appropriate health-care services. Your transition process needs to be patient-centered, and its cornerstones are flexibility, responsiveness, continuity, comprehensiveness and coordination.

The first step on your journey is to think about the medical care you’re receiving now. It is most likely pediatric-centered, perhaps even based at a children’s hospital. So let’s begin by discussing the differences between pediatric and adult-centered care.

Pediatric vs. Adult-Centered Care: What's the Big Deal?

THERE ARE A NUMBER OF WAYS in which pediatric-centered care differs from adult-centered care. As each person's experiences are different, not all the elements we discuss here will apply to you. The important thing to keep in mind is that for all young people, change in care will happen whether it's planned or not, so being prepared is an important step on your journey to independence.

Here is a list of some of the ways in which pediatric-centered and adult-centered care are different, with examples:

1. Experience with and interest in hydrocephalus
2. Personal relationships/emotional environment
3. Physical setting
4. Delivery and coordination of services
5. Legal issues

We will discuss each of these in detail below.

1. Experience With and Interest in Hydrocephalus

The estimated incidence of hydrocephalus is one out of every 1,000 births. Hydrocephalus is the most frequent neurosurgical problem encountered in the pediatric population, and it occurs in nearly one third of all congenital malformations of the nervous system. Many sources relate the growth of pediatric neurosurgery over the past 20 years directly to the improvement in diagnostic techniques, treatment protocols and improved shunt hardware for hydrocephalus, as it is believed that shunting procedures comprise roughly half of most modern pediatric neurosurgical practices.

One of the major challenges in transitioning of medical care is finding a neurosurgeon with interest and experience in hydrocephalus. Unlike their pediatric-focused colleagues, adult-focused neurosurgeons usually have seen few cases of hydrocephalus. As we mentioned

“It must be emphasized that any neurosurgeon that accepts the responsibility of caring for an infant with hydrocephalus is making a long-term commitment to the well-being of the child that in all likelihood will continue throughout the professional career of the neurosurgeon. This commitment extends beyond monitoring shunt function and includes long-term responsibility for supervising the treatment of a multitude of potential surgical and nonsurgical problems which may include seizures, psychomotor retardation, neurological disability, behavior disorders, etc. While many of these ‘long-term complications’ may not be related to shunt obstruction, it is the responsibility of the neurosurgeon to make that assessment and to assume responsibility for making the proper referral should other expertise be necessary.”

—Fred Epstein, M.D.

“A fundamental concept of pediatrics, pediatric surgery and pediatric neurosurgery is that ‘the child is not a small adult.’ Our entire subspecialty of pediatric neurosurgery is built around this concept and around the special needs of children, the particular diseases that they have, and the technical and physiological concerns of operating on the nervous system of a child. As neurosurgeons, we are members of a wonderful family of neuroscientists who all work together for the benefit of our patients as they progress from their childhood into adulthood.”

—Edward R. Laws, M.D., past president of the American Association of Neurological Surgeons

earlier, the first generation of children successfully treated with shunts is just now into adulthood, so it’s not surprising that adult-focused neurosurgeons have little knowledge about caring for people who have been shunted since infancy. These neurosurgeons often have little direct experience with hydrocephalus and they may be unfamiliar with recent diagnostic and treatment protocols. Multiple revisions and subtle signs of shunt malfunction may not be very familiar for them.

Additionally, there are a lot of unknowns about lifelong medical care and potential problems in shunted adults, as the first generation is just now in their early 40s. There are few, if any, case histories, research studies, statistics or textbook chapters to guide the doctors. They most likely have had little or no formal training in the specifics of pediatric disorders like hydrocephalus and are therefore ill-prepared to handle complex conditions that extend into adulthood.

We continue to meet adult-focused neurosurgeons who shake their heads in disbelief when we talk about young adults with hydrocephalus and the problems they have with their shunts. However, it’s our experience that this trend is slowly changing. We strongly suggest that you use your pediatric neurosurgeon as your guide in helping you identify a doctor who will welcome you into his or her care.

2. Personal Relationships/Emotional Environment

It is not unusual for children and their parents to form very strong attachments to the pediatric neurosurgeon that go beyond the typical doctor/patient relationship. One doctor, most likely, has been your primary caregiver for many years, fixing you up when you were very sick with a malfunctioning shunt—usually more than once. You and your family have a great deal of confidence in your neurosurgeon—he or she knows your brain inside-out—and they, no doubt, have been with you and your family during times of crisis, providing not only medical expertise but also support and a sense of reassurance to your troubled family. This level of trust is deeply rooted, and it’s scary to think about breaking these special bonds.

For the most part, it has been our experience that pediatric neurosurgeons are particularly caring, nurturing people who have chosen their professional career carefully. They thrive on the medical challenges, certainly, but they are also deeply committed to improving the quality of life for their young patients. They are often very closely involved with you and your overall medical care, and it gives them great pleasure and a real sense of accomplishment to watch you grow up.

One of the most comforting and unique aspects of pediatric neurosurgery in general, and in hydrocephalus specifically, is the emotional bond that develops between the doctor, you and your family. It is not unusual these days to hear eminent hydrocephalus experts declare that “mom knows best.” What these doctors are referring to is an all-too-common situation: You are a sick child with little or no concrete or measurable evidence of a shunt malfunction. Your mom—and then you, as you grow older—knows that there’s a shunt problem and the neurosurgeon trusts your judgment and intervenes, even though the tests and scans can’t pinpoint a problem.

The uniqueness of this powerful emotional bond and trust is hard to duplicate. As we have already stated, adult-focused neurosurgeons rarely have the experience and expertise in hydrocephalus that their pediatric colleagues do, nor do they have many years of personal history with you. It’s a stretch for them to rely on your word that you’re having a shunt problem, and it can be an emotionally challenging and upsetting experience for all involved.

While we hope this Guide will give you tips and strategies on finding an adult-focused neurosurgeon with whom you will be comfortable, it is important for you to understand that this very special relationship with your pediatric neurosurgeon probably will not be replicated in the future. You may need to find other sources for the kind of support that your neurosurgeon has been providing. It’s okay to ask for help, even after the transition to a new doctor has taken place.

3. Physical Setting

Many pediatric neurosurgical practices are located in, or closely associated with, children’s hospitals. Often there are playrooms, food courts that cater to kids’ tastes, child-life specialists to provide counseling, orientation programs that encourage children to ask questions about their surgery and/or upcoming hospitalization, facilities for parents to stay over in their children’s hospital rooms or in nearby family-centered residences, and other amenities geared to children and families. While it would be stretching things to say that nurses dressed in casual clothes, a cheeseburger and fries for lunch or a playroom filled with toys can make up for the fact that you’re in the hospital, all these amenities and attention to the very real needs of children are unique to the children’s hospital environment.

On the positive side, young adults have told us that while they miss some of the perks of the children’s hospital, a 21-year-old sharing a room with a two-year-old and receiving a Band-Aid with a smiley face is not very validating that they have matured into adulthood.

“As a doctor, I think transition into adult medical care is very important. It makes kids with special health-care needs feel like everyone else, and it gives them a vision that they are going to survive and go about their business like everybody else.”

“First of all, I always ask a youth, Are you seeing your doctor by yourself? By the time they're moving into their mid-teens, it's time for them to have developed a relationship in some format with their doctors that's one-to-one.”

“A few months ago, I had some severe headaches, abdominal pain and a couple times felt like I was going to pass out. It wasn't the same feelings I'd had with my previous shunt malfunction, but I still felt like they should be checked out. I had to go to a new neurosurgeon, and he excused every one of my symptoms, saying something like, 'You're fine. Everything looks great.' I was shocked to be so easily dismissed. Then he said that if I ever knew I needed surgery to come back and see him. He made it sound like I'm supposed to have outgrown my condition because I'm an adult. I would really love it if that were the case, but that's the first I've heard of it!”

4. Delivery and Coordination of Services

The manner in which care and services are delivered and coordinated in the pediatric setting is often very personalized. Not only is the physical environment warmer and more welcoming, the overall delivery of a multitude of services is commonly coordinated and directed from within.

