Health Care Transition

A Parent, Family and Caregiver's Guide

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The N.C. Family to Family Health Information Center A project of The Exceptional Children's Assistance Center



CAROLINA Health Transition PROGRAM

Carolina Health and Transition (CHAT) The North Carolina Division of Public Health Women and Children's Health Section Children & Youth Branch







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Introduction

CHAT | Carolina Health and Transition Project A federally funded project through the NC Division of Public Health, Children and Youth Branch.

Purpose: To ensure that children and youth with special health care needs receive coordinated, comprehensive care within a medical home and the needed services and supports to make the transition to adult health care systems.

The CHAT project targets barriers in the availability of, and access to, quality health care services by broadening awareness, teaching specific skills and changing systems of practice for Youth with Special Health Care Needs (YSHCN), their families and medical providers. Activities of the CHAT project build upon and link with other state-wide initiatives designed to improve health care opportunities and practices for all children, by including issues specific to transition and medical home in medical care for YSCHN.

Three Initiatives



health care systems within a medical home.

Goals of This Handbook

This handbook will help you:

- Understand the importance of health care transition
- Identify barriers to health care transition
- Learn about the medical home concept related to health care transition in North Carolina
- Identify the skills necessary for successful health care transition
- Learn how to develop a portable medical summary
- Be able to discuss a health care transition plan with your child's medical provider
- Be able to discuss partnering strategies with providers to support the health care transition process
- Identify insurance issues related to health care transition
- Realize that it is acceptable to ask questions of your child's provider if something is said or written that you do not understand
- Share advocacy skills to pass on to your child to increase their self-management of health care
- Identify resources to help you and your child with the transition process
- Learn how to identify sources of support as well as how to mentor other parents as they experience transition with their child

Chapter 1 Introduction to Health Care Transition

Chapter 1 What is Transition?

There are many transitions in life:

- School
- Work
- Independence
- Health

Our focus is on **health care transition** which involves the movement from pediatric to adult health care systems, with a primary focus on youth with special health care needs.

Keys to Understanding Health Care Transition

Health care transition is...

- a process:
 - > Different from **transfer** of care which is an *event*
 - ► Requires preparation and planning
 - ► Occurs in phases
- individualized:
 - ➤ One size does not fit all
 - Movement from one phase to the next depends on when the individual youth is developmentally ready
 - > Timing of transition may be different for youth depending on their needs

Why Understanding Health Care Transition for YSHCN is Important

Transition realities for YSHCN

- 90% of YSHCN reach their 21st birthday
- 45% of YSHCN lack access to a physician who is familiar with their health condition
- 30% of 18- to 24-year-olds lack a payment source for needed health care
- Many youth lack access to primary and specialty providers¹

The importance of health care transition

YSHCN should understand that addressing their health needs first and foremost is the key to having a more productive life as an adult. **Health care transition** is an important process that helps youth develop the necessary skills that can lead to positive health outcomes.

Successful health care transition is related to:

- Better health as an adult
- Self-sufficiency and independence
- Prevention of secondary conditions
- Decreased emergency room use and overall medical costs

Health care self-management skills -



Health care self-management skills are related to the youth's ability to manage their own healthcare. By learning these important skills,

YSHCN will have greater confidence in managing their health issues as an adult.

Some of these health management skills include:

- Scheduling appointments with health care providers (who to see and when)
- Medication management (what, why, when and how)

- Record keeping and documentation
- Medical decision making (especially if your child is now 18 years old)
- Knowledge of health condition
- Knowledge of insurance options

Potential Barriers to Health Care Transition

Even with increased awareness of the importance of health care transition, there are many YSHCN that are still not prepared to take responsibility of their own health needs as they enter adulthood. There are often barriers that prevent youth from receiving the necessary services to support a smooth transfer to the adult health care provider. These barriers are broken down into 3 categories: 1) personal; 2) service; and 3) structural.

