



Portable Medical Summaries

New York State Institute for Health Transition Training
Developmental Disabilities Planning Council

TRANSITION INFORMATION FORM

Adapted from the Emergency Information Form for Children with Special Needs
American College of Emergency Physicians – American Academy of Pediatrics

	Date Form Completed By Whom	Revised Revised	Initials: Initials:
Name: Jane Doe	Date of Birth: 1/25/87		
Home Address: 123 Maple Lane Anytown, USA 12345	Home Phone: 123-456-7890		
Health Care Guardian: <u>X</u> (N/A)	Work Phone: 234-567-8901		
Signature/consent:	Health Care Guardian Phone:		
Communication barriers: Non verbal learning disability: Provide written Instructions	Emergency Contact Names and Relationship Jane Doe		
	Phone Number(s): 234-567-8902		

Current insurance provider	Anticipated adult insurance provider
Primary: BCBC Account Number: XZ-2345-6789-20 Case manager: none	Primary: BCBS student rider Account Number: XZ-2345-6789-20 Case manager:
Secondary: Medicaid Account number: AB-123-456789- Case manager:	Secondary: Account Number: Case Manager:
ICD-9 codes: 741.03 (Spina Bifida with shunted hydrocephalus) 344.61 (neurogenic bladder)	

Current pediatric healthcare providers	Anticipated adult healthcare providers
Primary Care:	
Current Provider: Hometown Doc Address: Phone/fax:	Adult Provider: College Town MD Address: Phone/fax:
Specialty: Neurosurgery	
Current Provider: Hometown Doc Address: Phone/fax:	Adult Provider: College Town MD Address: Phone/fax:
Specialty: Urology	
Current Provider: Hometown Doc Address: Phone/fax:	Adult Provider: College Town MD Address: Phone/fax:
Specialty: Orthopedics	
Current Provider: Hometown Doc Address: Phone/fax:	Adult Provider: College Town MD Address: Phone/fax:
Specialty: Mental Health	
Current Provider: Social Worker: Spina Bifida Center Address: Phone/fax:	Adult Provider: College Town Counselor Address: Phone/fax:
Specialty:	
Current Provider: Address: Phone/fax:	Adult Provider: Address: Phone/fax:
Emergency Department:	
Current: Hometown ED	Anticipated: College Town/State Hospital
Tertiary Care Hospital:	
Current: Home Town Medical Center 123-456-6789	Anticipated: College Town/State Hospital 987-654-3210

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Current ancillary service providers	Anticipated ancillary service providers
Pharmacy:	
Current: Hometown Pharmacy Address: Phone/fax:	Anticipated: College Town Pharmacy Address: Phone/fax:
Durable Medical Equipment Vendor:	
Current: Hometown Vendor Company Address: Phone/fax:	Anticipated: College Town Vendor Company Address: Phone/fax:
Medical Service Coordinator:	
Current: Address: Phone/fax:	Adult: Address: Phone/fax:
Home Health Agency:	
Current: Address: Phone/fax:	Adult: Address: Phone/fax:

Diagnosis/Past Procedures	Physical Exam
<p>Problem List:</p> <ol style="list-style-type: none"> 1. Lumbar myelomeningocele s/p closure at birth. S/P detethering 1/1999 and 2/2004 2. Ventriculo-atrial shunted hydrocephalus, s/p V-P shunt placement at birth with revision x2 in first year of life. VP was changed to VA shunt when there was shunt malfunction after ACE/Mitrofanoff 3. Chiari I malformation, has problems swallowing pills and has mild dysarthria, otherwise asymptomatic. Is known to have C6-T4 syrinx, stable~ Does have weakness in hand intrinsics on left, but otherwise no symptoms 4. Neurogenic bladder: S/p augmentation cystoplasty and Mitrofanoff in 2/2002. Catheterizes via umbilical stoma q. 4 hours. Normal renal function. 5. Neurogenic bowel s/p Chaitt tube placement in 2/2004. Flushes with 800 cc's tap water nightly. Occasionally uses immodium. 6. Motor impairment: L2 paraplegia-primarily uses wheelchair for mobility. Has left dislocated hip. 7. Scoliosis s/p Harrington rod placement in 2000. 8. Osteoporosis s/p pathologic fracture left femur in 1996. DEXA scan in 2004, on fosomax 700 mg weekly. 9. Insensate in saddle distribution and below knees bilaterally. Coccygeal decubitus x 2, with hospitalization for osteomyelitis in 2/1999. 10. Depression, in remission. No longer on medications. <p>Synopsis: Dusty is a 17 year old with mild lumbar level paraplegia who had Chaitt ACE/Mitrofanoff procedures when he was 14. The Mitrofanoff stoma has been problematic and if he is not able to cath easily he needs to be seen promptly. He has short term memory problems.</p>	<p>Baseline physical findings: Venous stasis resolves when legs elevated (not lymphedema) See neuro exam below for pertinent positives</p> <p>Baseline vital signs: Normal</p> <p>Baseline neurologic status: Mild dysarthria (Chiari-related) Tongue deviates slightly to left Left exotropia End point horizontal nystagmus with leftward gaze L2 level paraplegia</p>