It is not unusual for children with hydrocephalus to receive a wide variety of services. As an infant, you may have received interventional services such as physical therapy (PT) or occupational therapy (OT), in your home or in a play-group-like setting. Depending on the cause of your hydrocephalus or any associated conditions, you may still receive PT or OT; you may see a neurologist, an ophthalmologist, an endocrinologist and other medical specialists. You may have scans on a regular schedule, take medication on a daily basis, see a counselor or a therapist or be part of a multidisciplinary clinic.

Many of these services are coordinated or overseen by the staff in your neurosurgeon's office. A clinical nurse specialist or a nurse practitioner is quite often a valuable and integral member of the health-care team working in the neurosurgeon's office. Although their role may be to manage and coordinate services directly related to your neurosurgical care, they are often the health-care team leader, making appointments for your scans, connecting you and your parents to outside services and other medical specialists, and being available by telephone or email to answer your or your parents' questions.

It often falls to the doctor, or one of his or her staff, to authorize services for schools and other public and private service providers, as well as complete paperwork for insurance companies, social-service agencies, camps, schools and so on. Once you make the transition to an adult-focused neurosurgical practice, this one-stop coordination of services is likely to end—and in most instances, the responsibility of pulling it all together will fall to you, and those you have chosen to assist with your transition.

It's also very likely that your neurosurgeon has been the person you and your family turn to for help in special circumstances. We have heard of many situations when a school refused to allow a student with a shunt to participate in regular physical education classes, or even class field trips and outings. In many cases, it's the neurosurgeon who writes a letter on your behalf, stating that your activities should not be restricted just because of your shunt.

It's very possible that some of the services you have been receiving will stop once you reach adulthood. Services for adults are not always as readily available, and even when they are, accessing them can be difficult. It is unlikely that anyone in the adult neurosurgeon's practice will be available to help you coordinate a multitude of services—not

because they are uncaring but because they do not have the knowledge or extensive experience with them.

5. Legal Issues

When you reach the age of 18, you are legally considered an adult. This means that your parents and/or your family have no legal right to make medical decisions for you. Should you fall ill with, say, a shunt malfunction, they have no legal right to your medical records and no say in your medical care, and they cannot automatically make health-care decisions for you. Unlike the care and treatment you receive as a minor (under the age of 18), your parents cannot make medical decisions for you.

For example: You're away from home—perhaps in college—and you end up in the emergency room. Hospital personnel can legally deny your parents information about your situation, including access to test reports. If it's a possible shunt malfunction and you haven't gone through transition and established a relationship with a new neurosurgeon, it could happen that decisions are made about a treatment plan for you by medical professionals that you don't know.

You can take control of this situation as part of transition planning by signing a Durable Power of Attorney for Health Care (DPAHC). A DPAHC gives the person, or persons, you designate as your agent the power to make health-care decisions for you in the event you are unable to do so. The person (known as your agent) you designate must act consistently with your wishes as stated in your DPAHC. This notarized document gives your agent the power to access your medical records, give consent for specific treatment or for not giving specific treatment.

You retain the power to speak and sign documents for yourself (and your parents can't overrule your decisions) and you can revoke or cancel the DPAHC. However, in an emergency this document insures that someone you designate is acting on your behalf, according to your wishes, and has access to your doctors, test results and medical records to insure that you're getting the specific care and treatment you need.

Creating a DPAHC is a smart, sensible and mature action for you to take during the transition period. It helps to give your parents peace of mind; it reflects your move into adulthood; it makes independent living a more safe and comfortable reality; and it helps to insure that you receive the best possible treatment in an emergency situation. A sample copy of a DPAHC is included at the end of this Guide.

“Another responsibility involved in being an adult is dealing with signing papers before undergoing surgery. Signing papers is not always the easiest of tasks when experiencing a shunt malfunction with blurriness, hard time focusing and even weakness. . . . I came across a situation where I was experiencing a really bad shunt malfunction and the hospital would not let my parents sign the papers because I was of age and the hospital could not find my Durable Power of Attorney on file. The papers had to be brought back up to me so that I could sign them.”

The Four Key Elements to a Smooth, Successful Transition

THERE ARE FOUR KEY ELEMENTS necessary to a successful transition:

1. Self-determination
2. Family support
3. Professional support

Taken all together, these three lead to your fourth goal:

4. Self-advocacy!

1. Self-Determination

Self-determination is a person's ability to control his or her own destiny. It is a significant change from earlier approaches in which decisions for persons with disabilities and chronic medical conditions were made by professionals, with little regard for the person's own desires and hopes for the future. Self-determination encourages the development of attitudes, skills and knowledge that empower you to control your own destiny, as much as possible. Self-determination is an integral part of transition, as it recognizes and honors your right to actively participate in decisions regarding your future.

To become an active participant in creating your destiny, you need to develop certain qualities, attitudes and beliefs: self-confidence, self-esteem, feeling valued by others, determination and a positive outlook. You need skills such as goal setting, decision making, self-advocacy, problem solving, communication, social interaction and independent living. Just as important, you need knowledge: knowledge of self, of resources and systems, and of your rights and responsibilities. No matter how complicated your medical condition might be, you have the right to actively participate in decisions regarding your own destiny to the best of your ability.

For the transition process to be successful, it must be based on the concept of self-determination. You have the right:

“Only you can tell when something isn't right. You can truly be your own best advocate.”

“Independence doesn't mean going it alone and doing everything yourself. It's okay, and important, to know when to ask for help.”

- To be asked directly and repeatedly for your opinions and preferences, and to have the decisions incorporate your views.
- To make mistakes. Learning to make decisions is part of the journey to adulthood. Finding people you trust and ways of encouraging you through this learning process will over time lead to better decision making. If you aren't engaged in decisions regarding your future, you are likely to lack confidence, mistrust your own judgment and even expect your opinions to be disregarded.
- To be encouraged, from a young age, to participate in decisions regarding your own destiny. No one can fully know what another person is capable of without allowing that person to demonstrate and grow in their capabilities. The adults in your life must not lower the level of expectations they have of you based on their own, or others', perceptions.

“It's more powerful when I speak for myself than when my parents do it for me.”

The process of transition means not only mastering a new set of skills but also experiencing a change of attitude—from dependence to independence—an attitude that should be fostered throughout your life. You must also learn, however, that it's okay to ask for help, and to recognize when you need to do so. Understanding your strengths and weaknesses, even your limitations, and knowing when to ask for help is an important part of the transition process.

Transition will be smoother when you have a good understanding of hydrocephalus and your unique medical needs, and when you have taken on some of the responsibility for your own care throughout childhood, such as recognizing a possible shunt malfunction, knowing your doctor's name and telephone number, how to make an appointment and so on.

You should be given opportunities to make decisions about your own health-care role. Parents and professionals should encourage you to maintain your own portable health-care records (*see the FollowMe resources in Appendix C*) and to begin functioning as your own “care coordinator” whenever possible. They should support you in your new role, and when you're ready, they must let go.

As we said earlier, this Guide is about you and you should be the focus of any transition. *This is your life*. Self-determination means that you, your family, friends, doctors, teachers and others work together to empower you to control your own destiny, as much as possible.

“I have learned to question things when it comes to my health. Take charge of your care, know how to access resources and don't be afraid to ask questions.”

2. Family Support

Most likely your family has been the cornerstone of your life since birth. Your parents have planned, connected, advocated and become

“Encouraging trial and error can't be emphasized enough. It's so important to learn from our own mistakes. For our daughter Amy, we stopped charging the battery on her wheelchair, unless she asked us to. That meant that if the battery went out, there was a 300-pound chair to push. When that happened, Amy would hear about it from us and her friends. That was in second grade. She learned that if she wanted to move the next day and not have a bunch of people griping, she had to be in charge. Age eight was not too early to get those kinds of skills going.”

“I was letting go of being parentally involved in the events of my children's lives, while still yearning to feel connected and protective of them in the old way. This resulted in a bitter-sweet sense of loss. We know we must foster their development towards independence, but how do we make the internal shift in order to encourage them on their way?”

educated on your behalf. Now is the time for you and them to join forces as you take a more active role in managing your health care. This section will discuss several aspects of health-care transition: the need for you to take on increased responsibility your own health care, and the need for you and your family to plan for the transfer of your care from pediatric providers to adult providers.

