

Helping Youth and Parents Prepare for Medical Transition

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What do parents and youth need to know about medical transition?

- Prepare to manage own medical care
 - Make appointments
 - Prepare to talk to doctor alone
 - Assemble health history
 - Manage prescriptions (taking, refills)
- Discussing guardianship if applicable
- Transitioning from the pediatrician to an adult care provider
- Use forms that help with managing care
- Learn more about resources and services

Forms

- Healthy and Ready to Work
 - Medical Summary

Medical Summary

NAME

Address, Home Phone, Cell Phone, Email

DOB 5/24/73 SS# 289-XX-XXXX ALLERGY: Sulfa Drugs, Adhesive Tape

- High intelligence (130 IQ), compliant patient, high tolerance to pain
- Incomplete Quad (has sensation), only movement left index finger 10 cm
- Need to explain EVERY procedure, when possible, ask for consent prior to doing
- If unable to talk => one blink = yes / two blinks = no - Read his lips - OR - letter/word board to direct his care.

PRIMARY DIAGNOSIS	AGE: 30	HEIGHT 4'3" (51inches)	WEIGHT 80lbs approx
1. NEURO/MUSCULAR 359 Muscular Dyst/335.1 SMA	Spinal Muscular Atrophy Type 2 (Severe Anterior Horn Cell disease, 3/4) incomplete quad (has full sensation), no functional movement		
2. RESPIRATORY V44 Trach, S18.81 Respir Failure 486, Pneumo Org NOS	Respiratory failure - trach and vent (9/01), Chronic RLL Atelectasis, Recurrent pneumonia (last hospitalization, 9/01) Respiratory insufficiency, poor residual functions and reserved capacities Decreased esophageal motility, s/p feeding gastrostomy tube (7/83)		
3. GASTRO V44.1 Gastro Status			
4. ORTHOPEDIC 737.4, 754.89, 754.81	Severe deformities: thoracic, pelvic obliquity, bilateral dislocated hips flexion contractures, spinal fusion (3/82 Lueke Rod), pectus excavatum		
5. UROLOGICAL 752.51	Undescended L testicle (since birth), intermittent cath (10/01), cath: 10 Fr, Cystoscopy/left ureteral stent (10/01), IVP (6/90)		
6. BLOOD TYPE	A + (positive)		
7. SPECIAL NOTES	IV: Porta Cath (10/24/01) RIS right clavicle (PC D603880 - lot 36H124)		

MEDICAL

ACUPUNCTURE PHYSICIAN Barbara XXXXX RN, AP, Ocala, FL O: 352-xxx-xxxx	HOSPITAL North FL Regional Medical Center, Gainesville, FL 4/95, 1/97, 5/01, 9-10/01
INTENSIVIST: Melvin XXXX, MD, Ocala, FL O: 352-622-xxxx	IMMUNIZATIONS Flu 02 Pneumo 79, 01 Tetanus 85 DPT 73, 79 Measles 74 Mumps 74 TB 78, 87
PULMONOLOGIST: Robert xxx MD, Gainesville, FL O: 352-xxx-xxxx Bpr: 352-xxx-xxxx	ENTERAL Pulmocare (237ml) x 2 cans, nocturnal 70 ml/hr
MEDICATIONS	HERBS / DROPS
Rx DAILY 1. Alprazolam (xanax) 0.5 mg QID anxiety 2. Aspirin-Child 81 mg 1 x prevent clots 3. Temazepam 15 mg H S sleeping pill 4. DuoNeb 1 vial QID nebulizer (ipratropium, Bromide & Albuterol)	1. Lymphatic 5 2X 2. Flu Balancing 10 2X 3. Respiratory 7 2X 4. Allertox -airborne 5 2X 5. - - Aller-Total 3 3x 6. - - Aller-train 10 4x 7. Immune 6 2X 8. Acute Rescue 5 2X 9. Urinary 8 2X 10. Digestive 3 2X 11. Mucous 5 2X 12. Cell 7 2x 13. Muscular 4 2x 14. Integumentary 8 2X 15. Er Cheng Tang 1 tsp 2X
Rx MONTHLY 1. Thiamine 100 mg monthly vitamin 2. Cyanocobalamin 1000 mcg/ml monthly (B12) vitamin	VENT / TRACH / O2 VENT - Pulmonic LTV 900 Breathis 05 Tidal Volume 310 Inspiration 1.1 Pressure Support 13 Sensitivity 02 High 40 Low 02 TRACH: Shiley 6 cuffed (deflated)
Rx PRN 1. Darvocet-N pain 2. Zithromax SUS PFIZ 200/5ml 45ml antibiotic 3. Diphnoxylate/atropine 1-2 tablets diarrhea	SPEAKING VALVE: Passy-Mulr PMV007 OXYGEN 1.5 liters

