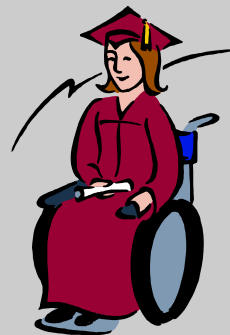


Transition

From Teen To Adult

**For People With
Special Needs**

Written By
Terri L. Gray



The transition process from teen to adulthood for any teen requires the forethought and patience of those who reared him or her. When your teen has a chronic illness or a disabling condition, even more planning is required to help him or her toward total independence. I wrote this book in hopes that my experience in the transition process will help you plan yours with confidence and effectiveness.

Theresa L. Gray

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When do I begin?

E d u c a t i o n

Now! Don't waste another moment worrying about your teen's future. Instead, start planning now. Remember that failing to plan is planning to fail.

Ideally, the transition process begins while your child is in his or her early teens, although you may wish to apply some of the steps much sooner.

Step 1:

Educate your teen about his medical condition.

Does Johnny know that he has cerebral palsy and it happened shortly after his birth due to lack of oxygen to his brain? Does Susie understand that her spina bifida occurred during the first three months of gestation? Does she know why she has a shunt? Are your daughter's blood sugar readings routinely charted to monitor her diabetes? Are you keeping track?

The education process should flow naturally. Children understand more than we give them credit for. Next time you take your teen to a doctor appointment, have a conversation beforehand explaining the reason for the visit. Allow him to answer some of the doctor's questions. Prepare him with the answers ahead of time so he won't feel intimidated. For example:

Mom: "Jennifer, today's visit at Shriners Hospital is to determine if your new braces are fitting correctly. What would you like to tell the doctor about your braces?"

Jennifer: "Well, I am getting red on the outside of my right ankle after wearing them all day."

Mom: "This is important for you to tell the doctors. Redness from the braces means the brace is rubbing your skin. When the doctor sees your red ankle, he will have the orthotist adjust the brace so you don't have any more redness. Do you know why this is important?"

Jennifer: "Redness is bad?"

Mom: "It can be bad, yes. Because you have spina bifida, you don't have feeling on your feet and ankles. When any part of your leg turns red, this means the skin may blister and eventually turn into a pressure sore. Because the blood does not circulate well in your legs, a pressure sore can take months to heal. Sometimes pressure sores can get infected. So this is very important for you to watch. Every evening when you get changed for bed, check your legs for redness. It's much easier to prevent a sore, than to treat one."

Jennifer: "O.K. Mom, I will watch for redness and if I see it, tell you right away."

You can see how naturally training can occur between parents and teen with the disability.

You may be asking...



“My son is already eighteen and I have not prepared him to communicate with the doctors. I have not taught him much about his medical condition. Is there any hope of catching up before he leaves for college?”

Absolutely! It’s never too late. In explaining to older teens or young adults, you need to present the information to them at their level. Vast resources are available for patient education, thanks to the World Wide Web, as well as from your family physician. Organizations such as United Cerebral Palsy Association, Muscular Dystrophy Association, Spina Bifida Association of America and many more are tremendous places to start your search for educational materials for your teen’s medical condition.

These resources will explain the general information regarding their disability or medical condition.

You are the best resource for the specific details. After all, you were there for it all! The next step will require some time if you have not kept up with record keeping in the past.

R e c o r d K e e p i n g

Step 2: Create records for your teen to take with him when he leaves home.

When we moved to California, our daughter, Jennifer, had been treated at numerous medical facilities across the country because my husband and I were both Active Duty in the United States Army. After unpacking boxes and setting up housekeeping, I began my search for civilian physicians to care for Jennifer. She already had numerous operations, and I knew her new pediatrician would want to know the following:

- The name of the operation.
- Hospital name and location.
- Physician/surgeon name(s)
- Date of operation.