All parents hope that their children will become independent, happy, fulfilled individuals. This should be no different for parents of children with hydrocephalus. Certainly, there may be obstacles and challenges along the way, but with family love and support, your independence can be accomplished.

It's important to understand that for most parents it's hard to let their children make their own decisions, and the inevitable mistakes that go along with that. When the child (you) has a complex medical condition like hydrocephalus, the process of letting go and empowering you can be even more difficult and heart-wrenching. They have seen you in pain, they have tended to you in the hospital. They want to make life easy and wonderful for you, and without really thinking, they may have overprotected you.

One of the first places for you to demonstrate your readiness for transition is with your parents. You can help them help you move toward independence. You might begin by thinking about things that they do for you that you could do for yourself. *For example*, you have a checkup coming up with your neurosurgeon. You think this is just a waste of time—another few hours away from school and friends, another scan, and your mom and the doctor chatting away as though you weren't in the examining room. Well, you *are* in the room and they're talking about *you*—this is your chance.

Begin by preparing ahead of time. With your parents, plan what you would like to happen during the appointment. Make a list; think of things you'd like to know about hydrocephalus, anticipate questions you might be asked and the answers you might be giving. (*See Appendix D for a sample list of questions to ask your doctor.*) Make notes together and take them to the appointment. Role-playing is a great way to practice communication skills. By anticipating different situations, and being prepared for them, you will have greater confidence.

At the same time that parents encourage independence for their kids, they must also be willing to let go of control. (*See Appendix A, "Tips Just for Parents."*) With encouragement and support from your family, you can take an increasingly more active role in your own health care. Your family can help you identify a support system early on. Talk together about who you can trust and feel comfortable talking to. You need to have people you can turn to for help, especially when you leave home.

3. Professional Support

Doctors—and particularly neurosurgeons who treat children and teens with hydrocephalus—have a responsibility to encourage your independence and actively participate in your transition process. Just as you and your family transition toward your independence, so must your pediatric health-care providers be ready for your transition. Medical professionals must invest their time to transfer the information and coordination of your medical care among many specialists in the process of your transition from pediatric to adult care.

The process should be planned in advance, rather than take place during a medical crisis, and it should take place gradually, allowing you to be responsible for as much self-care as early as possible. As a patient, you should be encouraged to ask questions during medical appointments. The doctor should direct questions to you, not your mom or dad, and they should be addressing your needs and concerns. As we said earlier, you should go to appointments with your own list of questions for the doctor. And when you're ready, it's okay to ask for some time alone with your doctor, without your parents in the room. Showing that you are interested in taking on more responsibility will encourage the doctor to respect your growing independence and maturity.

Medical professionals should also be willing to help identify adult health-care providers, including an adult-focused neurosurgeon, who will be taking over your care. Included in this Guide is a list of questions for you to consider asking your doctor. (*See Worksheet 5 in Appendix D.*)

Your doctor is of special importance in your transition and we hope that you are comfortable looking to him or her for guidance. Successful transition requires communication and collaboration among all primary-care specialists, subspecialists, you and your family. Whether or not your transition entails a transfer of care from pediatric services to an adult neurosurgeon, you deserve the same optimal medical care as an adult that you had with your primary-care specialists when you were younger.

Creating and maintaining a good relationship with your doctor is one of the most important elements of your overall health-care planning. To insure the best possible outcome, there needs to be an atmosphere of mutual respect where you both participate actively in the decision-making, planning and evaluation process. In terms of specifics, either the pediatrician or the neurosurgeon should:

- Be prepared to have an orientation with you and your family that is future-focused and flexible. This involves an awareness of your future demands and expectations of living as an independent young adult as well as specific goals and dreams.

Above all else, doctors can and should, in the words of Robert W Blum, M.D., Ph.D., "celebrate transitions." Celebrate transitions just as they occur with graduation ceremonies, certificates of completions and other rites of passage.

- Have an open discussion on your readiness as a patient to function as an adult in an adult setting.
- Work with you to identify specific issues and develop a plan. This might include suggesting a new doctor and giving you an introduction to that person.
- Help you anticipate changes in your medical needs and develop a flexible plan for the future—a plan that includes such issues as insurance coverage, health-care providers, equipment if needed and skills necessary to navigate the adult health-care system.
- Help foster your personal and medical independence and creative problem solving—this should start at or near the time of diagnosis or when you were very young. If it hasn't, now is the time to begin.

Family members and health-care providers can also foster personal and medical independence by teaching you to be responsible for as much self-care as early as possible. *For example*, if you take medication, you should understand why the medication is needed and what the medication is supposed to do for you, and you should learn to be in charge of taking your medication.

The Neurosurgeons Speak

Many of the pediatric neurosurgeons we know and work with are just as concerned as we are about the transition process. Here is what some of them had to say:

“It is important for the patient to be seen on a regular basis at times when shunt failure is not expected. There are three goals to this surveillance. One goal is to ascertain the probability that the patient will experience an insidious shunt failure that is not obvious to the caregiver. Such failure to diagnose could lead to death, blindness or a decline in intellectual performance. Such insidious shunt failures can be seen in many different contexts but is most commonly in the context of spina bifida. The second goal is to ensure that the patient and the patient's family are educated with regard to the functioning of the shunt and the signs and symptoms of shunt failure. Possibly the most important aspect of shunt surveillance is to ensure that the patient has access to medical care in a timely manner at the time of shunt failure.... Recent experience has shown that care sought at an inappropriate location can lead to a life-threatening delay in treatment.

“The follow-up of these patients is the responsibility of the neurosurgeon.... What is important is that whoever performs the

evaluation should be thoroughly schooled in the evaluation of shunt dependent patients, be willing to let the patient and the patient's family speak about potential problems, understand the need for a rapid response and be able to converse with the treating neurosurgeon immediately and frequently about problems that have been identified.”

—*Harold L. Rekate, M.D.*

“A CSF shunt, like any prosthetic device, requires lifelong medical follow up monitoring, which ideally should be provided by the surgeon who inserted the shunt. Children with shunts, as well as their parents, should be educated and made aware that medical visits and revisions are part of their lives.”

—*Matthieu Vinchon, et al.*

“While physicians who are experienced in shunt management will not rely exclusively on CT scans in the assessment of shunt function, a relatively inexperienced physician may. A physician could, for instance, wrongly assume that a CT scan, which shows the ventricle to be ‘unchanged,’ indicates that the shunt is working properly. Acute deterioration due to shunt failure may occur relatively quickly.... Explicit hydrocephalus and shunt care guidelines should be given to patients, families and primary caregivers and the urgency of diagnosis should be emphasized.”

—*Jerry Oakes, M.D., et al.*

“As the number of patients with shunts increases, neurosurgeons and obstetricians will be faced more frequently with the problem of managing women with hydrocephalus in pregnancy. Careful management by a team of obstetricians and neurosurgeons will enable these patients to accomplish a successful pregnancy.”

4. Self-Advocacy

Self-advocacy is the ability to understand your strengths, identify your needs and personal goals, know your legal rights and be able to communicate these to others. With each element, you will develop the ability to advocate, or speak up, for yourself. In the past, self-advocacy was a term applied mostly to adults with disabilities, but recently more focus has been placed on teaching these skills to preteens and teenagers. A key component of self-advocacy is knowing how to communicate knowledge about yourself to others. You will become a partner with health-care professionals instead of the object of their treatments. You accept responsibility for decisions because you are the person who will live with those decisions.

Your parents have probably been your biggest and best advocates so far, doing their best to protect you from life's harsh realities. While this was fine when you were little, the earlier you learn to advocate for yourself, the more prepared you will be for your adult life ahead—especially with issues facing you with your health care.

Self-advocacy will give you a deep sense of empowerment and fulfillment, and bring you closer to realizing your dreams. The ability to self-advocate is important for you to learn in order to be successful at every stage of your life, not just with your health care. And remember, this journey to independence is not meant to be a solo flight. Asking for help when you need it is a sign of strength and maturity.

