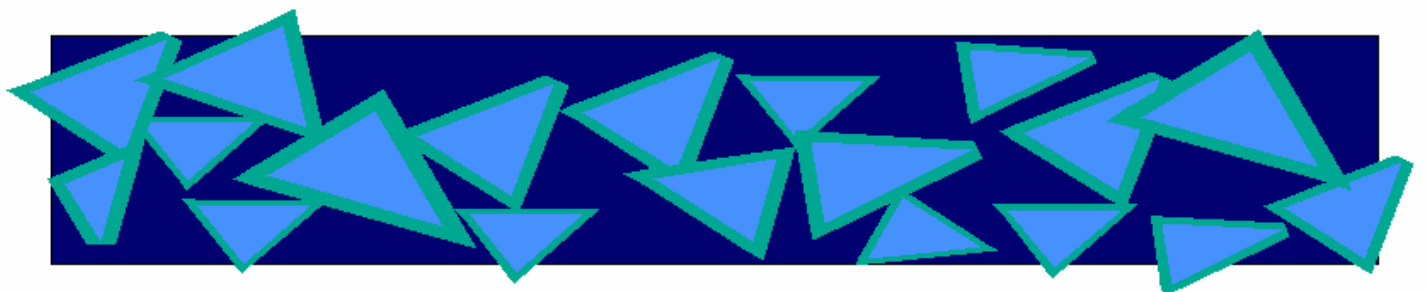
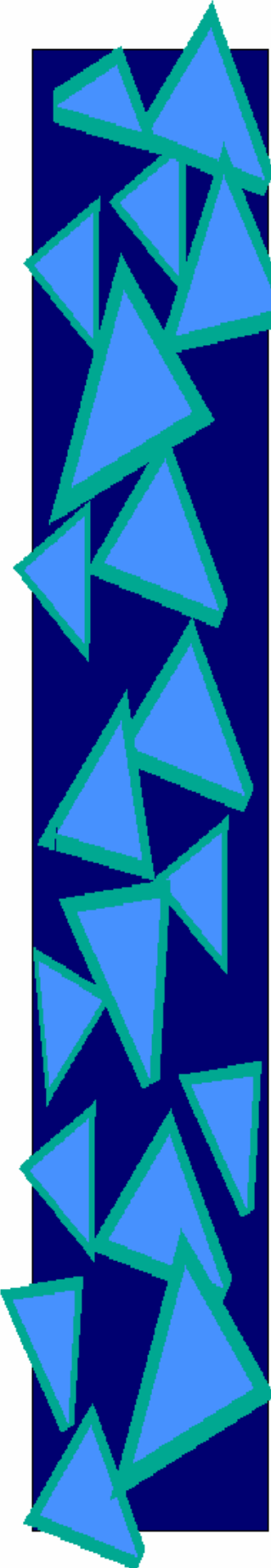


It's All About ME!!

Helping teens take charge
of their own medical care.





No matter who you are or the medical problems you have; everybody knows the doctors, nurses, therapists, and everyone behind the scenes at Children's Mercy are **AMAZING!**

Children's Mercy Hospitals and Clinics is such a wonderful place that teens with medical problems, like us, don't have to worry about much, except trying to follow the treatment plans the doctors recommend. They do their best to make sure we have the chance to do what ever is possible and not miss out on life, but we have to do our part by following their medical advice. This notebook can be a great tool to do just that!

As hard as it is to believe, Children's Mercy may not be able to help you all of the time. Think about it... what if you are on vacation with your family, visiting relatives out of the state or country, traveling with school or church, or even going to college away from home? Look at this notebook as your ticket to travel, be yourself, and go any where you want to go. Whether you have a small problem or even a very serious problem, with this notebook you can go just about any where and be cared for. The more information you give to doctors who don't know your history, the more aware they will be of you and your diagnosis and the better they can treat you.

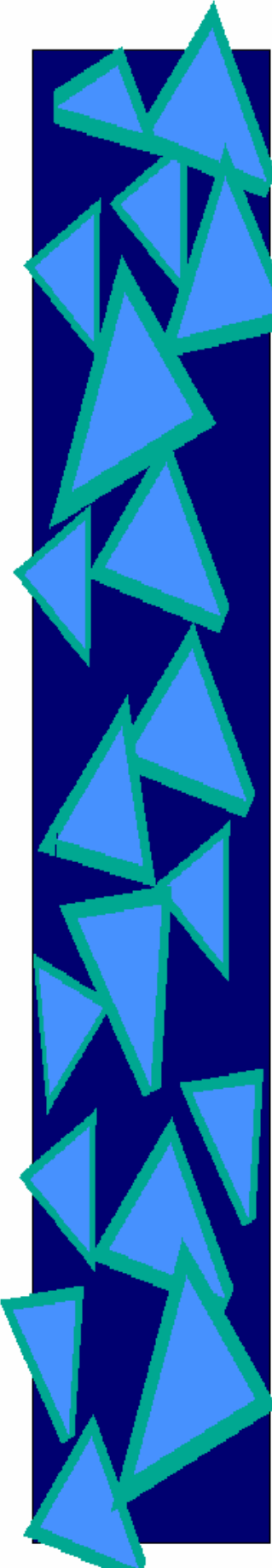
As much as we would like to, we can't be patients at Children's Mercy forever... We are all growing up, getting older, our bodies are changing and some diseases may move into different stages. There comes a time when we have to move on to different doctors and treatments; we need to prepare for transitioning into adult medical care. This binder can also help your future doctors' by providing them with information that will help make life changing treatment plans. Being firm and knowledgeable about your needs is important. Take the time to make sure this book is all about you!

Doctors will need to know about all surgeries and all procedures you have had. They will need to know what meds you have taken and are currently taking. They also need information on your symptoms, like what triggers them and which strategies work best for you.

The more details you provide in this book, the better care you will receive in the future. Keep careful records and ask a lot of questions. Remember this book is **ALL ABOUT ME!!!**

Courtesy of Leah Dawson

CMH Teen Advisory Board



In December 2002, the American Academy of Pediatrics (AAP) published a policy statement that states that planning for transition for health care from child-oriented to adult-oriented focus should begin no later than age 14. We realize that medical, developmental, behavioral and social factors all need to be considered.

The points that the AAP states are critical for successful transition of care involve:

- Identifying a health care professional currently providing care that will be responsible for assisting with future health care planning. This can be a primary or specialty physician or nurse, social worker, case manager, or other treatment provider.
- Making sure that young adults understand their medical conditions, specifically- signs and symptoms that require urgent medical attention, long term implications of their condition and treatments on their general medical, sexual, and reproductive health.
- Patients should keep an up-to-date medical summary that is portable and accessible. That's what this notebook is!!
- The patient, family and health care team should create a detailed written plan for health care transition by age 14. The plan should be followed, with review and updated as needed (at least annually and when there is a transfer of care). Look elsewhere in this book for forms to help with this.
- Assure that young adults have access to properly trained adult-oriented health providers and adequate health insurance to cover their needs.