I requested copies of Jennifer's military and civilian records from the locations where she received treatment. Once I had it all before me, I set up a spreadsheet on Microsoft Excel with the four pieces of information mentioned above.

I also requested a summary of Jennifer's medical history from her developmental pediatrician at our last Duty Station.

These two documents were invaluable to Jennifer's new pediatrician. I sent them to her ahead of Jennifer's first visit so she had time to review her medical history before the office visit.

I continued to update the operation list and kept it on file in my computer. I also gave a copy to Jennifer for her records. This would be your next step in preparing your teen for transition. I realize this is time-consuming, but it will be invaluable to your teen when she takes over all aspects of her medical care. Once it's on your computer, you don't have to re-invent the wheel. In fact, once it is on your computer, copy the files and send them as an attachment on your e-mail to your teen's computer.



List of Operations

Date	Operation	Hospital	Physician
6/1/83	Right Club Foot Repair	Seattle Children's Hospital, Seattle, WA	Dr. Schaefer
3/28/87	End Sigmoid Colostomy	Eisenhower Army Medical Center, Ft. Gordon, GA	Dr. Greene

The next important step in record keeping is to write a list of all your teen's major childhood illness. You cannot imagine how many teens do not know if they had chicken pox, rheumatic fever, mumps, etc. It is our job as parents to give them this very important information. Again, this can be easily documented on the computer and sent to your teen. I also recommend printing out a hard copy to be maintained in her medical file.

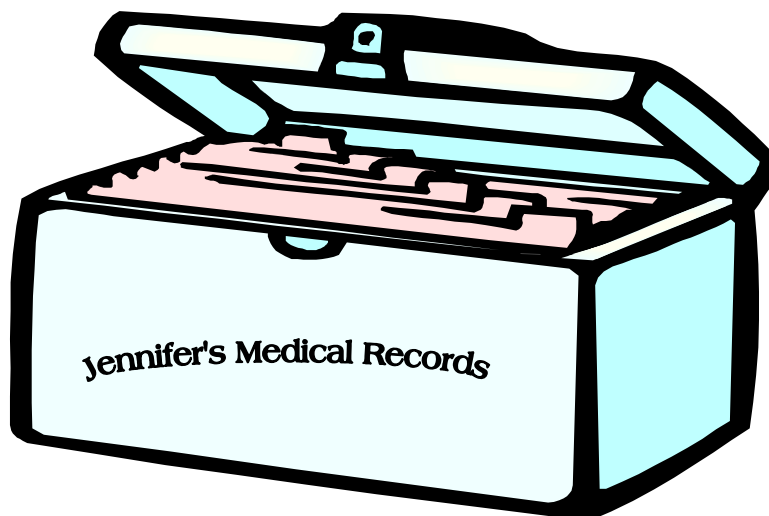
Date	Illness
6/15/90	Chicken Pox
4/11/92	Scarlet Fever

Since both my daughter and husband have multiple medical conditions, I keep a list of their current medications for each of them on a 3x5 card in my wallet. Again, this list should be updated each time medication is discontinued or a new medication is added. Your teen should also carry a copy of his medication list in his or her wallet or purse at all times.

Keep an updated list of medication in wallet for easy reference.



By the time your teen is a high school senior, it would be beneficial for him to have a portable plastic file box that carries hanging folders. In this file box, keep the lists of operations, childhood illnesses and any pertinent medical records helpful for his future physicians. Also, keep a current list of medications and allergies to medications in this file box. Finally, any research on your teen's disability or medical condition can also be kept in this file for his easy reference.



Set up hanging folders for List of Operations, Childhood Illnesses, Copies of Medical Records, Current List of Medications, and Research about current illness or chronic condition.

Seek Assistance

Step 3:

Seek Assistance for Independent Living

There is a vast array of services available to those living with chronic medical conditions and disabilities. Often times, people go without needed services just because they were unaware of the availability.