Personal barriers (Individual factors)

Youth –

- Fear, anxiety, sense of loss or risk with transfer to an adult provider
- Supporting choice of healthy life styles
 - ► Diet
 - ► Exercise
 - ► Safety
- Relationships
 - ► Sexuality
 - > Preparing for parenthood
- Progression of health concerns

Family/Caregiver -

- Ability to support and to let go
- Family members working together toward a common goal
 - Agreement and support among caregivers





- Trust that your young adult can manage his/her own health care
 - ► Having input without interfering with doctor/patient relationship (between youth and doctor)

Service barriers (Access to care) —

- Finding age appropriate, quality and approachable health care providers
- Paying for health care
 - ► Insurance
 - ► Availability of public assistance programs

Structural barriers (External factors related to care)

- Transportation
- Employment
- Living independently (the ultimate goal)

Overcoming the Barriers: How and When Do I Support My Child Through Health Care Transition?

What you need to know in order to successfully support your youth during the transition process

Teachable moments _

- It's never too early to start talking about independence and the transition to adulthood
- Recognize opportunities to talk about transition issues
- Model behavior, advocacy, and skills they will need as an adult
- Ask your youth what they want you to do do not just assume









Assess your situation (the variables)

- Age of youth, age appropriateness of tasks and skills
- Abilities (cognitive, physical, emotional) of youth
- Remember, he or she is a teenager, help them understand their priorities
- Determine how much time you have to plan
- Discuss how your culture/beliefs affect the healthcare your family receives
- Availability of family support; get help from other family members to develop a plan
- Find out if your youth's physician is willing to do a formal transition plan

Work with others to help youth in health care transition

- Schools, counselors, school nurses, Individualized Education Plan (IEP) team
- Pediatricians and pediatric specialists
- Dietician/nutritionist
- Coaches or health teachers
- Other parents and other youth

Other Ways I Support My Child Through Health Care Transition

Make sure your child knows

- About her or his condition or disability
- Symptoms of concern
- How to determine an emergency
- Who to call in case of an emergency



- How to schedule his or her own appointments
- How to arrange for her or his own transportation
- · How to keep track of and order his or her own medication refills
- To write down questions before she or he visits the doctor
- To speak up and ask questions (advocacy)
- That he or she can talk to the healthcare provider about difficult subjects that may be hard to discuss with family in the room, like relationships, sex, and birth control
- To ask for an explanation of medical tests and reports
- To carry her or his insurance card and portable medical summary
- How to order and take care of medical equipment and assistive technology

Ages and Stages of Transition

Many checklists, questionnaires, and profiles are available to help determine your youth's transition needs. This is an excellent opportunity for you to discuss knowledge and skills and assess your youth's readiness to participate in the health care transition process. Some of the checklists may include age-specific

Check the Toolkit for Checklists and Timelines for Healthcare Transition!

guidelines, but please remember these are recommendations only, not hard and fast rules! We've included several check sheets for your review.

Generally, discussion of health care transition should begin **early** in adolescence. It is important to remember that it is never too early and never too late to begin the process. The actual transfer of care occurs when everyone feels it is time. The pediatric physician, parents, youth and adult healthcare provider should all be in agreement about when the actual transfer of care should occur.



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Chapter 2 What is a Medical Home?

Medical Home – Definition

A medical home is not a building, house, or hospital but an approach to providing health care services in a high-quality manner.

The medical home concept is the framework for establishing parents and youth as equal partners with medical providers.

One of the objectives of a medical home is to support health care transition for youth and young adults. This makes your medical home a logical first step for a discussion about transition.