There are five steps to self-advocacy:

- 1. Self-advocacy begins with *self*.** Never doubt what your body is telling you—no one can know how you feel as well as you do! This does not mean that you can or should try to figure out what every symptom means. It means that you should feel comfortable discussing what is important to you with your doctor. You should be taken seriously by every medical professional you come in contact with.
- 2. Educate yourself about your medical condition.** *For example:* You should know what caused your hydrocephalus, the type of shunt you have and the signs and symptoms of a shunt malfunction. Know where to go for help and resources. Use the Hydrocephalus Association as a valuable resource and support tool. Join advocacy groups such as KASA (Kids As Self-Advocates). (*See Appendix C for a list of resources.*) There are many great Internet sites associated with neurology and neurosurgery that have wonderful information. If you find something on a website that may be valuable, print it out. Having the information on one page is helpful if you bring it to an appointment.
- 3. Learn about the health-care system.** *For example:* Many people are being placed into managed-care plans. In these plans, you do not have the ultimate decision-making authority over what services you receive (at least not if you want the plan to pay for them). Before you run into any problems, check to see if the plan has a patient advocate—someone who has been hired to consider *your* needs as a patient and who can help you get the most out of the system. Find out if there is an appeals process in case your doctor recommends a procedure that the plan does not automatically cover.

Knowing how to make the system work saves time and grief and helps you get the best medical care you need with as little delay as possible. *For example:* If you think you are having shunt failure symptoms, you need to be seen as soon as possible by your neurosurgeon, who will want to have a CT/MRI scan done. You will need to know what the procedures are to get the scans, what your plan covers and how those services are coordinated.

4. Take action. Use your knowledge to communicate with your specialist. Effective communication is a two-way street. *For example:* At an appointment with your neurosurgeon, talk to them about what you know about your shunt and the cause of your hydrocephalus (show off a little bit!), and ask if they have any more information to share with you. Tell them you want to educate yourself to the best of your ability about your hydrocephalus. Different people have different expectations for their relationships with their doctors—that's normal. The best way to know you have a good match with your doctor is to have frank and ongoing communication.

5. Think about how you want to deal with other doctors and medical professionals in your life. When you have hydrocephalus, it can enter into every other medical relationship you have. *For example:* For all young women, it is important to have regular checkups with a gynecologist. Your ob/gyn needs to know about your hydrocephalus, and during pregnancy should be collaborating with your neurosurgeon.

Beyond the health-care system is your real life. You can bring self-advocacy skills into your non-medical relationships, too. By doing this, you extend your philosophy about wellness and medical condition to all realms of your life.

Finally, as a self-advocate, *know your rights and the laws that protect you.* Federal laws include the Americans with Disabilities Act (ADA) and the Fair Housing Amendments Act (FHAA).

Develop and use whatever resources you can, including government agencies, elected officials and advocacy organizations such as the Hydrocephalus Association. Attend workshops and conferences that are pertinent to your needs. Get involved! Assert yourself!

Remember: *You take control of how your hydrocephalus fits into your life, rather than waiting to see how your life takes shape around your hydrocephalus.*

Transition—The Plan

TRANSITION PLANNING CAN BEGIN AT ANY AGE, and while it may not be labeled as such, it should be a part of your life from an early age. It's a long-term process that changes and adapts to your level of awareness, and the focus will, and should, change as you mature. As we describe the general plan, we will refer to various worksheets that are provided at the back of this Guide, in Appendix D. We suggest that you make copies of the worksheets, as you will likely redo them as you grow and mature toward independence.

1. Ready! Assess the current situation.
2. Set! Define and set your immediate and long-term goals.
3. Go! Put *your* plan into place.

1. Ready!

► See Worksheet 1, on page 40.

The first worksheet, titled “Who Am I?,” is on page 40. It is designed to be filled out every couple of years—first, if possible, between ages 8 and 12, then later as a teenager. We suggest making copies of the worksheet and keeping completed ones in a folder, so you can track your progress and see how your skills and goals have changed over the years.

Once you've completed “Who Am I?” and have a sense of who you are and what your goals are, it's time to start thinking about your hydrocephalus and your health care in general. The next worksheet, on page 42, is called “Ready to Manage Your Own Health Care?” and it will help you assess your current situation and make suggestions for things you should know how to do. For example,

► See Worksheet 2, on page 42.

- **Know about hydrocephalus and be able to explain the symptoms.**
- **Know the names and phone numbers of your doctors.**
- **Know who to call and how to schedule appointments.**

- **Know what to do in an emergency.**
- **Have a contact list on hand of people close to you who understand hydrocephalus and shunts.** These are family and friends you can call on when you need them, in an emergency or otherwise.
- **Learn to take medications and understand the effects of treatments and medications associated with your hydrocephalus.**
- **Take charge of your medical records.** *For example:* Sign up for FollowMe. com, a website designed to empower people by keeping important medical information stored in one location, on the Internet, so it can literally “follow them” wherever their travels take them throughout their lives.
- **Understand your insurance policy.** If you’re still covered by your parents’ insurance, find out how long (until what age) you can stay on their policy. If you’re going to work, find out if the job offers health insurance and, if so, how much will it cost each month, and whether your doctors and hospitals are covered by the insurance.
- **Learn how to speak up for your needs—self-advocacy.**

2. Set!

Having completed the worksheet “Ready to Manage Your Own Health Care?,” you should have a good overview and understanding of your health-care needs. Below are some suggestions for concrete goals to help you manage your own health care. You should be able to:

- **Describe the signs and symptoms of a shunt malfunction.**
For example: When I have a shunt malfunction, I get a bad headache and I throw up a lot. Sometimes it feels like the flu, but I know it’s not.
- **Describe your medical condition and any treatments you have had.**
For example: I have hydrocephalus and it is a chronic (lifelong) medical condition (not an illness or a disease). My hydrocephalus is managed by a shunt that is implanted in my brain.
- **Describe the long-term complications of your condition.**
For example: I have seizures and I take pills to control them. It’s important that I take them at a certain time of each day.
- **Know what to do and whom to see if you have a shunt malfunction.**
For example: If I think I am having a shunt malfunction, or a problem with my shunt, I call my neurosurgeon’s office and talk to Betty

the nurse. If it is at night or on the weekend, I leave a message on my neurosurgeon's answering machine, then I get my friend Mike to take me to the emergency room at Hope Hospital.

- **Keep a file with your medical records—including recent scans—and wear or carry information that identifies the fact that you have hydrocephalus and a shunt.** *For example:* I have all my medical information online with a service called FollowMe and I also have copies of my scans in the top drawer of my desk. My brother and my friend John know about my records on FollowMe and they know where I keep my scans. I also have a shunt card, which I update every time new scans are made.
- **Know how to obtain a second opinion when you need one.** *For example:* My new adult-care provider is not taking my headaches seriously, tells me to take Tylenol and rest. I feel sure these are high-pressure headaches and I should have scans and other tests done to make sure they aren't shunt-related. I'm going to get a second opinion from another neurosurgeon who I found listed in the HA's *Directory of Neurosurgeons for Adults*. I have copies of all my medical records and latest scans to take to the new doctor.
- **Understand and sign a Durable Power of Attorney for Health Care (DPAHC).** *For example:* Now that I'm over 18, a DPAHC is a critical tool for me to have. The designated people who are listed on the form are authorized to make medical decisions for me if I am unable to do so myself. I keep a copy of my DPAHC in my top drawer and Aunt Susan, who is one of those authorized to make decisions for me, has a copy. (*See Appendix D for a sample DPAHC form.*)
- **Name several people who love you and have a good understanding of your hydrocephalus, the shunt and the problems that can arise for people with hydrocephalus.** (Some of these people may be good people to have designated on your Durable Power of Attorney.) *For example:* My family and several close friends at college, including my roommate Ann, have complete understanding of my hydrocephalus and know what shunt failure signs and symptoms look like. They have the emergency contact numbers for where I need to go if I show signs of shunt problems.

Now that you're ready to manage your own health care, it's time to begin the transition process by setting some goals. The third worksheet, "Individual Transition Plan," will help you chart out your long-term goals.