INSURANCE

BlueCross BlueShield of Massachusetts Primary Subscriber: xxxxx xxxxx BC/BS PPO Plan Code 200 Customer service: 800-299-xxxx XXP XXXXXXXX 10 PPO	BlueCross BlueShield of Massachusetts Secondary Subscriber: xxxxx xxxxx BC/BS Blue Choice Plan 2, POS Code 200 Customer service: 800-222-xxxx XX XXXXXXXX 10
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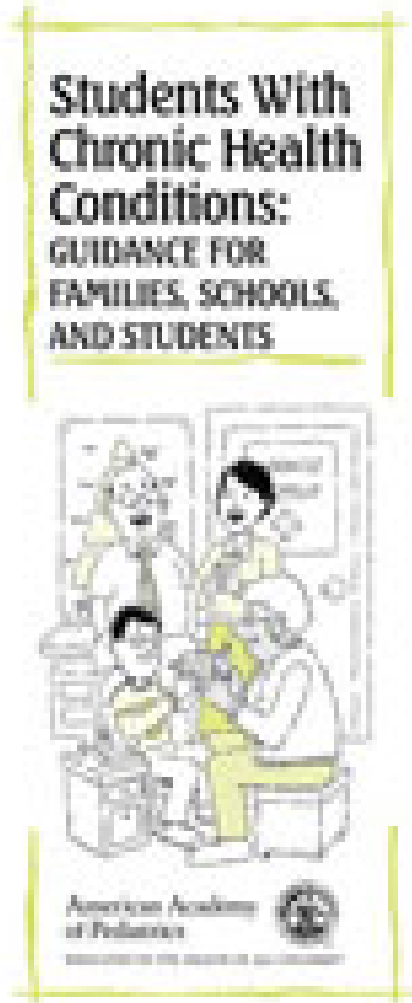
HEALTH SURROGATE P H (mother) c 352-xxx-xxxx h 352-xxx-xxxx

BC/BS Case Manager Health Vendor Home Nursing Agency Pharmacy	Debra XXXXXXX Option Care House Calls Billing's	800-362-xxxx 800-825-xxxx 352-xxx-xxxx 352-732-xxxx	ext. xx 352-373-xxxx acc'l. # xxxxx acc'l. # xxxxx
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Handouts

- **American Academy of Pediatrics**
 - Students with Chronic Health Conditions: Guidance for Families, Schools, and Students
- **Children with Special Health Care Needs**
 - Transition to Adulthood for Youth and Young Adults with Special Health Care Needs
 - Transition Information for Parents and Medical Providers of Youth and Young Adults with Special Health Care Needs
- **Healthy and Ready to Work**
 - Getting What You Need at Your Doctor Visit

Students with Chronic Health Conditions (AAP)



- “What does the school need to know?”
 - Medicine or procedures required during the school day
 - Possible problems, special precautions...
- School Responsibilities:
 - Provide staff training and support
 - Keep parents informed
 - Keep information confidential...”
- Much more...
- Order from www.aap.org/bookstore

Transition to Adulthood for Youth and Young Adults with Special Health Care Needs (in development...)