I cannot give you an exhaustive list of resources, but I can point you in the right direction. The following are suggestions of where to begin. Not everyone will qualify for every service listed below, but it's a place to start.

Department of Rehabilitation (DOR)

DOR's primary mission is to assist people with disabilities obtain and retain employment and maximize their ability to live independently in their community. Services are tailored to each person to help reach their employment goal. Individuals with disabilities and counselors work together to determine which services will provide the best support to prepare, find or retain a job. Examples of services include, but are not limited to:

Career education and training, job search and interview skills, career assessment and counseling, transportation, independent living skills and assistive technology, such as, adaptive computers, listening devices, etc.

Independent Living Centers (ILC)

ILC's are typically non-residential, private, non-profit consumer-controlled, community-based organizations providing services and advocacy by and for persons with all types of disabilities. Their goal is to assist individuals with disabilities to achieve their maximum potential within their families and communities.



Supplemental Security Income (S.S.I.)

S.S.I. not only provides income for the qualified person with a disability, but it also qualifies them for your state's medical program along with In Home Supportive Services. Some families already qualify for S.S.I. because of their teen's disability. Others may have been disqualified because your income exceeds the allowed amount. Once your teen turns eighteen, he can apply for S.S.I. as an independent person and his parents' income cannot be included.



- For additional information on these resources, see our resources page in the back of this booklet.

Transportation

If your teen requires adaptive equipment to drive an automobile, Department of Rehabilitation and rehabilitation hospitals are set up to assist with this. For our daughter, we felt the transition process would be less complicated if she started driving at sixteen. This way, she would have a few years of driving under her belt before facing the other aspects of transition.

If driving is not an option, check with your local bus system and begin introducing your son or daughter to public transportation. For people using wheelchairs, most public transportation buses will provide door-to-door service with a discounted monthly pass.

One small note I would like to add regarding resources is to network with other families whose young person has made a successful transition. Many support groups are available throughout the country for various medical conditions. Don't be afraid to attend a meeting or go online and check out the resources for yourself.



Transition

Step 4:


Setting up a Transition Goal Timetable

At whatever stage you have started the transition process, it is wise to set reachable goals and map out a timetable for reaching these goals.

Because each young person's medical condition is unique, his goals and timetables will be equally unique. For example, if your son has a developmental delay and will remain in the school system until he is 21, you do not need to rush at 18 to see that all his transition goals are met. On the other hand, if your 19 year old is already at a Community College while living at home, but plans to transfer to a four year college away from home next year, most of your timetable goals will need to be met before he or she leaves home.

What should I include in my Transition Goal Timetable?


1. Education regarding specific medical conditions.
2. A completed Record File Box.
3. Successfully ordering medications and/or medical supplies unassisted.
4. Successfully communicating with physician at medical appointment, to include scheduling medical appointment.

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5. Locating physician(s) to care for special needs for wherever your teen relocates.
 6. Independence in self-care.
 7. Seeking out services to aid in independent living through the resources mentioned in Step 3. (Included in this might be visit or series of visits with an occupational therapist for instruction in preparing meals, housekeeping skills, etc.)
 8. You and your teen should visit his future college campus to ensure its accessibility. Also, locate adequate medical facilities in the near vicinity for his special needs.

When making this timetable, you may want to take each step and break it down into smaller reachable goals. For example, if your teen has never ordered his own medications or supplies, perhaps the first step would be to help him plan out how often to order each item.

Creating this timetable is like creating a budget. It won't work if you write it out and then stuff it in the desk drawer. Place it in a location where both you and your teen will see it on a daily basis. Check off the goals accomplished and reward him with something special like a night out at the movies or buying his favorite C.D.

Just remember, even when he moves out on his own, you may need to make frequent visits at the beginning to help work out unexpected issues. Transition is definitely a process. This is a time of celebration as your young person prepares to meet the world and actively participate as an important member of society. Give it your best effort and be confident that many others have gone before you to help pave the way to a bright future for your teen.