When you feel you are ready to take the first exciting step in begin-

► See Worksheet 3, on page 43.

ning to manage your own health care, sit down with your parents with this Guide and discuss what you have read. Remember: Transition is a gradual process and requires a change of attitude—that is, from dependence to independence.

3. Go!

Having determined you are ready, it is time to put your transition plan into place. The fourth worksheet, “Getting from Where I Am to Where I Need to Be,” is designed to help you make your dreams a reality.

After you’ve completed Worksheet 4, you’re ready to take some action. A great first step would be to call and make an appointment with your neurosurgeon to discuss transition. The appointment would not be your annual/biannual examination but rather a special time for discussing your future health-care needs. This appointment would be a good time to practice your self-advocacy skills by being the one to ask the questions with your parent in the room as a support person/second pair of ears.

It’s a good idea to write down all your questions—or, even better, when you make the appointment ask if you can send your list of questions to the doctor to review before you meet with him or her. If you ask the doctor a question and don’t understand the answer, let them know. Ask the question again and explain your need to understand.

At this appointment it will be important to establish whether you will continue seeing your pediatric neurosurgeon for your hydrocephalus or if you will be transferred to an adult neurosurgeon. Many pediatric medical practices are not able to continue seeing teens once they are 18 or older (especially so for children’s hospitals). If you are no longer able to see your present pediatric neurosurgeon after the transition discussion appointment, ask about the adult neurosurgeon you will be referred to. Your doctor should make a personal referral for you to visit with the recommended neurosurgeon, and perhaps have a consultation with him or her regarding your medical history. Ideally, your pediatrician or pediatric neurosurgeon and the new doctor would enter a partnership of care during the first three to six months. Open communication between your old and new doctors could mean a smoother and better-planned transition.

Creating and maintaining a good relationship with your neurosurgeon is one of the most important elements of your overall health-care planning. To insure a good outcome, there needs to be an atmosphere of mutual respect where both of you (and perhaps your parents or a friend) participate actively in the decision-making, planning and evaluation process. Many people feel nervous when first speaking with a doctor—especially a neurosurgeon. It is important, however, to find

► See Worksheet 4, on page 44.

“When looking for a neurosurgeon, first of all, have faith in yourself.... I have gone to several different doctors, and I can always tell from that first meeting whether or not I want him or her as my doctor. If I don’t connect with him, then I know I’m not going to be able to gain trust in him. It’s okay to shop around!”

out about the doctor's experience and whether there is a good fit for you before entrusting him or her with your care.

Questions for Your Doctor

➡ See Worksheet 5, on page 45.

Worksheet 5, "Questions for Your Doctor," is a little different from the previous ones. We have compiled a list of questions that we believe are important in establishing a good relationship with your doctor. You might want to try out these questions with your current neurosurgeon for practice, before you go to a new neurosurgeon for the first time.

“I'm 23, and there are times that I still feel it vital to have my mom there for appointments and shunt adjustments.”

These questions are worded in a conversational way that is respectful of the neurosurgeon's experience and expertise and, we hope, empowering for you. We want you to feel comfortable asking questions that will give you some insight into the doctor's level of familiarity and success with treating your particular condition. It's possible that not all the questions will pertain to you, and there may be other issues that are not listed that are important to you. Remember, this is your chance to take charge, so use our suggestions as a starting point.

We strongly recommend that you take someone with you to your doctor's appointment for comfort, support, advocacy, an impartial opinion and a second set of ears to review the information with afterward. If at all possible, do not go to your doctor alone. Some people like to audiotape their doctor appointments for later referral and clarification.

➡ See Worksheet 6, on page 47.

Okay—you're almost off and running, but first there are just a couple more things to take care of, like the final worksheet, "My Medical Information." This worksheet is the final product of your transition plan. Keep a copy for yourself with your medical records. It may need to be updated over time, or you may need to add additional information.

Once you complete Worksheet 6, you're almost done. The final things to do are:

- Call and schedule an appointment with your neurosurgeon for a regular checkup (even if it is six months to a year from now). Put it on the calendar. Don't wait for an emergency.
- Start a list of questions for the appointment—perhaps in a separate notebook just for this purpose. Keep the notebook in a special place so you'll always know where to find it.
- Get copies of your latest scans.

- Decide whether you want to use a shunt card or a Medic Alert bracelet/necklace. Call the appropriate company and get an application. (*See Appendix C for more information.*)
- Identify your support person or persons. Arrange a time to talk with them about how you may need their help.
- Decide who you will designate on your Durable Power of Attorney document and ask them if they are willing to do it. Fill out the form and get it notarized. Make copies for each person listed on the document, and a couple of extra ones for yourself. Keep these in a special place—perhaps with copies of your latest scans.
- Get your medical folder/file together, or go online and join FollowMe to store your records on the Internet.
- Ask for help when you need it. Remember: Independence doesn't mean going it alone and doing everything yourself. It's okay, and important, to know when to ask for help.
- **Finally, *celebrate!* Pat yourself on the back and smile. You're on your way, so be proud of yourself.**

Conclusion

WE HOPE THAT READING this Guide (by yourself or with a parent or friend) and completing the worksheets is a positive and even powerful experience for you. Acquiring the skills that we've talked about here is a process, not a single event, and will continue throughout your life. We encourage you to review all the resources listed at the end of the Guide; some of them may be helpful with issues you're facing now, while others will be useful later on.

Life is a journey, for all of us. Some of the steps you will take on this amazing trip may be difficult and emotional for you and your family, but they are worthwhile tasks and experiences. Remember: This is *your* life. The sooner you—with the help and guidance of your family, your friends and your medical providers—take charge of planning for *your* future, the sooner you will reach your goals. We celebrate with each and everyone of you as you journey toward independence and adulthood.

Tips Just for Parents

WE RECOMMEND THAT YOU REVIEW THIS GUIDE with your child. Parents of children with hydrocephalus need to plan, connect, advocate and find information on behalf of their child. Planning ahead is very important and makes a difference to your teen's transition into adulthood. Until now, you have been your child's best advocate—protecting, caring for and making the right decisions for him or her. But the earlier you teach your child to advocate for himself or herself, the more prepared he or she will be for life ahead—no matter what path he or she takes after high school. Your child must understand his or her strengths and limitations, know how they will affect him or her and be able to communicate this to other people.

Here are some tips for how you can help provide your teen or young adult with opportunities to learn and practice the skills they will need to develop to manage their own health care:

- **Locate centers of support.** You know your child best. It is worth your time to attend trainings and workshops on available resources, and to consult with parent training and information centers in your area. Many of these organizations have parent mentors.
- **Know the law.** Parents need to know (not just be familiar with) the law, in particular the ADA and IDEA. Knowing your child's legal rights helps you be their best advocate, and in turn teach them self-advocacy.
- **Organize.** Many high schools sponsor special parent informational nights, IEP workshops, post-secondary-education information nights and meetings with local regional center representatives. Get connected with vocational training programs, recreation programs and businesses that offer work opportunities. Attend all meetings that become available.
- **Give your child adequate information to make educated decisions.**
- **Talk to your child directly and frankly** about his or her condition. Information is power, and you can help allay your child's fears by

“We have guided our children for 18 years, participating in their accomplishments as well as their hardships. We identify with their feelings and experiences so personally. How do we emotionally let go of our children while they still abide as such in our hearts?”

removing some of the uncertainty or misinformation he or she may have.

- **Give your child plenty of decision-making opportunities, and listen to your child's opinion.** Does your son prefer to see the doctor early in the morning so that appointments don't conflict with afternoon activities? Now that your daughter is a teenager, would she rather go to a female doctor? It can be hard to separate your own ideas and preferences from your child's wishes.
- **Remember that the parent's role is to guide children through this process of transition, not coerce them.** If you frequently override your child's decisions, he or she is likely to feel helpless and lose interest in the issue.
- **Talk to your child about his or her dreams and goals.** If you believe a goal is unrealistic, do not criticize, but rather help your child break it down into smaller steps that can be accomplished more easily.
- **Maintain realistic limits.** While you want to support your child and give your child opportunities to learn from mistakes, do not give up more responsibility than you should.
- **Be willing to laugh at yourself and point out your own mistakes when you make them.** Describe the decision-making process you use in daily life, and talk to your child about how you made certain decision. Talk about the consequences—positive and negative—of your decisions.
- **Take opportunities to develop acquaintances and friendships with other adults who have disabilities, especially adults who have hydrocephalus.** One of the people you meet may become a role model for your child with hydrocephalus.
- **Arrange for your child to talk with peers who have hydrocephalus.** Your child can trade experiences and information with others who are also learning to manage their needs successfully.