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Medication List Bicitra 10 MEq BID 16 French catheters Water soluble lubricant Prostheses/Appliances/Implantable Devices: Quicki manual wheelchair with ROHO cushion	Significant baseline ancillary findings (lab, x-ray, ECG) CT Head (2004, when asymptomatic): Mild Ventriculomegaly of lateral ventricles. Thickened calvarium
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Management Data	
Allergies: Medications/Food to be avoided Latex	And why: Latex sensitive (hives)
Procedures to be avoided MRI studies Prolonged immobilization without pressure relief surface	And why: Harrington rods Insensate L2: Prone to pressure sores

Immunizations (mm/yy)			
Dates			

Common Presenting Problems/Findings with Specific Suggested Managements		
Problem 1. Unable to catheterize 2. Odiferous urine, no fever	Suggested Workup Cystogram No urine culture is needed. Please follow guidelines for management of asymptomatic bacterium	Treatment considerations This is potentially a surgical emergency. Call urologist immediately for inability to catheterize. At high risk for bladder rupture Increase fluid intake. Re-evaluate in 24 hours if symptoms persist or if symptoms worsens or if febrile

Condition-specific health maintenance recommendations: Augmentation cystoplasty: 1) Beginning 10 years after surgery, annual cystoscopy 2) Urinary alkalinization to prevent osteoporosis, 3) Annual B12 level. SBAA Guidelines for Health Maintenance in Adulthood: http://www/sbaa.org/site/PageServer?pagename=about_livingadults

Additional comments: Jane has impairment of short term memory and non-verbal learning disability. Please provide written healthcare instructions. Thorough skin examination is recommended. He has recently has several decubitus ulcers.

Physician/providers signature:	Print Name:	Date:
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Emergency Information Form for Children With Special Needs

Last name:



American Academy of Pediatrics



Date form completed
By Whom

Revised
Revised

Initials
Initials

Name:		Birth date:	Nickname:
Home Address:		Home/Work Phone:	
Parent/Guardian:	Emergency Contact Names & Relationship:		
Signature/Consent*:			
Primary Language:	Phone Number(s):		
Physicians:			
Primary care physician:		Emergency Phone:	
		Fax:	
Current Specialty physician: Specialty:		Emergency Phone:	
		Fax:	
Current Specialty physician: Specialty:		Emergency Phone:	
		Fax:	
Anticipated Primary ED:		Pharmacy:	
Anticipated Tertiary Care Center:			

Diagnoses/Past Procedures/Physical Exam:	
1. _____	Baseline physical findings:
_____	_____
2. _____	_____
_____	_____
3. _____	Baseline vital signs:
_____	_____
4. _____	_____
_____	_____
Synopsis:	Baseline neurological status:
_____	_____
_____	_____
_____	_____

*Consent for release of this form to health care providers

Diagnoses/Past Procedures/Physical Exam continued:

Medications:	Significant baseline ancillary findings (lab, x-ray, ECG):
1.	
2.	
3.	
4.	Prostheses/Appliances/Advanced Technology Devices:
5.	
6.	

Management Data:

Allergies: Medications/Foods to be avoided	and why:
1.	
2.	
3.	
Procedures to be avoided	and why:
1.	
2.	
3.	