Table of Contents

Section 1- *Getting started on the road to independence*

- Goal Setting Sheet
- How to interact with your providers
- How your parents can support your growing independence
- Transition Check List

Section 2- *Just the facts—Patient Information*

Section 3- *Planning Tools—Calendar, Medication Log*

Section 4- *General Information—Condition Specific*

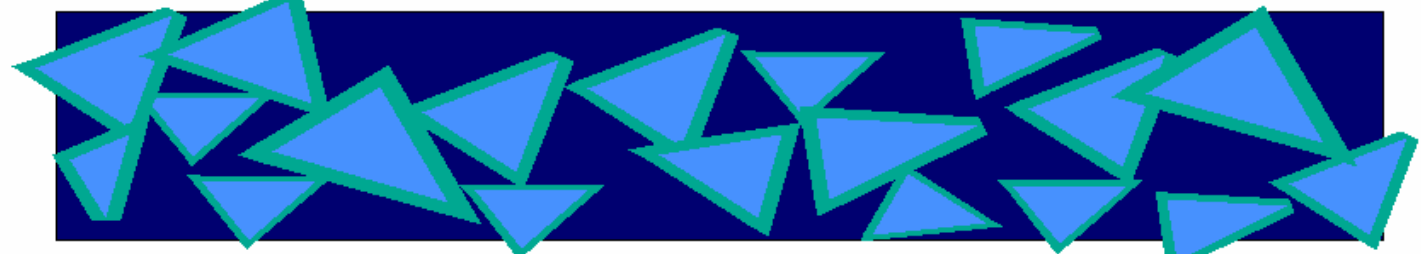
Section 5- *Medical Reports/ Clinic Visits/ Other Results*

- Problem List
- Treatment Summary
- Personal and Family Health History
- Immunizations

Section 6- *Just for Young Men and Women*

Section 7- *Resources to Help Along the Way*

Section 8- *Venturing out into the Adult World- General Health Concerns for Adults*

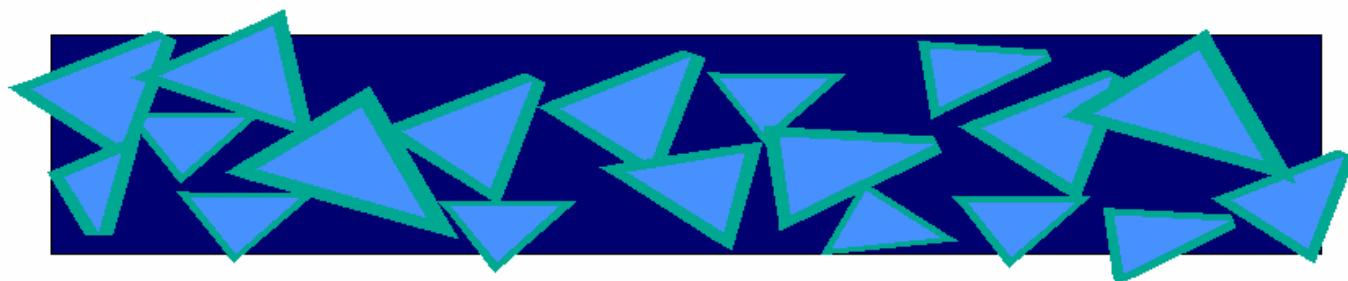
- Legal Issues—Advance Directives, Power of Attorney, guardianship for mentally challenged
 - Release of Information Form
 - Interviewing Potential Providers
- 



1. Getting Started on the Road to Independence

The process of going from a teen to an adult is complex in many ways. We will help you assume responsibility for your own health care as part of that process.

The resources in this section will help you establish your transition plan. To make sure your plan is a success, you, your doctors, and your family all have to be aware and willing to follow all the steps.



Things you can do to be more responsible for your own health care:

Ages 13 – 14 and onward:

- Ask questions and become actively involved in your healthcare visits!
- Consider meeting with your healthcare provider alone for at least a part of your appointments, so you can feel completely free to talk and share concerns.
- When you feel comfortable, let your parents know that you want to do the talking and answering of questions.
- If you feel your healthcare provider is rushing through an appointment, tell them to slow down a little. Ask them to explain the things you don't understand.
 - Make sure you are being responsible to keep yourself healthy.
 - Make sure you understand what to do to keep yourself healthy
 - Keep notes, schedules or use a planner to remind you to do the things you need to do to take care of yourself (this binder will help you)
- These are great years to talk to your parents and providers about what your goals are for the future.
 - Talk to your parents about becoming more independent, scope out a plan together!
 - Do you plan to finish high school?
 - After high school will you want to get a vocation or attend college?
 - What type of job would you like to have?
 - Do you want to be able to drive a car?
 - Talk about these or other questions and goals you want to achieve!

Ages 15 – 17 and onward:

- Learning and practicing your skills to carry out your health care activities will lead toward being more independent.
 - Spend most of your time with your health care provider by yourself.
 - Have a list of questions for your provider. Your parents can offer suggestions, listen to your concerns and help you with planning, but try to keep track of and manage your care as much as possible.
 - Continue keeping your medical journal (All About Me) and review your goals frequently.
- Talk to your care providers about transitioning.
 - Find out at what age your doctor will refer you to an adult care provider.
 - Understand your medications and why you are taking them.
 - Understand the difference between a primary care provider and a specialist.
- Start learning about your legal rights when you turn 18. Everyone's situation is different so ask questions about yours.
- Talk to your parents and providers about your goals.
 - Are you independently taking care of chores around your home?
 - Do you have a part time job?
 - Are you responsible with homework and school activities?
 - Are the friends you have chosen supportive of you?
 - Are you being a good friend?
- Be aware of your surroundings and how they affect you and your health.

Age 18 and Beyond!:

- ❑ When you turn 18 you legally became an adult. You have been preparing for independence for several years now, and the time has come to take charge and manage your medical care. Refer to the section on Legal Considerations for more information.
- ❑ Understand your Health Care Insurance! Plans vary and you will need to understand what type of coverage you have and how long it will carry you.
 - Insurance can change due to age so make sure you understand your coverage.
 - Do you understand your insurance, Medicaid, SSI or what your situation is?
 - If you have or are getting a job do you understand you benefit package and how it affects you?
- ❑ Do you understand the effects your health condition brings to your future?
 - Do you understand what your medications are and can communicate those needs?
 - Do you have adult care providers?
- ❑ Continue to be aware of your surrounding and how your decisions affect your health.

Parent and Child Interactions that Encourage Independence...

By ages 6-11, or according to your child's developmental ability

- Help your child start talking directly with doctors, nurses, therapists and teachers.
- Find out what your child knows about his/her special health care need. Build on their understanding.
- Continue teaching your child normal self-care skills as well as skills related to his/her special health care need.
- Work with school to assure equal access to school programs; ask if your child qualifies for a 504 plan.
- Encourage hobbies and leisure activities
- Continue to encourage decision-making skills by offering choices.
- Continue assigning your child chores appropriate for his/her ability level.
- Let your child choose how to spend some or all of allowance.
- Teach your child the consequences of his/her behaviors and choices.
- Allow your child to experience the consequences of a poor choice as well as a good choice.
- Begin teaching your child how to advocate for himself/herself.
- Begin asking your child "What will you do when you grow up?"