Finding and Maintaining Health Insurance

IT IS IMPORTANT TO FAMILIARIZE YOURSELF with health coverage and insurance options before you change or lose your existing coverage. It is also important to know and understand the federal health-insurance laws. Being proactive gives you time to become fully informed and to be able to make the right decision.

Medical Insurance Options

Know your insurance plan—including what limitations it has. Anticipate change and develop a flexible plan for the future. Clinics, children's hospitals, insurance policies and providers often have time and service limits. Many programs discontinue services after you reach a certain age.

Federal law provides certain protections for people with pre-existing conditions such as hydrocephalus. Generally, once someone has been covered for a particular condition, the law guarantees access to continued health coverage (this is called COBRA). After COBRA eligibility ends, there is another federal law, the Health Insurance Portability and Accountability Act (HIPAA), which further protects your access to health care.

Some young people with hydrocephalus also qualify for Supplemental Security Income (SSI). In most states, a person who is entitled to SSI benefits will also get health coverage through Medicaid. Even if you are not disabled and not entitled to SSI, there are other ways in which you may qualify for Medicaid. To learn what sort of assistance you may be eligible for, call your local Medicaid office. Many states also provide high-risk insurance pools for people who are otherwise unable to obtain health coverage. Help is often available from local government agencies as well. Look in your phone book under Health Departments and Department of Health and Human Services.

Tips on Choosing Health Insurance

- **Do not just chose the lowest-cost plan.** These plans often have very limited coverage and you may also be limited to certain hospitals and doctors.
- **If possible, choose a higher deductible.** Many plans come with a \$250, \$500 or even \$1,000 deductible. If possible, open a savings account for your deductible and then choose the highest deductible you can afford. The higher-deductible plans often have broader coverage.
- **Make sure your existing doctor is covered under the health plan you choose.** If your doctor is not on the provider panel, make sure that the panel includes a neurosurgeon, neurologist and any other specialty providers you may need.
- **When job hunting, look at the benefits carefully.** It may be more important to take a lower-paying job that offers health insurance than a higher-paying job that does not.

Visit the Consumer Union's website to get additional information on health-insurance coverage (www.consumersunion.org/health/health-tips01.htm).

Additional Resources

General Resources

Hydrocephalus Association, 870 Market Street, Suite 705, San Francisco, CA 94102; (415) 732-7040, toll-free (888) 598-3789; fax (415) 732-7044; www.hydroassoc.org; info@hydroassoc.org.

Pacer Center, 8161 Normandale Blvd., Minneapolis, MN 55437; toll-free (888) 248-0822. Numerous materials for students in transition. They publish an informative newsletter by and for parents of children and young adults with disabilities.

National Center for Youth with Disabilities (NCYD), University of Minnesota, Box 721, 420 Delaware Street SE, Minneapolis, MN 55455; (612) 626-2825. They do transition research and publish a directory of transition projects as well as numerous practical materials.

Person-Centered Planning and Life Building—Opening Windows to Change, by Dr. Beth Mount. Published by Capacity Works, P.O. Box 271, Amenia, NY 12501-0271; (888) 840-8578.

Transition Planning: A Team Effort. NICHCY, (800) 695-0285; nichcy@aed.org.

Exceptional Family Resource Center, 9245 Sky Park Court, Suite 130, San Diego, CA 92123; (858) 268-8252 or (858) 292-9092; efrc@mail.sdsu.edu. Provides information, resources and referral, support and understanding for individuals with disabilities and special needs.

Exceptional Parent magazine, toll-free (877) 372-7368; epar@kable.com. *EP* magazine advocates for all children, young adults and their families with special needs. They write many excellent articles on health-care transition.

National Council of Independent Living, 211 Wilson Blvd., Suite 405, Arlington, VA 22201; (703) 525-3406. They will provide information on centers for independent living around the country.

National Transition Alliance for Youth with Disabilities, Transition Research Institute at Illinois, University of Illinois, 113 Children's Research, 51 Gerty Drive, Champaign, IL 61820; (217) 333-2325; www.dssc.org/nta.

Shunt ID Cards/MedicAlert

MedicAlert, (800) 432-5378; www.medicalert.org.

Shunt Card, Bel-Med, Inc., 2810 Gleneagles Pointe, Alpharetta, GA 30005; (800) 531-9614, fax (800) 727-6137; belmed@attbi.com.

Vital Card, (518) 569-8595; karen@vitalcard.net; www.vitalcard.net.

Websites

There are many excellent websites on transition in education, school to work and home to independence but fewer on transition in health care. Below we have listed some of the sites we found to be very informative on medical/health-care transition.

www.followmezone.com Designed to empower people by keeping important medical information stored in one location, on the Internet, so it can literally “follow them” wherever their travels take them throughout their lives.

www.lapublishing.com Lash and Associates Publishing/Training Inc. Excellent publications on transitioning.

<http://dept.washington.edu/healthtr/resources.htm#national>

Websites of interest to teens (on national transition and health resources), excellent links to sites for teens who have disabilities or chronic conditions.

www.raisingpecialkids.org Raising Special Kids. Includes “My Dreams...My Plan...My Future,” a self-determination toolkit for high school and beyond.

www.nichcy.org National Information for Children and Youth with Disabilities. Many excellent links on education, health care, transitioning.

<http://hctransitions.ichp.edu> About health-care transition for youth with special health-care needs.

<http://hctransitions.ichp.edu/connections.htm> Listserv for youth and young adults with special health-care needs.

www.familyvillage.wisc.edu/sp/TRANS.HTML Provides comprehensive Internet resources in all aspects of transition for youth.

www.brookespublishing.com Excellent publications on employment and transition for youth with special needs.

www.dralegal.org Disability Rights Advocates. Site on health care, insurance and public health benefits.

www.mchbhrtw.org Hosted by Department of Health and Human Services. Excellent transition sites.

www.tea.state.tx.us/special.ed Very user-friendly for all IDEA regulations (300 pages).

- www.disabilityinfo.gov** Supported by the federal government, contains many topics of interest to people with disabilities; extensive links and a children and youth section.
- www.ssa.gov/disability** Social Security online disability programs. Has a screening tool to find out which programs may be able to pay benefits.
- www.heath.gwu.edu** HEATH Resource Center, a national clearinghouse on postsecondary education and individuals with disabilities.
- http://disabilityresources.org/KIDS.html** The DRM WebWatcher just for kids—sites for, by and about kids and teens with disabilities and chronic illnesses.
- www.faculty.fairfield.edu/fleitas/contteen.html** Band Aids and Blackboards for Teens, a site about growing up with any type of medical problem.
- www.fvkasa.org** Kids As Self Advocates. Youth with special health-care needs speaking on behalf of themselves.
- www.encourageonline.org** A place for teens with chronic illness and their family and friends to talk, connect and have fun with someone who understands.
- www.ssa.mainstream-mag.com/health.html** On managing your own health care.
- www.sbaa.org** Spina Bifida Association of America. Look for the section “Transition in Adolescence.”
- www.pacer.org** The Pacer Center expands opportunities and enhances the quality of life for children and young adults with special needs
- www.cahrtw.org/healthassess.htm** “Healthy and Ready to Work” (HRTW) transition health-care assessment guide can be downloaded as a tool for personal use.
- www.aap.org/policy/01203.html** Policy statement from American Academy of Pediatrics on “Transition of Care Provided for Adolescents with Special Health Care Needs.”