Transition to Adulthood for Youth and Young Adults with Special Health Care Needs

"Transition is a process, not an event."

--from the National Center for Youth with Disabilities

You have experienced many transitions, large and small, over the years. Transitions involve changes, adding new expectations and responsibilities, finding new resources, and letting go of others.

If you are twelve or older, you will need to start thinking about moving into new programs and working with new agencies and providers.

We hope the information we have provided will help you as you plan for your future.

Becoming More Independent

- Learn as much as you can about your health care needs. Ask your parent(s) about areas where you have questions.
 - Ask your medical provider to help you write an up-to-date record of your medical history. Include conditions, operations, medications and treatments (with dates, doctors and recommendations).
 - Learn to make and keep your medical appointments, refill prescriptions and order supplies.
 - With your parent(s), begin to look for adult health care providers.
 - If you have an Individualized Education Plan (IEP) or 504 Plan at school, we encourage you to attend the meetings and express your goals. Keep a copy of the plan that is developed and make sure that it is being followed.
 - Explore volunteer and work activities. Begin to think about possible career interests.
- Identify and attend support groups if you are interested.
 - If you plan to enroll in a technical school or college, think about resources you will need such as transportation, accommodations and financial aid.
 - Find and participate in social, recreation and leisure activities.
 - Discuss with your parents your daily living situation and the possibility of living independently, if this is in your future.
 - Continue to gain knowledge and ability of self-help skills for independence and additional skills related to your health care needs.
 - At age 18, males must register for the Selective Service.



Transition Information for Parents and Medical Providers of Youth and Young Adults with Special Health Care Needs (in development...)

Transition Information for Parents and Medical Providers of Youth and Young Adults with Special Health Care Needs

"Transition is a process, not an event.
--from the National Center for Youth with Disabilities

As a parent or medical provider for a youth or young adult with special health care needs, you may be caught up in day-to-day details.

This brochure is a reminder that your teen is growing up and it is time to start thinking about key decisions you will need to help them make in the next several years.

We hope the information and related resources provided help you and your young adult plan for the future.



Our future exists in the hopes of our children . . .

Encouraging Independence

- Evaluate your teen's knowledge of his/her health care needs. Fill in any gaps in understanding.
 - Continue to teach self-help skills for independence and additional skills related to specific health care needs.
 - Teach your teen to talk with medical providers about age-appropriate information such as physical and emotional development and sexuality.
 - Help your young adult write an up-to-date record of their medical history with his/her medical provider. Include conditions, operations, medications and treatments (with dates, doctors and recommendations).
 - Teach your teen to make medical appointments and be responsible for refilling prescriptions and ordering supplies.
 - For transfer of medical care, research adult health care providers or Community Health Clinics.
- Begin exploring health care financing and coverage options for your young adult.
 - If your young adult has not received SSI due to parental income or assets, contact SSI prior to your young adult turning 18 to see if he/she will become eligible.
 - If appropriate, apply for guardianship so that it is in place before your young adult turns 18.
 - If your teen has a 504 Plan or Individualized Education Plan (IEP) at school, attend meetings with your teen. Encourage your teen to actively participate. Keep a copy of the plan that is developed to assure that it is followed.
 - Help your teen explore volunteer and work activities. Encourage him/her to think about possible career interests and investigate resources or support needed for meaningful employment or education.
 - Support your teen in identifying and attending support groups and participating in recreation, social and leisure activities.

Getting What You Need at Your Doctor Visit



Getting What You Need at Your Doctor Visit

When you make an appointment to see your doctor, whether if it's for a routine check-up or for a new health issue, there is more to do than just call the office to schedule the appointment. Planning ahead and being prepared can help lower your stress and make your visit more productive, both for you and your doctor.

BASIC IDENTIFICATION (ID) – ALWAYS CARRY WITH YOU

- State issued identification card
- Health Insurance Card(s) – private and Medicaid/Medicare
- Updated portable medical summary/emergency information sheet (1 page)
- Signature stamp (if you have trouble writing your name)

Before Your Appointment – Medical Information and Health Insurance

MEDICAL INFORMATION FOLDER/BAG – TAKE TO THE DOCTOR

Sometimes it's easier to have things organized ahead of time. Some folks have a plastic folder or canvas bag already packed with items they will need for their appointments.