By ages 12-18, or according to your child's developmental ability

- Find out your teen's understanding of his/her special health care need. Fill in knowledge gaps.
- Continue teaching your teen normal self-help skills as well as skills related to special health care need.
- Begin helping your teen keep a record of his/her medical history, including conditions, operations, treatments (dates, doctors, recommendations) and 504 plan if he/she has one.
- If has a 504 plan, encourage teen to participate in any 504 meetings.
- Begin helping your teen take responsibility for making and keeping his/her own medical appointments, ordering their own supplies, etc.
- Begin exploring health care financing for young adults at age 17. With teen, check eligibility for SSI the month he/she turns 18. At age 18, the teen's financial resources are evaluated, not the parents/guardians
- Discuss sexuality with your teen.
- Help your teen identify and build on his/her strengths.
- Help your teen be involved in age and developmentally appropriate activities. Explore support groups, talk about possible career interests, find work and volunteer activities, hobbies and leisure activities, seek out adult or older teen role models.
- Begin, with your teen, looking for an adult health care provider.
- Encourage teen to contact campus disabled student services to request accommodations if he/she will be attending college.

By ages 18-21, or according to your child's developmental ability

- Act as a resource and support to your young adult.
- Encourage your young adult to participate in support groups and/or organizations relevant to his/her special health care need.

My Goal Setting Worksheet

Name _____

Date _____

1. I want to be able to _____

2. These are things that are bothering me _____

3. In order to take charge of my health and life activities, I need to clearly communicate my needs and wishes to these people:

- a. _____
- b. _____
- c. _____

4. In order to take charge of my health and life activities, I need to know more information about the following areas:

- a. _____
- b. _____
- c. _____

5. In order to take charge of my life, I need to be able to do the following:

- a. _____
- b. _____
- c. _____

6. What are some “speed-bumps” that might delay meeting my goals?

- a. _____
- b. _____
- c. _____

7. In order to succeed, I am going to ask for help from the following people and agencies:

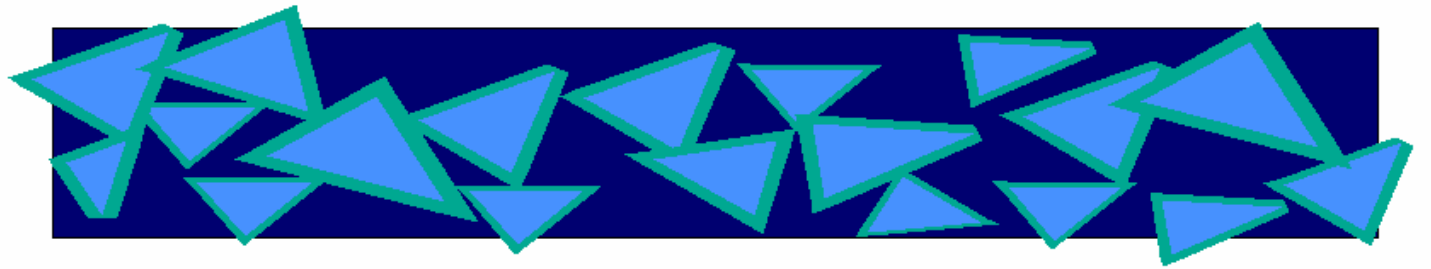
- a. _____
- b. _____
- c. _____

Checklist: Health Care Self Management

This checklist should be followed by all teens, their families, and health care providers. It should be adjusted according to the teen's developmental ability.

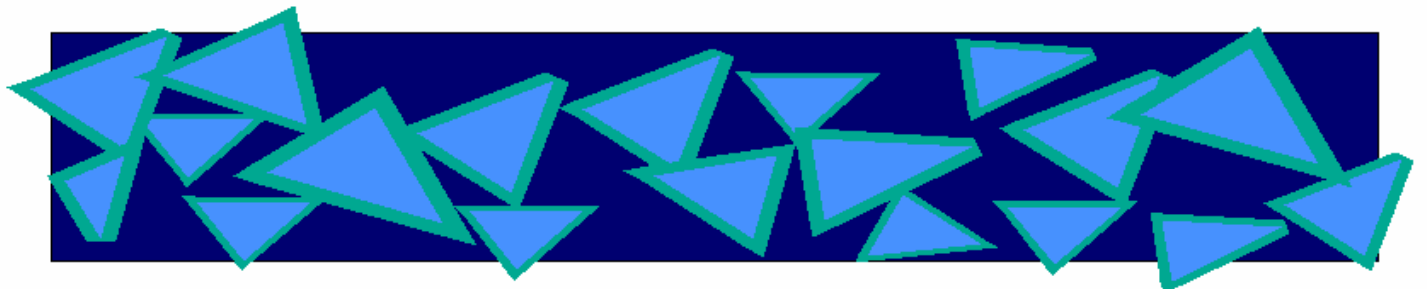
Health Care Skills	Start Date	Reviewed	Goals Complete
Meet independently (as able) with health care providers <input type="checkbox"/> For history and physical exam at age 14-16 <input type="checkbox"/> For complete visit including treatment recommendations at age 18 and over			
Understands medical condition <input type="checkbox"/> Diagnosis <input type="checkbox"/> Changes/symptoms caused by medical condition and effect on daily life <input type="checkbox"/> Treatments and medications including use, side effects, interactions <input type="checkbox"/> Laboratory tests and procedures needed <input type="checkbox"/> Obtains Medic Alert bracelet/necklace <input type="checkbox"/> Long term complications of chronic condition			
Manages Own Health Care	Start Date	Reviewed	Goals Complete
Makes own medical appointments			
Can tell when changes/symptoms require medical attention			
Refills medications and supplies, proper disposal of used supplies.			
Can tell when to replace durable medical equipment, need for extra back-ups			
Knows how to hire personal care assistants and is responsible for their supervision			
Responsibly manages daily treatments			
Knows medications and what they're for: Carries information in wallet or purse			
Knows health emergency phone numbers: Carries information in wallet or purse			
Knows what to do in a medical emergency			
Has identified an adult health provider/facility			
Has considered genetic counseling and knows genetic risks if applicable			
Knows nature and levels of sexual activity related to health condition			
Consents to medical care, prepares and asks questions of medical health care providers			
If unable to make own health care decisions, complete process for appointing legal guardian			
Accesses information and responds to health providers' questions			
Knowledge of Health Insurance	Start Date	Reviewed	Goals Complete
Knows medical insurance coverage: <input type="checkbox"/> Carries card in wallet or purse <input type="checkbox"/> Knows insurance requirements regarding covered providers, referrals, pre-certifications			
Knowledge of Resources	Start Date	Reviewed	Goals Complete
Knows how to apply for insurance/income assistance, including Medicaid/Medicare			
Contacts appropriate services and agencies for assistance			
Knows how to use community transportation if needed			
Knows that he/she may have a 504 plan or IEP and benefits of these plans for school or vocational center			

Health Records	Start Date	Reviewed	Goals Complete
Knows how to access health information			
Has consented to transferring medical health records to new provider			
Has consented to release of information to parents or other providers after age of 18			
Has and uses a planner for appointments			
Education	Start Date	Reviewed	Goals Complete
Knows that federal law requires that transition planning begin at age 14			
Knows that at age 16, transition services must be included in IEP evaluations			
Knows his/her educational rights (504, IDEA, ADA)			
Knows his/her interests, skills, strengths and challenges			
Knows his/her educational goals and transition plans			
Knows how to make decisions independently			
Knows which resources and services end at certain age, or high school or college graduation			
Plans for Independent Living	Start Date	Reviewed	Goals Complete
Have plans about living arrangements: <ul style="list-style-type: none"> <input type="checkbox"/> Live alone <input type="checkbox"/> Live with parent/guardian <input type="checkbox"/> Live in group home <input type="checkbox"/> Live with other adults <input type="checkbox"/> Other _____ <input type="checkbox"/> Modifications required based on needs _____ 			
Have an emergency evacuation plan			
Plans for employment, school, vocational programs			
Knows financial responsibilities such as: <ul style="list-style-type: none"> <input type="checkbox"/> paying bills <input type="checkbox"/> utilities <input type="checkbox"/> manage a checking account <input type="checkbox"/> budgeting <input type="checkbox"/> Savings <input type="checkbox"/> Medical costs 			
Notify utility companies and emergency services of special needs			



2. Just the Facts—Patient Information

Fill this form out so that you have all the important information with you when you need it.