Bibliography

- “A Constant Fight, Our Survey on Your Service Needs,” *Link*, Association for Spina Bifida and Hydrocephalus, January 2003.
- “A Consensus Statement on Health Care Transitions for Young Adults With Special Health Care Needs,” American Academy of Pediatrics, American Academy of Family Physicians and American College of Physicians—American Society of Internal Medicine, *Pediatrics*, December 2002.
- “Achieving Success for All Children and Youth with Special Health Care Needs: A 10-Year Action Plan to Accompany Healthy People 2010,” U. S. Department of Health and Human Services, 2001.

- Adolescent Health Transition Project, Center on Human Development and Disability at the University of Washington, 2002.
- “Call Forth the Light in Community Life,” by Connie Lyle O’Brien and John O’Brien, Responsive Systems Associates, no date.
- “Comparison Between Pediatric and Adult Neurosurgery: Management and Future Perspectives,” by Joon-Ki Kang, M.D., and Kwan Sung Lee, M.D., *Child’s Nervous System*, 1999.
- “Death in Shunted Hydrocephalic Children in the 1990s,” by Bermans J. Iskandar, M.D., et al., *Pediatric Neurosurgery*, 1998.
- “Growing Up and Getting Medical Care: Youth With Special Health Care Needs,” by Daniel V. Schidlow, M.D., Healthy & Ready to Work National Center, 1999.
- “From Child to Adult,” by Edward R. Laws, M.D., *Child’s Nervous System*, 1999.
- “Health Care Transition: Destinations Unknown,” by John Reiss, Ph.D., and Robert Gibson, MSOTR, *Pediatrics* (Supplement), December 2002.
- “Healthy & Ready to Work, Key Transition Issues for Youth with Disabilities and Chronic Health Conditions,” by Rhoda Schulzinger, Esq., U.S. Department of Health and Human Services and Institute for Child Health Policy, 2000.
- “How to Keep Shunts Functioning, or “The Impossible Dream,” by Fred Epstein, M.D., *Clinical Neurosurgery*, 1985.
- “Implementing Transitions for Youth with Complex Chronic Conditions Using the Medical Home Model,” by Anne M. Kelly, M.D., P.M.H., et al., *Pediatrics* (Supplement), December 2002.
- “Improving Transition for Adolescents with Special Health Care Needs from Pediatric to Adult-Centered Health Care,” by Robert W. Blum, M.D., Ph.D., *Pediatrics* (Supplement), December 2002.
- “Inadequacy of Health Care for the Nation’s Chronically Ill Children,” by Carol A. Gale, M.N., R.N., *Journal of Pediatric Health Care*, 1989.
- “Learning Self-Determination Skills Can Affect Young Adults’ Future Self-Sufficiency and Independence,” by Deborah Leuchovius, *Pace-Setter*, winter 2003.
- “My Dreams...My Plan...My Future: A Self-Determination Toolkit for High School and Beyond,” *Raising Special Kids*, November 2001.
- “Paradigms of Care for Children with Special Healthcare Needs,” by Cheryl H. Hack, M.D., *Pediatric Annals*, 1997.
- “Plan Smart,” Exceptional Family Resource Center, no date.
- “Protocol, Transition to Adult Treatment from Pediatric Treatment,” Hemostasis Thrombosis Center, Children’s Hospital of Michigan, 2000.
- “Ready to Manage Your Own Health Care?,” Project Youth, PACER Center, 1999.

- “Self-Determination: A Critical Educational Outcome for Children and Youth with Disabilities,” by Brian Aberly, University of Minnesota’s Institute on Community Integration, 1999.
- “Shunt Revision for Asymptomatic Failure: Surgical and Clinical Results,” by Matthieu Vichon, M.D., et al., *Neurosurgery*, 2003.
- “Six Postschool Case Studies of Mildly Learning Handicapped Young Adults,” Andrea B. Zetlin, Ph.D., *Exceptional Children*, 1989.
- “Transition for Youth With Chronic Conditions: Primary Care Physicians’ Approaches,” by Peter Scal, M.D., *Pediatrics (Supplement)*, 2002.
- “Transition from Pediatric to Adult Services for Adolescents with Chronic Conditions: Report of a Group Research Project,” by Maureen A. Frey, Ph.D., R.N., et al., no date.
- “Transition In Adolescence,” by Chris P. Johnson, M.Ed., M.D., and Jane Dorval, M.D., Spina Bifida Association of America, no date.
- “Transition of Care Provided for Adolescents with Special Health Care Needs (RE 9645),” Policy Statement, Committee on Children with Disabilities and Committee on Adolescence, American Academy of Pediatrics, December 1996.
- “Transition to Adult Living,” by Paula Kolher, *The Special EDge*, summer 2001.
- “Transition to ‘Empty Nest,’” by Dorie Rosenberg, LMFT, *The Contact*, May/June 2003.
- “What Is Transition? Health Care Skills Checklist,” Adult Metabolic Transition Project, University of Washington, no date.
- “Where Am I Going? How Will I Get There?,” Nevada Department of Education Educational Equity Team, Nevada Parents Encouraging Parents and the Nevada Parent Network, 1997.

Worksheets & Sample Forms

THESE WORKSHEETS ARE DESIGNED to be filled out by you, with help from your parents if necessary. As you read through this booklet, fill out the worksheets now—but also plan to come back and redo the worksheets in a few years. That way, you can track your progress and see how you’ve come closer to your goal of independence. We suggest you make photocopies of the worksheets before filling them out, and then keep all your worksheets in one place—maybe with your medical records.

Worksheets

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Who Am I?

Date: _____ Name: _____

The following questions are about you, who you are and what you like. Think about the people you know and who know you, your skills and abilities, and your dreams. Take time to think about your answers. Discuss them with family, teachers and friends. The choices are yours, but the people around you may have some important information to give you.

I am good at:

I am not so good at:

I like doing these things:

I don't like doing these things:

I wish I could:

I learn best when:

These are some things I can do by myself:

These are some things I need help with:

I would like people to know this about me:

If I have a problem, I usually talk to:

These people are some of my friends:

If I could pick any career or job, it would be:

To do that, I will need to:

Worksheet 2

Ready to Manage Your Own Health Care?

Read the following statements, then decide whether or not the statement sounds like you.

Health Condition/Hydrocephalus	Yes	No	Not Sure
1. I know a lot about my hydrocephalus	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. I feel my hydrocephalus controls my life.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I worry about my hydrocephalus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I think my hydrocephalus will get in the way of what I want to do in the future.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Sometimes I am embarrassed about my hydrocephalus.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Health Records & Health Insurance	Yes	No	Not Sure
6. I have my own copy of my health records.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. I have an insurance card or copy of it.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
8. I know what kind of health insurance I have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. I know how to call my doctor and make an appointment.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. I know how often I should see my doctor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Emergency Situations	Yes	No	Not Sure
11. I have (and know where to find) the phone numbers of family and friends to call in emergencies.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. I have my doctor's/nurse's phone number.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
13. I know where the closest emergency room is.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. I can recognize the signs and symptoms of a shunt infection or malfunction.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

General Medical Information	Yes	No	Not Sure
15. I know what kind of shunt I have.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
16. I know what medications I take.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
17. I know when to take my medications.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
18. I know how to get and refill prescriptions and medications.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
19. I know why it is important to have a copy of my medical records.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
20. I'm prepared for emergencies, have plans and know who to contact.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
21. I only see the doctor when someone makes me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
22. I know how to use transportation to get to medical appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
23. I schedule my own doctor's appointments.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
24. I have an adult doctor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
25. I have nice doctors who work with me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
26. I like to have someone with me when I visit my doctor.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
27. I know how to get a health advocate if I need one.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
28. I have someone to talk to when I feel sad.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Worksheet 3

Individual Transition Plan

Date: _____

My strengths are: _____

Some things I need to work on are: _____

I have these concerns: _____

These things are very important to me: _____

My long-term goals are:

1) Education: (Example: Graduate from high school, attend community college for two years and transfer to four-year college)

2) Work: (Example: Become a licensed child-care provider)

3) Living Arrangement: (Example: Get an apartment with roommates when I go to college)

4) Relationships: (Example: Get married someday; maybe have kids?)