Immunizations

Dates						Dates					
DPT						Hep B					
OPV						Varicella					
MMR						TB status					
HIB						Other					

Antibiotic prophylaxis:

Indication:

Medication and dose:

Common Presenting Problems/Findings With Specific Suggested Managements

Problem	Suggested Diagnostic Studies	Treatment Considerations

Comments on child, family, or other specific medical issues:

Physician/Provider Signature: _____ **Print Name:** _____

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** Spinal Muscular Atrophy Type 2 (Severe Anterior Horn Cell disease, dx 3/74)
359 Muscular Dystr/335.1 SMA Incomplete quad (has full sensation), no functional movement
2. **RESPIRATORY** Respiratory failure - trach and vent (9/01), Chronic RLL Atelectasis, Recurrent pneumonia
V44 Trach, 518.81 Resp Failure Respiratory Insufficiency, poor residual functions/reserved capacities
486, Pneumo Org NOS
3. **GASTRO** Decreased esophageal motility, s/p feeding gastrostomy tube (7/83)
V44.1 Gastro Status
4. **ORTHOPEDIC** Severe deformities: thoracic, pelvic obliquity, bilateral dislocated hips, flexion contractures
737.4, 754.89, 754.81 spinal fusion (3/82 Lueke Rod), pectus excavatum
5. **UROLOGICAL** Undescended L testicle (since birth), intermittent cath (10/01), cath: 10 Fr,
752.51 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 0603880 - lot 36HI124)

MEDICAL

<p>ACUPUNCTURE PHYSICIAN Barbara XXXXX RN, AP, Ocala, FL O: 352- xxx -xxxx</p> <p>INTENSIVIST: Melvin XXXX, MD, Ocala, FL O: 352-622-xxxx</p> <p>PULMONOLOGIST: Robert xxx MD, Gainesville, FL O: 352- xxx -xxxx Bpr: 352- xxx -xxxx</p>	<p>HOSPITAL North FL Regional Medical Center, Gainesville, FL 4/95, 1/97, 5/01, 9-10/01</p> <p>IMMUNIZATIONS Flu 02 Pneumo 79, 01 Tetanus 85 DPT 73, 79 Measles 74 Mumps 74 TB 78, 87</p> <p>ENTERAL Pulmocare 237ml x 2 cans, nocturnal, 70 ml/hr</p>
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MEDICATIONS	HERBS / DROPS	VENT / TRACH / O2
<p><u>Rx DAILY</u></p> <p>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)</p> <p><u>Rx MONTHLY</u></p> <p>1. Thiamine 100 mg monthly vitamin 2. Cyanocobalamin 1000 mcg/ml monthly (B12)</p> <p><u>Rx PRN</u></p> <p>1. Darvocet-N pain 2. Zithromax SUS PFIZ 200/5ml 45ml antibiotic 3. Diphnoxylate/atropine 1-2 tablets diarrhea</p>	<p>1. Lymphatic 5 x2 2. Flu Balancing 10 x2 3. Respiratory 7 x2 4. Allertox -airborne 5 x2 5. " " Aler-Total 3 x3 6. " " Allerdrain 10 x4 7. Immune 6 x2 8. Acute Rescue 5 x2 9. Urinary 8 x2 10. Digestive 3 x2 11. Mucous 5 x2 12. Cell 7 x2 13. Muscular 4 x2 14. Integumentary 8 x2 15. Er Cheng Tang 1 tsp x2</p>	<p>VENT - Pulmonetic LTV 900</p> <p>Breaths 05 Tidal Volume 310 Inspiration 1.1 Pressure Support 13 Sensitivity 02 High 40 Low 02</p> <p>TRACH: Shiley 6 cuffed (deflated)</p> <p>SPEAKING VALVE: Passy-Muir PMV007</p> <p>OXYGEN 1.5 liters</p>

INSURANCE

<p>BlueCross BlueShield of Massachusetts</p> <p>Primary Subscriber: xxxxx xxxxx BC/BS PPO Plan Code 200 Customer service: 800-296-xxxx XXP XXXXXXXX 10 PPO</p>	<p>BlueCross BlueShield of Massachusetts</p> <p>Secondary Subscriber: xxxxx xxxxx BC/BS Blue Choice Plan 2, POS Code 200 Customer service: 800-222-xxxx XX XXXXXXXX 10</p>
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HEALTH SURROGATE Pxxxx Hxxxx (mother) c 352-xxx-xxxx h 352-xxx-xxxx

<p>BC/BS Case Manager Health Vendor Home Nursing Agency Pharmacy</p>	<p>Debra XXXXXXXX Option Care House Calls Bitting's</p>	<p>800-392-xxxx ext. xx 800-825-xxxx 352-373-xxxx 352- xxx-xxxx 352-732-xxxx</p>	<p>acc't. # xxxxx acc't. # xxxxx</p>
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A black and white photograph of medical syringes and a stack of cash. In the foreground, two syringes are positioned diagonally, their needles pointing towards the bottom right. In the background, a stack of banknotes is visible, slightly out of focus. The overall scene suggests a connection between healthcare and finance.