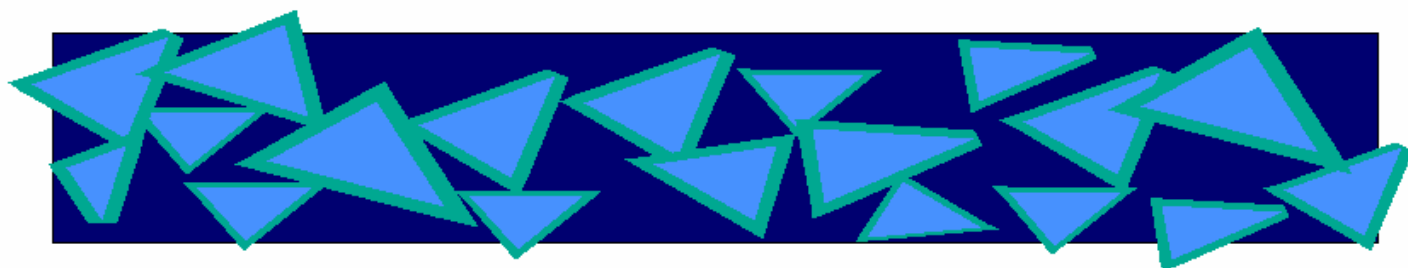


Just the facts

Patient Name:
Diagnosis:
Date Diagnosed:
Allergies (medications, foods, environmental, bee sting):
Providers/Physicians:
Emergency Contact Information:
Do you have an advanced directive? <input type="checkbox"/> Yes <input type="checkbox"/> No Location of directive _____
TYPE: Living Will Medical Power of Attorney Legal Guardianship

Insurance Information

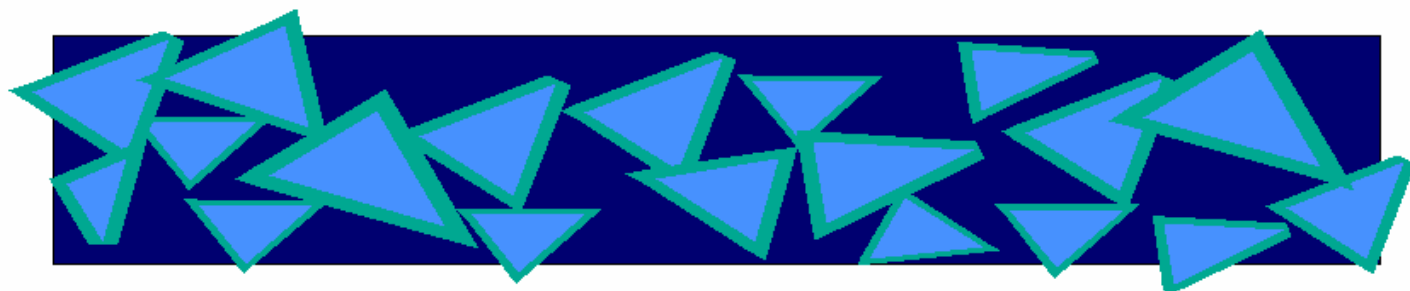
Insurance Company Name, Address, and Phone Number:
Name of Policy Holder:
Policy Number:
Group Number:
Employer Name:



3. Planning Tools— Medication Log & Calendar

- Keep track of your current and past medications as well as any allergies on your *medication log*.
- Record future appointment dates and times as well as any past medical episodes on your *calendar*.

(Contact the Children's Mercy Child Life department or go to the Children's Mercy teen website <http://www.childrens-mercy.org> for extra print outs for this section)



Calendar

Month: _____ Year: _____

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Calendar

Month: _____ **Year:** _____

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday

Calendar

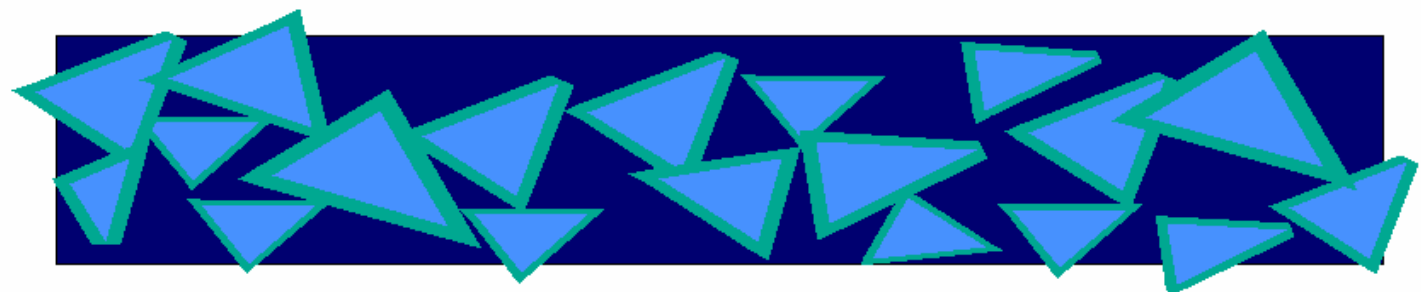
Month: _____ **Year:** _____

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday



4. General Information — Condition Specific

- Ask your physician or nurse for information about the clinics that you are seen in.
- Look in the Kreamer Family Resource Center at Children's Mercy for info about your health concerns.
- Put whatever helpful information you find on the internet or elsewhere into this section as well.

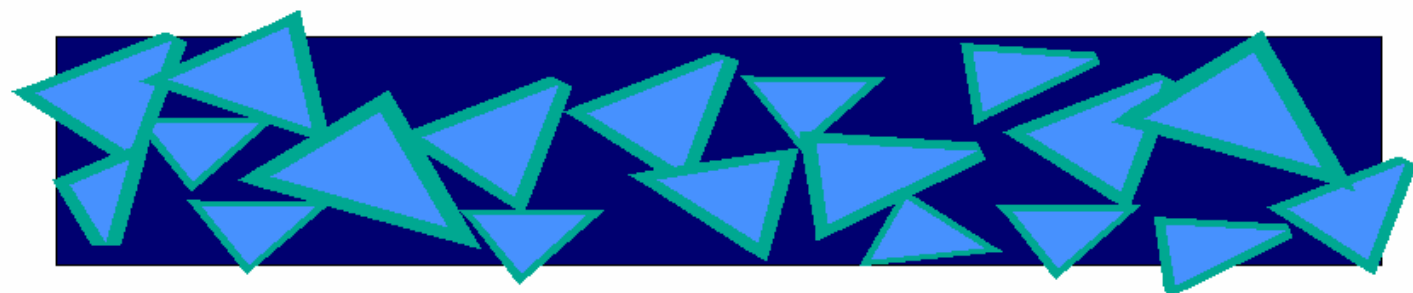




5. Medical Reports/ Clinic Visits/ Other Results

- Ask your doctor or nurse practitioner to give you copies of pertinent results to keep in this section.
- Ask for a copy of your clinic letters to be mailed to you and keep them in this section.
- Take this book with you to *ALL* your appointments to keep it updated.
- Also, remember to take your book with you on vacations and other trips so you have your medical information in case you need unexpected medical care while away from home.