5) Health Care: (Example: Apply for SSI so I know I have coverage OR Get a job with good health benefits)

Worksheet 4

Getting From Where I Am to Where I Want to Be

Moving toward the future, what do you need, want or hope to happen?	How much of what kind of support will you need? Who can do what?		
	By when?	I will . . .	If I need help, I will . . .
<i>Example: Make my own doctor's appointment</i>	<i>July 2004</i>	<i>Get the phone number from my mom</i>	<i>Ask her when a good time is for her</i>
<i>Example: Get a shunt card</i>	<i>December 2003</i>	<i>Research the different kinds</i>	<i>Call the Hydrocephalus Association</i>

Questions for Your Doctor

1. Do you have a lot of patients with hydrocephalus in your practice?
 - Do you have other teens and young adults you treat?
 - Is there a way I may be able to connect with them?
2. If I need to have surgery, will you personally do the surgery?
 - How many shunt surgeries have you done (in the last year? ever?) specifically for teenagers and young adults?
 - In general, what were the outcomes?
 - What were the common complications, if any?
 - If you personally cannot perform my surgeries, who will? May I meet with them?
3. What kind of shunt(s) do you use?
 - I have a [*your shunt name here*] shunt. Do you use this kind?
4. In the case of an emergency, whom do I call first (you, your nurse, etc.)?
5. If I have to go to a hospital emergency room, which one should I go to? Is there anything I should take with me—previous scans, etc.?
6. What can you tell me about my surgery and hospital stay?
 - How long will I have to stay in the hospital?
 - How much of my head will you shave?
 - I am little afraid of having more brain surgery. Is there anything you can tell me about your personal experience that will make me feel less scared?
7. What can you tell me about my recovery and follow-up care?
 - Who will be in charge of my follow-up care?
 - How long is the recovery time—when can I expect to get back on my feet?
 - Who can I call when I have a question or if I suspect there is a problem?
8. I have had a few complications (*list them*). How do you handle problems like this?

- Insidious shunt failure (shunt failure with very subtle symptoms)
- Infection—I have/have not had a shunt infection in the past.
- How can I recognize the signs of infection?
- What do you do if there is an infection?
- Does infection happen often in your experience?
- How long do I need to continue to watch out for an infection after I leave the hospital?

9. Slit Ventricle Syndrome

- How often does this occur in your personal experience?
- What steps do you take to prevent this?

10. I would like to keep copies of my medical records, including test results and copies of CTs and MRIs. Who do I speak to in your office about this?

11. Where should I go to get more information about my type of hydrocephalus, or hydrocephalus in general?

12. I would like to have medical identification on me, like a shunt card or MedicAlert card. Could you help me go about getting this?

13. You are a busy person, and I appreciate the time you have taken to answer my questions. After I get home and have time to digest all this information, I will probably have more questions. Is there a medically knowledgeable person I could call—like a physician's assistant (PA) or nurse practitioner (NP)—as these questions arise? Or should I contact you directly?

My Medical Information

Personal Information

Name: _____

Address: _____

Telephone: _____ Email: _____

My Social Security Number is: _____

My neurosurgeon's name is: _____

His/her address: _____

Telephone: _____

Other contact people in my neurosurgeon's office are: _____

My primary care physician's name is: _____

Address: _____

Telephone: _____

Other contact people in my primary care physician's office are: _____

Emergency Information

In an emergency situation, please contact:

Name: _____

Address: _____

Telephone: _____ Relationship to you: _____

There is a copy of my Durable Power of Attorney (*for example, in the top drawer of my desk*):

People designated in my Durable Power of Attorney are:

1) Name: _____

Address: _____

Telephone: _____

2) Name: _____

Address: _____

Telephone: _____

The Emergency Room closest to me is: _____

Their telephone number is: _____

Insurance Information

My health insurance is: _____

My insurance number is: _____

The telephone number for my insurance company is: _____

I receive SSI and my I.D. number is: _____

My SSI case worker is: _____

The telephone number for my case worker is: _____

Information About My Hydrocephalus

I have hydrocephalus due to _____ (for example, aqueductal stenosis, spina bifida, IVH, don't know, etc).

I have a shunt: _____ (name of shunt manufacturer, name of shunt)

My first shunt was placed in (year) _____ when I was _____ years old.

I have had _____ (number) of revisions.

My last revision was _____ (date).

When I have a shunt malfunction, some of my symptoms are _____

_____.

I had an Endoscopic Third Ventriculostomy (ETV) on _____ (date) and no longer have a shunt; but I still have hydrocephalus.

I have a copy of my medical records. I keep them: _____

Other people who have copies of my medical records are:

Name: _____ Telephone: _____

Name: _____ Telephone: _____

I wear or carry: A Shunt Card
 A ETV Card
 A Medic-Alert bracelet/necklace

I take medications for _____ and _____ (*for example, seizures*).

The medications I take are _____ and _____.

The prescription numbers for my medications are _____ and _____.

To refill my prescriptions, I call _____.

If I need help or assistance with medical issues, I call:

Name: _____ Telephone: _____

Name: _____ Telephone: _____

If I need more information about hydrocephalus, I can contact the:

Hydrocephalus Association
870 Market St., #705
San Francisco, CA 94102
415-732-7040 or 888-598-3789
info@hydroassoc.org
www.hydroassoc.org

SAMPLE—State of California

Durable Power of Attorney for Health Care

By this document, I intend to create a durable power of attorney by appointing the person designated below to make health care decisions for me as allowed by Section 2410 to 2443, inclusive, of the California Civil Code. This power of attorney shall not be affected by my subsequent incapacity. Health care decision means any consent, refusal of consent, or withdrawal of consent to health care.

I _____, residing at _____
_____ hereby designate and
appoint _____ residing at _____
_____, telephone _____
as my attorney in fact to make health care decisions for me as authorized in this document. If for any reason
(*person designated above*) _____ shall fail to qualify or cease to act as my attorney, I
appoint _____ residing at _____
_____, telephone _____ as
my attorney in fact to make health care decisions for me as authorized in this document. In the event (*2nd per-
son designated above*) _____ is not available then I appoint _____,
residing at _____
_____, telephone _____ as my attorney in fact to make health care
decisions for me as authorized in this document.

If I become incapable of giving informed consent to health care decisions, I hereby grant to my agent full power and authority to make health care decisions for me including the right to consent, refuse consent, or withdraw consent to any care, treatment, service or procedure to maintain, diagnose or treat a physical or mental condition, and to receive and to consent to the release of medical information regarding my physical or mental condition, including, but not limited to, medical and hospital records.

My agent has the power and authority to execute on my behalf documents entitled or purporting to be "Refusal to Permit Treatment," "Leaving Hospital Against Medical Advice," as well as any necessary waiver or release from liability required by a hospital or physician.

I sign my name to this durable power of attorney for health care on _____ (date) at
_____ (location).

(Signature)
(Type Name)

Notary Seal

Note: Laws and requirements for DPAHC forms vary from state to state. Call your state's Consumer Affairs office or the state office of the American Medical Association. You can also search for state-specific forms on the Internet or consult an attorney or paralegal.

SAMPLE—Authorization for Release of Medical Information

I hereby authorize _____, M.D., to furnish medical information concerning _____ (patient) to _____

(name and address of person to receive records).

Any and all information may be released, including but not limited to mental health records protected by the Lanterman-Petris-Short Act, drug and/or alcohol abuse records and/or HIV test results, if any, except as specifically provided below: _____

The information may only be used for the following purpose: _____

This authorization is effective now and will remain in effect until _____ (date).

I understand that I have the right to receive a copy of this authorization.

Signed: _____ Dated: _____

If not signed by patient, please indicate relationship:

- () parent or guardian of minor patient (to the extent minor could not have consented to the care)
- () guardian or conservator of an incompetent patient
- () spouse or person financially responsible (where information solely for purpose of processing application for dependent health care coverage)

Note: To be valid, this authorization must be handwritten by the person who signs it or in typeface no smaller than 8-point type (this is 8-point type). It must be clearly separate from other language on the page and executed by a signature that serves no purpose other than to execute the authorization.