Health Insurance

Mock Insurance Card (Sample)

The Right Stuff	Your choice to better healthcare	PPO
Subscriber # AQKR83240918		
NC GoodDecision Premium		
Group # M36100		
	Member Effective	
01, Tom Hamerick	05-20-06	
02, Mary Hamerick	05-20-06	
03, Sarah Hamerick	05-20-06	
www.rightstuffhealthcare.com		

*This is an example of what a **group insurance** card would look like.
This is not a real insurance company.

Here is what we know:

- **NO HEALTH INSURANCE** - Two out of five college graduates and one-half of high school graduates who do not go on to college will experience a time without health insurance in the first year after graduation. (*Commonwealth Fund 2003*)
- **DROPPED FROM HEALTH INSURANCE** - Young adults are often dropped from their parents policies or public insurance programs at age 19, or when they graduate from college and struggle to find jobs with health benefits. Young adults are far more likely to be uninsured than older adults: four of 10 young adults between the ages of 19 and 29 can expect to be uninsured at sometime during the year--twice the rate of adults ages 30 to 64. (*Commonwealth Fund 2003*)
- **BARRIERS TO GETTING AND KEEPING HEALTH INSURANCE** - "Americans with disabilities face a number of distinct barriers in obtaining, maintaining, and using health insurance and in accessing and using health care services. At the same time, Americans with disabilities also confront the barriers, problems, and frustrations with which most Americans routinely struggle in the insurance and health care systems."
(*National Council on Disability 2002 annual National Disability Policy: A Progress Report*)

PUBLIC HEALTH INSURANCE: Changes after reaching majority age

MAINTAIN MEDICAID

- Passed SSI Redetermination - continue benefits
- Emancipated Minor - by marriage or court decision may qualify or continue Medicaid due to income or disability status.

DROP FROM MEDICAID

- Former childhood SSI recipient at age 18 did not qualify under SSI redetermination and loses benefits (income too high or does not meet disability criteria.)

NOT APPROVED - SECTION 301: PROVISION TO CONTINUE RECEIVING SSI BENEFITS

- Individuals found ineligible during SSI redetermination may continue to receive SSI benefits *IF* they began receiving state vocational rehabilitation agency services before their 18th birthday.
- Section 301 allows the young adult to retain benefits (SSI & Medicaid) while he/she participates in approved vocational rehabilitation program.
[Http://policy.ssa.gov/poms.nsf/lnx/0412515001](http://policy.ssa.gov/poms.nsf/lnx/0412515001)

NEW to MEDICAID

- Child did not qualify for SSI under 18 due to family income.
- At age 18 may qualify for SSI and Medicaid as an adult single head of household.

NOTE: "209B States," require separate application to Medicaid, not linked to SSI.

11 States have elected to have at least one more stringent requirement than the SSI rules for Medicaid eligibility: CT, HI, IN, IL, MN, MO, ND, NH, OK, OH, and VA.

PUBLIC HEALTH INSURANCE: Continued Medicaid Eligibility

MEDICAID BUY-IN WHILE WORKING: Section 1619(b)

- Still meets SSI criteria,
- Needs Medicaid in order to work; and
- Gross earned income is insufficient to pay for other supports

TICKET TO WORK

- Worker could opt to buy-in and receive Medicaid benefits
- Program is too new to assess if states are providing full benefit packages and at what level of sliding fee

Creative – MaineCare for Childless Adults

- Meets low income eligibility
- Plan pays insurance premiums for those who meet certain criteria
- Plan uses employer-sponsored insurance for the expansion

PRIVATE HEALTH INSURANCE: Continued Benefits via Family Plan

ADULT DISABLED DEPENDENT CHILD

- Youth over 18 may continue on family plan if dependent for life.
- Must be on the family plan prior to turning 18. (Legal Statute: 40 states)
- No substantial gainful employment
- Annual re-certification - disability & dependent

STUDENT STATUS

- Proof of college class load each semester (often requires full-time status)
- Ages 18-22, sometimes older
- Annual re-certification

PRIVATE HEALTH INSURANCE: Young Adult Pays Premium

OPTIONS to buy private insurance health care benefits:

- College - student plan
- Employed - group plan
- Self-pay: single plan
- Ticket to Work (Medicaid Buy-in)
- COBRA
- State High Risk Pools

Concern: What happens if health status changes and affects continuous employment or attending school? There is no safety-net or easy on/off for health care benefits.