(Contact the Children's Mercy Child Life department or go to the Children's Mercy teen website <http://www.childrens-mercy.org> for extra print outs for this section)



Health History Summary

*As you make the transition from pediatric to adult health care, you will be assuming more responsibility for your health care. When you go to your new adult care provider, you will be asked about major health events in your life. **Your parents and your pediatric providers can be a great resource to you in filling out this form.** Take it with you when you go to your new adult care provider, and you will be prepared for the questions that you will be asked.*

How would you describe your overall general health? (Please circle one and add comments if you want to)
Fair Good Excellent

What are your special health care needs? Is there anything in particular that your doctor needs to know about your special needs?

As a child and teenager, what were your major health problems?

Past medical history:

Your birth weight: _____ Were you born early? _____ If so, how many weeks early? _____
Were you hospitalized at the time of your birth? _____ If yes, how many days? _____ or weeks? _____

Did your mother have any problems with her pregnancy or delivery of you? What problems did you have at birth? _____

Please list any serious illnesses you have had and any injuries that included loss of consciousness.

Personal health history: Have YOU ever had the following:

Condition:	Yes	Age	Condition:	Yes	Age
Anemia			Depression		
Asthma			Suicide attempt		
Blood Transfusion			Conduct Disorder		
Cancer			Anxiety		
Constipation			Learning Disability		
Diabetes			Developmental Delay		
Ear Infections			Eating Disorder		
Eating Problems			Other Conditions not Listed:		
Heart Disease					
Hepatitis					
Seizures (Epilepsy)					
Tuberculosis					
Attention Deficit Disorder					

If the answer is yes to any of the above conditions please use this space to make any additional comments about the conditions. **For individuals with seizures**, describe the seizures and include how often the seizures occur, how long they last, and when was your last one?

Your immunization dates: (Or attach a copy of your immunization record)

DPT/DT					
TD					
Polio					
MMR					
HIB					
Hep B					
Varicella	1.	2.			
Hep A	1.	2.			
Pneumococcus	1.	2.	3.	4.	5.

Family Health History: Have any of your blood relatives had the following:

Condition:	Relation	Condition:	Relation
Anemia		ADD/ADHD	
Breast Cancer		Alcoholism	
Cancer (Other)		Depression	
Diabetes		Drug Abuse	
Heart attack		Learning Disability	
High Blood Pressure		Manic Depressive	
High Cholesterol		Suicide	
Seizures		Schizophrenia	
Sickle Cell Anemia		Other Conditions?	
Stroke			
Thyroid Problems			
Tuberculosis			

Comments _____

Resource Information:

School: _____ Grade in School: _____
 Do you have an Individual Education Plan (IEP)? _____ Do you have a 504 plan? _____
 Name of contact person at school _____ Telephone: _____
 Do you use Vocational Rehabilitation services? _____ Contact person at VR _____

Recent medical records:

List the name, address, and telephone number of any doctors or other health care provider who have the latest medical records about your health conditions.

Name	Specialty	Address	Telephone #

Other resources:

List the name, address, & telephone number of any other person that has worked with you in regard to your health condition in the past two years (such as a physical therapist, pharmacist, medical supply house, caseworker, school nurse, etc.).

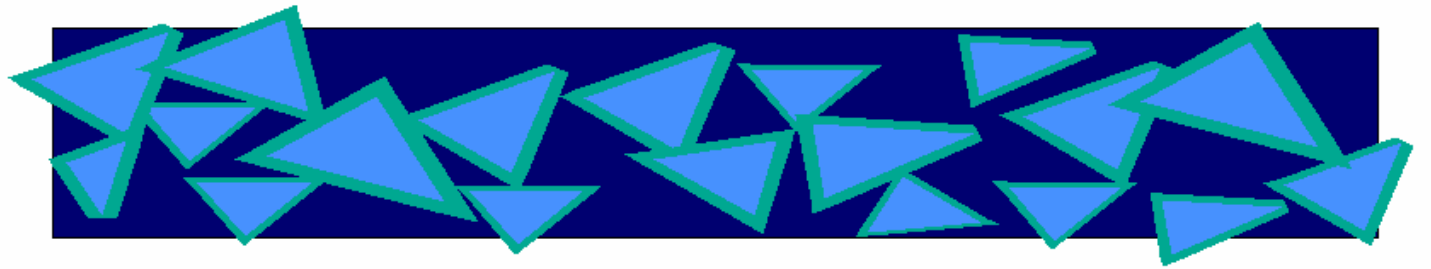
Name	What They Do	Address	Telephone #

Do you receive social security income (SSI)?	YES	NO
Do you receive medical benefits through the SSI program?	YES	NO

Activities of Daily Living

	YES (Explain)	NO
Are you visually impaired?		
Do you wear glasses or contacts?		
Are you deaf or hard of hearing?		
Do you use a hearing aid?		
Do you have any speech problems?		
Do you use sign language?		
Is English your preferred language? If no, what language do you speak?		
Can you walk?		
Do you use a walker?		
Do you use a wheelchair?		
Do you routinely wear medic alert identification?		

What other aids do you use to accomplish daily activities? Do you have any restrictions?