GOAL CHECKLIST

Starting Date	Goal Date	Date Achieved	Objective
11/1/02	11/14/02	11/10/02	Review list of medications and frequency administered
11/15/02	11/30/02	11/19/02	Order prescription medicine by telephone
12/1/02	12/15/02	12/3/02	Call Department of Rehabilitation for Application Process information

Adult Career

Step 5:

Transitioning from Pediatrics to Adult Care



Typically, children with special needs see pediatric specialists. Somewhere between the ages of 18 and 21, many pediatric specialists refer their young adult patients to adult practitioners. This can be frightening and unsettling to both parent and young adult if you have not prepared for this transition.

“Where do I begin?” You may ask. “My teen sees so many different specialists.”

Begin with your teen’s primary care physician. This would be his pediatrician or in family practice, his primary care practitioner. Set up an appointment at least six months before he reaches the age where he is referred to adult practitioners. It might be helpful to send a letter ahead of time to notify the doctor of the purpose of the appointment. He or she may want to schedule your teen for an extended visit so there is plenty of time to address all issues.




Transition Appointment

At this transition appointment, prepare a list of questions, preferably in writing, to address at the office visit. The important matters to discuss would be:

- Who do you recommend my son/daughter sees for a primary care physician?
- Can you recommend adult specialists to replace the pediatric specialists who are familiar with my child's condition?
- Can you send letters to these doctors introducing my son or daughter and the care he received under your practice?
- Is there an adult multi-disciplinary clinic in our area for my son or daughter's medical condition?

When your teen begins seeing his new doctors, it may be helpful to set up a time to review what occurred at his appointments. Keep the door of communication open with your son or daughter. Questions will arise, and he may need information from his childhood only you can provide. It might even be helpful if you accompany him to a few office visits throughout the first year of his independence.

In summary, the most important part of the process of transition is effective communication. By providing the proper learning environment along with a well-organized file of necessary documents, your teen will gain the self-confidence necessary to be in charge of his health and welfare. You will have accomplished your job as a parent, and your teen will safely move into the next stage of his life in a smooth and confident manner.





Resources

- **Smooth Transition**

See our “Resources” page at smoothtransition.us for website links for the following organizations:

- **Department of Rehabilitation:**

Phone listing different for each state located in the front of the white pages under “State”

- **General information about federal programs for Americans with disabilities**

www.disAbility.gov

- **Independent Living Centers**

www.virtualcil.net/cils/

Phone listing different for each state located in yellow pages.

- **Medic*Alert**

www.medicalert.org 1(800)432-5378

- **Muscular Dystrophy Association**


www.mdaua.org 1(800)572-1717

- **Spina Bifida Association of America**

www.sbaa.org 1(800)621-3141

- **United Cerebral Palsy Association**

www.ucp.org 1(800)872-5827





THE AUTHOR—Theresa Gray

Born in Redwood City, California, Theresa resides with her husband, David, and children, Jennifer and Christopher, in Lompoc, California. Assisting Jennifer, born with spina bifida, through the transition process, inspired Theresa's decision to write.

Theresa's career commenced in the military as an Army Medic. Following Jennifer's birth, Theresa opted not to re-enlist in order to devote her complete attention to Jennifer's needs. This also enabled Theresa to be actively involved in Spina Bifida Association chapters wherever David's military orders sent the family. She held offices as president, treasurer and newsletter editor. She also volunteered to work with the Army's Exceptional Family Member Program and received the Outstanding Family Service Award for her devotion to community service at Ft. Lewis, Washington.

When David retired from the Army, Theresa found employment with United Cerebral Palsy Association, Santa Barbara County, as the Program Coordinator of the Children's Community Integration Program for the next ten years. On April 14, 2003, California's Gov. Gray Davis appointed Theresa to the Area IX Board on Developmental Disabilities.