Tip Sheet Developed by: Patti Hackett & Glen Gallivan, Ocala, FL



The HRTW National Center www.hrtw.org enjoys a working partnership with the Shriners Hospitals for Children and KASA. The National Center is funded through a cooperative agreement (U93MC00047) from the Integrated Services Branch, Division of Services for Children with Special Health Needs (DSCSHN) in the Federal Maternal and Child Health Bureau (MCHB), Health Resources and Services Administration (HRSA), Department of Health and Human Services (DHHS).
HRSA/MCHB Project Officer: Monique Fountain, MD.

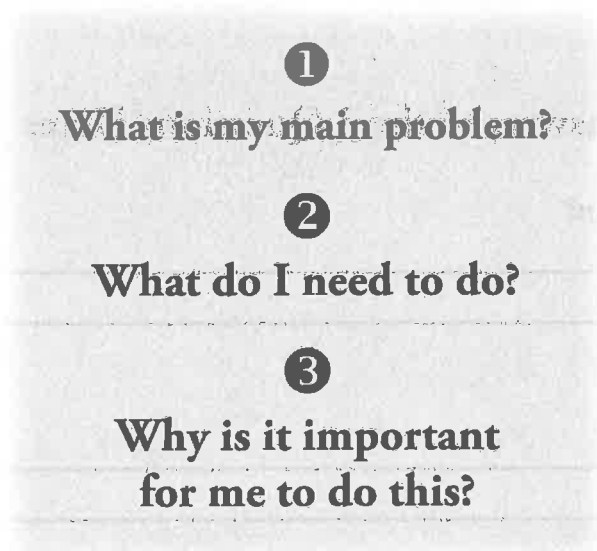
HRTW Phase II Projects are currently active in Arizona, Iowa, Maine, Mississippi, and Wisconsin.

The opinions expressed herein do not necessarily reflect the policy or position nor imply official endorsement of the funding agency or working partnerships.



Good Questions for Your Good Health

Every time you talk with a doctor, nurse, or pharmacist, use the **Ask Me 3** questions to better understand your health.



When to Ask Questions

You can ask questions when:

- You see your doctor, nurse, or pharmacist.
- You prepare for a medical test or procedure.
- You get your medicine.

What If I Ask and Still Don't Understand?

- Let your doctor, nurse, or pharmacist know if you still don't understand what you need to do.
- You might say, "This is new to me. Will you please explain that to me one more time?"

Who Needs to Ask 3?

Everyone wants help with health information. You are not alone if you find things confusing at times. Asking questions helps you understand how to stay well or to get better.

The **Ask Me 3** questions are designed to help you take better care of your health.

To learn more, visit www.npsf.org/askme3

Your Doctor, Nurse, and Pharmacist Want to Answer 3

Are you nervous to ask your health provider questions? Don't be. You may be surprised to learn that your medical team wants you to let them know that you need help.

Like all of us, doctors have busy schedules. Yet your doctor wants you to know:

- All you can about your condition.
- Why this is important for your health.
- Steps to take to keep your condition under control.

Asking these questions can help me:

- Take care of my health
- Prepare for medical tests
- Take my medicines the right way
- I don't need to feel rushed or embarrassed if I don't understand something. I can ask my doctor again.
- When I **Ask 3**, I am prepared. I know what to do for my health.

Bring your medicines with you the next time you visit your doctor or pharmacist. Or, write the names of the medicines you take on the lines below.

Like many people, you may see more than one doctor. It is important that your doctors know all the medicines you are taking so that you can stay healthy.

Write Your Doctor's Answers to the 3 Questions Here:

1 What is my main problem?

2 What do I need to do?

3 Why is it important for me to do this?

Ask Me 3™ is an educational program provided by the **Partnership for Clear Health Communication at the National Patient Safety Foundation™** – a coalition of national organizations that are working together to promote awareness and solutions around the issue of low health literacy and its effect on safe care and health outcomes.

Partnership for
Clear Health Communication
at the National Patient Safety Foundation™

www.npsf.org/askme3