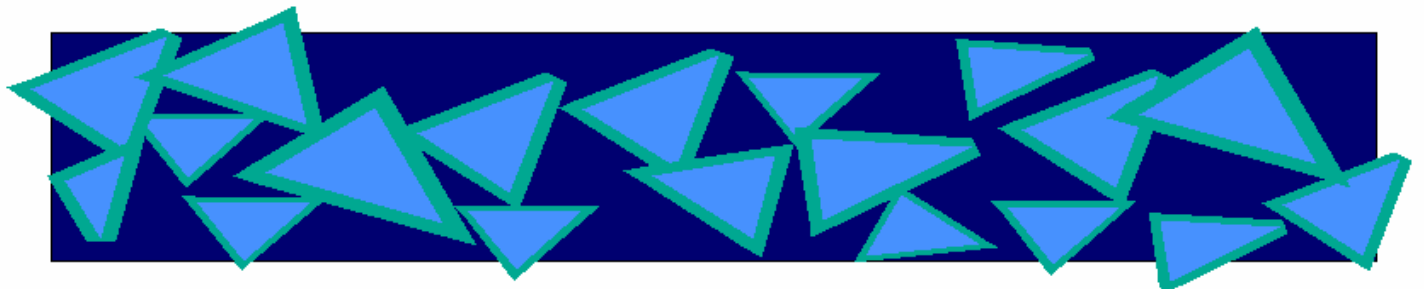
6. Just for Young Men and Women

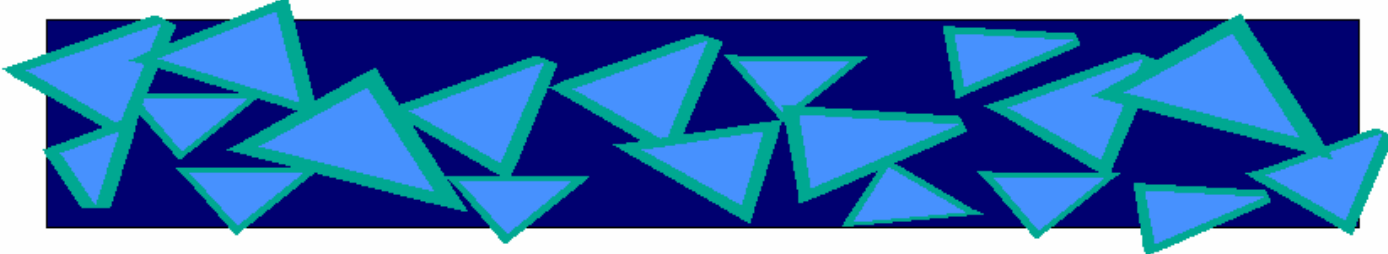
A variety of information may be found on the Children's Mercy website at:

<http://www.childrens-mercy.org/ParentsChildren/childhealth.asp>

This includes care cards for teens and young adults on a variety of wellness topics, as well as information from the Kreamer Resource Center on specific conditions and concerns.

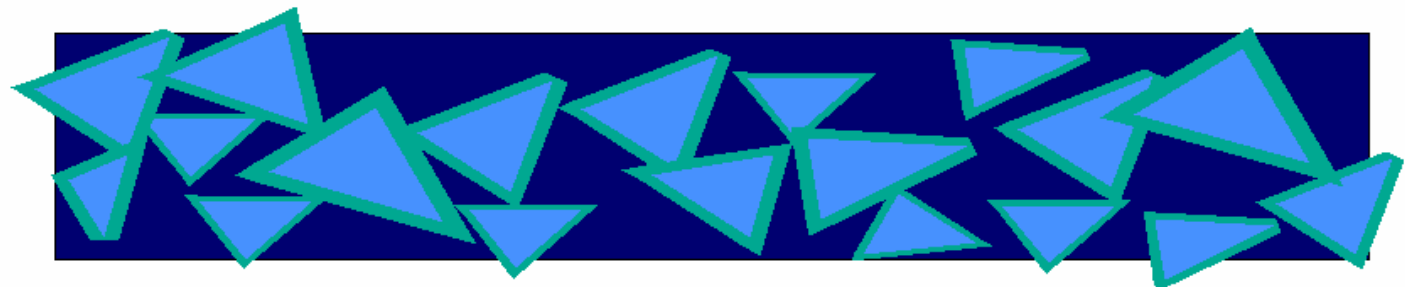
You can also get information from your health care providers. Just ask!





7. Helpful Resources Along the Way

The Kreamer Family Resource Center (KFRC), located on the main campus of Children's Mercy Hospitals and Clinics, has several items that may be helpful in preparing teens for their eventual transition to adult health care. In addition, there are materials for teens with learning disabilities or developmental delay transition to higher education or to work.



Books in the KFRC to consider:

Brown--Learning a living: a guide to planning your career and finding a job for people with learning disabilities, attention deficit disorder, and dyslexia

Huegel--Young people and chronic illness: true stories, help, and hope

This book is written for adolescents themselves, and includes information on how to work with one's doctor to manage one's own illness. Note the chapter called "Your Future."

Issues & answers: exploring your possibilities, a guide for teens and young adults with epilepsy

Keene--Childhood cancer survivors: a practical guide to your future

This book discusses the late effects of cancer therapy, cancer recurrence, and how to get on with life as an adult after surviving childhood cancer.

Nadeau--Survival guide for college students with ADD or LD

Pueschel--Adolescents with Down syndrome: toward a more fulfilling life

Discusses school, work, community, sexual maturation, and promoting self-competence.

Seguin—Transition from school to adult services in Prader-Willi syndrome: what parents need to know

Stengle--Laying community foundations for your child with a disability: how to establish relationships that will support your child after you're gone

Turnbull--Disability and the family: a guide to decisions for adulthood

Written for the parents, this book discusses decision-making issues such as consent and guardianship, financial planning, and community life issues such as sheltered employment and residential services.

Unlocking potential: college and other choices for people with LD and AD/HD

Videos:

What am I, chopped liver? Communicating with your doctor (15 min., 1998) Teens talk about learning to speak up concerning their treatment goals and how to work with their doctors to manage their own health.

Epilepsy in the teen years (12 min., 1990)

All of Us: Talking Together, Sex Education for People with Developmental Disabilities (24 min., 1999)

It's All Part of the Job : Social Skills for Success at Work (21 min., 1993)

Helpful Websites:

Healthy and Ready to Work National Center (includes funded projects, national and state transition initiatives, and links to other transition systems and resources) <http://www.hrtw.org/>

Adolescent Health Transition Project: a resource for teens with special health care needs, chronic illnesses, physical or developmental disabilities (includes information for teens, parents, health care providers, transition timelines in Spanish, Vietnamese, Russian, Chinese) <http://depts.washington.edu/healthtr/>

American Academy of Pediatrics National Center of Medical Homes Initiative: Information and tools for how to organize medical care through a comprehensive and coordinated planning process. <http://www.medicalhomeinfo.org/>

DSCC Transition Information and Resources <http://internet.dsc.uic.edu/dscroot/parents/transition.asp>

Youth in Transition (British Columbia Children's Hospital; includes a transition planning checklist) <http://www3.bc.sympatico.ca/steeksma/Medical/transition.htm>
Health Care Transitions (note the Resources section) <http://hctransitions.ichp.edu/>

The National Information Centers for Children and Youths with Disabilities (NICHCY) Transition Guides <http://www.nichcy.org/transitn.asp>

YouthHood.org (National Center on Secondary Education and Transition) <http://www.youthhood.org/youthhood/index.asp>

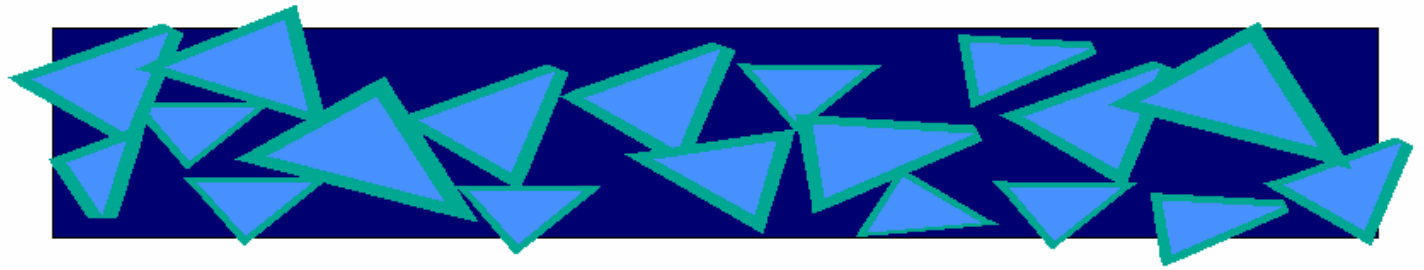
Supplemental Security Income (SSI) for children 1-800-772-1213 <http://www.ssa.gov/pubs/10026.html>

Planning for Self Sufficiency in the Adult World

MAKE SURE that you consider your needs for education, vocational training medical equipment and assisted living needs

Your state has information regarding programs available to assist you. Contact your state's department of vocational rehabilitation and department of health to find out more about these programs.