- Copies of items listed in "Basic ID"
- Any new test results you have received, list of questions
- Money for co-pay, parking, taxi and phone calls

PREPARE A HEALTH FILE – KEEP AT HOME IN A SAFE PLACE

While your doctor and hospital will create and keep a file on you that has your medical information, immunization records and hospitalizations, what happens when YOU need information from these files when the office is closed or when you are out of state? It's a good idea for YOU to have a duplicate file at home. Here's what you need to file in a safe place. If you do not have these items ask your doctor for help in getting copies.

FILE 1 – PERSONAL HEALTH INFORMATION

- Copy of your health insurance card(s) front and back
- Copy of State issued identification card (Drivers' License or state ID card)
- Portable medical summary/emergency medical information sheet (1 page)

FILE 2 – RECORDS AND TEST RESULTS

- Immunization records
- Copies of medical tests, blood work, height/weight chart and other test results

FILE 3 - RECEIPTS

- Receipts from insurance company of bills they have paid or reimbursed you
- Receipts from out-of pocket medical expenses: co-pays for office visits, prescriptions, equipment and other related items (may be tax-deductible)

FILE 4 – MEDICAL HISTORY & NOTES

- Copies of hospitalization discharge summaries
- Copies of discharge summaries from any specialists

FILE 5 – NOTES FROM YOUR DOCTOR

- Copies of progress notes from your doctor
- Copies of letters that your doctor writes to other doctors about your health
- Ask your doctor to cc you on these letters

FILE 6 – CORRESPONDENCE

- Copies of letters you have written: medical justification documentation, appeals to insurance companies, requests for services and other medically related correspondence
- Replies to your letters paper clipped or stapled to your letter

Web Sites

- Kentucky
- Louisiana
- Utah

Finding and Using Adult Health Care

- “Do you need an office that is wheelchair accessible?”
- Refer to your health insurance company booklet of approved providers.
- Find a university health center (sometimes there are research studies going on which offer free care).
- Developing a plan of action for when you need emergency care...”
- Kentucky: <http://chfs.ky.gov/ccshcn/ccshcntransition.htm>

Life Maps

14-16 & 17-21

- “Do you go to school/work regularly?”
- Do you think that your school/work assignments are at the right level for you?
- Does your school/work give you the necessary time and space to take care of your health needs?
- Have you talked to someone about special programs that can help you pay for job training and college?...”
- Kentucky: <http://chfs.ky.gov/ccshcn/ccshcntransition.htm>

Transition Developmental Checklist

- “Discusses job and career interests
- Has friends for social activities
- Knows about school to work, VR, and other community resources for work preparation
- Participates in IEP, 504, transition meetings
- Can grocery shop, cook, plans meals, do laundry, and keep house
- Kentucky:<http://chfs.ky.gov/ccshcn/ccshcntransition.htm>

Fact Sheets

- Vocational Assessment
- Social Security and Work Incentives
- How Working Affects Supplemental Security Income (SSI) Benefits
- Home Ownership
- Money Management
- Medicaid
- Friendship Networks
- Self-Advocacy and Self-Determination
- And may more...
- Louisiana: <http://www.hdc.lsuhsu.edu/Programs/CDP/ashstprd.htm>

Young Adult Voices

- Respecting the Young Adult Patient video
- Utah: http://blt.cpd.usu.edu/Training_for_Providers.html
- Helping Youth and Parents Prepare for Medical Transition (copy of this presentation)

Becoming Leaders for Tomorrow (BLT) Project

- Advisory Committee Members
 - Justin Olson
 - Kaysie Solomon
- Tips for professionals:
 - How schools could have helped me with transition.
 - How medical providers could have helped me with transition.
 - What I could have done to make my transition easier.
- Questions