Your department social worker and your school transition coordinator are also good resources. Start working on this as early as possible. Many programs have waiting lists.

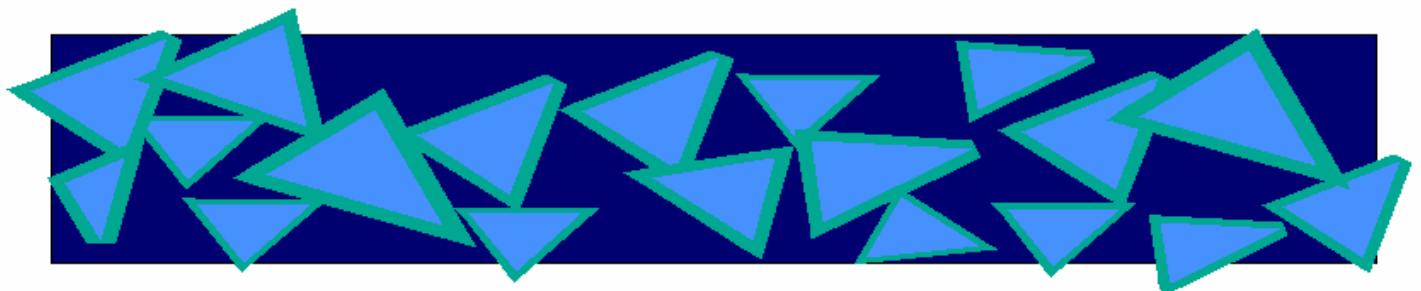


8. Venturing out into the Adult World- General Health Concerns for Adults

As you approach adulthood, you will need to incorporate all the needs of ongoing medical care activities.

This section outlines the most common tasks in that process and will be a good place to keep track of future medical needs including:

- Appropriate exercise regimens
- Nutritional needs
- Potential outcomes of at-risk behaviors such as smoking, drug and alcohol use
- Sexual considerations/reproductive counseling

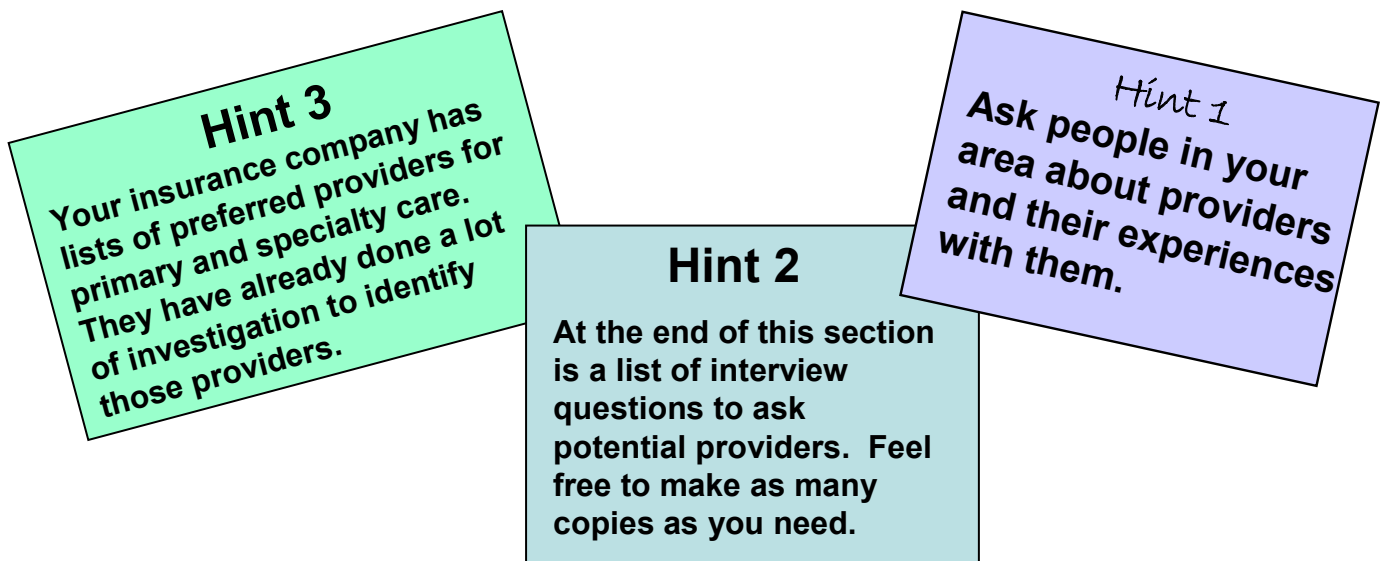


As you approach adulthood, you will need to incorporate all the needs of ongoing medical care activities. This section outlines the most common tasks in that process.

A. Identifying an adult care provider.

Not all conditions will require a specialist for care as an adult. Several conditions come to a steady state after growth is completed, so that an internal medicine physician can care for your medical needs. Be sure to ask your Children's Mercy physician what your long term health needs are.

Selecting an adult care provider does not have to be a scary process. Here are some helpful hints:



You can call and talk to someone in the office, or bring the list along to your first appointment. Take notes for your reference. Making sure that these issues are discussed at the beginning will help prevent any unpleasant surprises later.

B. Getting your (medical) records straight.

When you are ready to go see your new providers, they will need to have copies of your past medical history. Many of their decisions will be based on what's happened in the past.

We encourage teens and parents to keep track of this information all along the way. It is likely though, that your new doctor will need some specific information from your Children's Mercy medical team. To get that information sent to your new doctor, here's what to do:

- Send a written release of information to Children's Mercy Hospital and Clinics to the attention of the Medical Records department.
 - Remember that once you are 18 years old, you need to sign for your own records.
 - The release of information form must have the name, address, and phone number of your new physician so that they can send the records directly.
 - Indicate on the form that this release of information is for transfer of ongoing care.
- There is a sample form at the end of this section for you to copy and use.

C. School and work choices

Having a chronic condition can obviously influence your further school and work choices. Here are some questions to help evaluate your choices.

- *What will I do after leaving high school?*
- *What are my life goals?*
- *Where to find employment and training services, if needed?*
- *What about getting around - transportation?*
- *What kinds of accommodations and technology do I need?*
- *What will I do for income?*
- *What would the physical requirements of my role/position be?*
- *What type of insurance coverage is offered? Are there any exclusions or waiting periods?*
- *What community agencies/ programs are available to assist me?*
- *Where will I live?*
- *How close is the nearest hospital? Are they able to handle the type of care I would likely need? What type of emergency transportation is available?*
- *What do I want from my social life, hobbies, leisure time, and relationships?*

There are many resources available to help you sort out these questions. Your parents, doctors and nurses, social workers, teachers, guidance counselors, and community organizations can all help you.

D. Processes for getting medications and medical equipment

By now hopefully you have learned all your medications, what they do, and why you need them. Continuing to take your medications is a major factor in staying healthy!

Make sure that you understand how to get your prescriptions (new and refills) from your doctor, how to get them filled at the pharmacy, and what to do when you're running low.

Find out who and when to call to replace equipment and supplies. What do you do if your equipment quits working?

Each provider and insurance plan varies, so be sure to ask in detail. Medication and equipment costs need to be considered too when figuring your living expenses.

E. Ongoing insurance coverage

Most teens have insurance coverage either through their parents or a state agency such as Medicaid. These programs all have age limitations, depending on work status and physical status.

Talk with your social worker or case manager to explore other coverage options. Public Insurance/ Services such as EPSDT, SCHIP, Medicaid Home & Community Based Waivers, Medicaid & Section 301, Medicaid Buy-in, Medicare, Medicaid & Medicare/Dual Eligibles, Medicaid & Medicare While Working are options to explore.

Questions for your new provider:

1. Do you take my insurance and/or Medicaid? _____ If I don't have insurance, are you willing to work with me regarding payments? _____

2. Where do you send patients for emergency care and what hospitals do you have privileges at?

3. How many patients with my condition do you follow or have you followed?

4. How do you handle appointments if I need to be seen on short notice due to an acute problem with my condition?

5. Who covers your duties after hours and for vacations? _____

6. What practices do you have with regards to following long term complications associated with my condition? _____

7. Can some of the issues regarding my condition be followed by my primary care provider?

8. Do you have support services such as social workers, dieticians, physical and occupational therapy that I can be referred to if needed? _____

9. Who coordinates for care by additional specialty providers if this is needed?

10. Do you communicate by email? _____ What is the process? _____

11. What is the turn-around time on phone calls? Who returns phone calls?

Legal Considerations

There are several legal issues that you should consider as an adult with a chronic medical condition. This section provides you with some basic information on legal considerations. This section is for information only and does not replace legal advice or recommendations.

When you turn 18 years of age, your parent(s) or primary caregivers are no longer be able to make decisions about you or your care. (The exception to this is if your parent(s) or primary caregiver is given guardianship. This is explained in detail below.) Therefore, it is important for you to understand all of the following:

Clinic or Health Care provider Visits:

During your medical clinic or visit with your health care provider, be sure to:

- Update your address, phone number and people to contact in the event you have a medial emergency
- Read and understand all documents before you sign them. You will be asked to sign a consent for medical treatment and that you will be financially responsible for the medical bills
- Obtain and sign that you have received the providers Privacy Notice so you understand how your medical information can and will be used
- If you want your parents to be able to talk with your healthcare providers or get information about your health care, ask to sign the provider's authorization/release of information form
- If applicable, provide copies of Advance Directives and/or Power of Attorney
- if your parents still have insurance coverage on you, ask the provider what information will be shared with them

Every capable adult has certain rights, such as:

- Ability to execute an Advance Directive
 - An Advance Directive is also called a Health Care Treatment Directive or Living Will. This legal document tells your health care providers how much or little care you want if you are not able to tell them. For more information on Advance Directives, speak with your clinic social worker or access information through The Center for Practical Bioethics website.
(<http://www.practicalbioethics.org/>)

- Ability to execute a Power of Attorney – There are two types of Power of Attorneys, one is a Medical Power of Attorney and the other is a Durable Power of Attorney.
 - A Medical Power of Attorney is a legal document that allows you to give someone else permission to make medical decisions on your behalf if you are mentally or physically unable to.
 - A Durable Power of Attorney is a legal document that allows you to give someone else permission to make medical and other decisions such as financial decisions on your behalf if you are mentally or physically unable to tell someone.
 - If you execute either type of Power of Attorney be sure you fully understand when the other person can make decisions for you. Select someone you trust and discuss your wishes so they may act as your advocate. A Power of Attorney cannot change your Advance Directive.
 - If you need assistance with doing a Power of Attorney, please ask your clinic social worker for assistance.
 - If you do a Power of Attorney, please make sure your health care provider gets a copy for your record.

- Understanding Consents, Authorizations and Release of Information
 - There are two (2) types of consents, Medical Consent and Financial Consent. Medical Consent gives your health care providers permission to give you care such as general medical care and invasive procedures (surgery, etc.) Financial Consent outlines your financial responsibilities for the health care you receive, how the provider will bill you, and their expectations on payment.
 - Authorizations or Release of Information tells your providers who can get copies of your medical records, or who they can talk to about you and your care. You may change or cancel your authorization at any time. Let your health care provider know if you need to do this.
 - When you transfer to your new provider, you will need to sign their consent forms. You will also need to complete a Release of Information for them to get copies of your records.

Legal Guardianship and Conservatorship:

Legal Guardianship and/or Conservatorship may be needed if the teen is not physically or mentally able to make their own decisions or handle their financial affairs.

- Guardianship is a legal process. The court is asked to appoint a personal representative for the patient who will make medical and environmental decisions such as placement in a nursing or group home. The court requires that a physician complete an assessment that states why the patient can not make decisions on their own. This could be due to physical, mental or developmental concerns.
- Conservatorship is a legal process. The court is asked to appoint a personal representative to take care of only the patient's financial concerns.
 - If the reason for seeking guardianship or conservatorship is due to mental illness the patient must be evaluated by a psychiatrist, who sends a report to the court.
 - The court makes the final decision on who can become the guardian or conservator. This does not have to be a family member and there are some agencies that will act in this capacity.
 - If you need assistance with guardianship or conservatorship, please discuss this with your clinic social worker. You may also contact Legal Aide of Western Missouri at 816-474-9868 or your family attorney.

Organ Donation

As an adult, you have the right to decide if in the event of your death, you would like to donate your organs. Some States offer you the option of becoming an organ donor when you renew your driver's license. Or you may discuss your desire to donate with your social worker or contact the Midwest Transplant Network at 913-262-1668.

Long term health needs related to disease

Virtually all chronic health conditions require some sort of long term follow-up. Those specifics are based on the condition and therapy given. New information is always being discovered, leading to changes in your treatment, and treatment of newly diagnosed patients based on long term results. For both these reasons, it is important that you continue to follow- up with your medical care, even if you no longer have a condition that requires active treatment. (Example: childhood cancer survivor)

In addition, your new providers will continue to monitor your general health. Some aspects of this care include:

- Appropriate exercise regimens
- Nutritional needs
- Potential outcomes of at-risk behaviors such as smoking, drug and alcohol use
- Sexual considerations/ reproductive counseling

We hope that this notebook will help you manage your health care more easily and effectively.

Growing into a young adult is an exciting journey. We hope this information takes some of the bumps out of your road. We wish you all the best.

Acknowledgements:

Thank you to the following organizations for materials upon which much of this information was based:

University of Illinois at Chicago

Institute for Child Health Policy - Florida Children's Medical Services Program.

Adolescent Health Transition Project, University of Washington, Seattle and the Washington State Department of Health

Healthy and Ready to Work

Institute for Community Inclusion

American Academy of Pediatrics National Center of Medical Home Initiatives



Children's Mercy
HOSPITALS & CLINICS
www.childrensmercy.org