The American Academy of Pediatrics (AAP) defines a medical home as, "an approach (idea) to providing health care services in a high-quality (good), comprehensive (complete) and cost-effective manner."²

The AAP definition of medical home can be broken down into specific categories that are related to the quality of primary care. A medical home describes primary care that is:

Accessible

- Care is provided in the child's community
- All insurance, including Medicaid, is accepted and changes are accommodated
- Families or youth are able to speak directly to their medical home provider when needed

Family-Centered

- Mutual responsibility and trust exists between the patient and family and the medical home
- The family is recognized as the principal caregiver and center of strength and support for the child
- Clear, unbiased, and complete information and options are shared on an ongoing basis with the family

Continuous (relates specifically to health care transition)

- Same primary pediatric health care professionals are available from infancy through adolescence and young adulthood
- Assistance with transitions (to school, home, adult services) is provided
- The medical home provider participates to the fullest extent allowed in care and discharge planning when the child is hospitalized or care is provided at another facility or by another provider

Comprehensive

- Health care is available 24-hours-a-day, 7-days-a-week
- Preventive, primary and tertiary care needs are addressed
- The medical home provider advocates for the child, youth, and family in obtaining comprehensive care, and shares responsibility for the care that is provided

Coordinated

- A plan of care is developed by the physician, child or youth, and family and is shared with other providers, agencies, and organizations involved with the care of the patient
- A central record or database containing all pertinent medical information, including hospitalizations and specialty care, is maintained at the practice. The record is accessible, but confidentiality is preserved

Compassionate

- Concern for well-being of child and family is expressed and demonstrated in verbal and nonverbal interactions
- Efforts are made to understand and empathize with the feelings and perspectives of the family as well as the child or youth

Culturally Effective

- All efforts are made to ensure that the child or youth and family understand the results of the medical encounter and the care plan, including the provision of professional or paraprofessional translators or interpreters, as needed
- Written materials are provided in the family's primary language

Check the Toolkit for the Medical Home Index Tool!

You can use the Medical Home Family Index to help understand how a medical home can help make your child's health care better. Take a few minutes to complete the index and use it to evaluate your child's current health care provider.

Health Care Transition and the Patient Centered Medical Home

As your youth becomes a young adult and moves from a pediatric medical home into the adult health care systems, the characteristics of medical home are more focused on patient centered care. Below are some characteristics of the patient centered medical home that are important to remember as he or she begins the process of health care transition. These elements of medical home are more focused on the principles of coordinated care, which includes:³

A **plan of care** is developed by the physician, practice care coordinator, youth, and family in collaboration with other providers, agencies, and organizations involved with the care of the patient.

A **central record or database** containing all pertinent medical information, including hospitalizations and specialty care, is maintained at the practice. The record is accessible, but confidentiality is preserved.

The **medical home physician shares information** among the youth, family and consultant, and provides a specific reason for referral to appropriate pediatric sub-specialists, surgical specialists, and mental health/developmental professionals.

Linkages to support groups and other community-based resources.

The medical home **physician assists the young adult in understanding clinical issues** when he or she is referred for a consultation or additional care.

The medical home **physician evaluates and interprets the consultant's recommendations** for the patient and, in consultation with them and the sub specialists, implements recommendations that are indicated and appropriate.

The **plan of care is coordinated** with educational and other community organizations to ensure that the special health needs of the patient are addressed.

Chapter 3 Pediatric vs. Adult Health Care Providers

Roles and Responsibilities of Health Care Providers

Make sure the pediatric provider is involved in educating your child about lifelong transition skills such as proactive planning, problem solving, self-advocacy, and negotiation.

There are many differences in pediatric health care vs. adult health care. These differences are important to remember during the transition process.

Examples of these differences include:

PEDIATRIC HEALTH CARE	ADULT HEALTH CARE
One doctor provides almost all medical care	Different doctors for different health needs
Informal and relaxed	Business-like, more formal setting
Warm, optimistic	Rigorous exams for health problems
Scheduling is more flexible	Advance planning for appointments required
Family management of health needs	Patient self-management
Family centered	Patient centered

Collaboration Between Youth, Families and Health Care Providers

One of the most important keys to successful collaboration between youth, families, and health care providers is communication.

As a parent of a youth (teenager) with special needs you should discuss their concerns and priorities and how the changes these may change as they are going through the transition process.

Share assessment tools (checklists, etc.) with your child's provider that you have completed with your child. This will give the provider a good idea about how to support your family through the health care transition process.

Support Services and Ongoing Education

One of the best sources for support and ongoing education are your youth's primary care providers – both the pediatrician and adult/family physicians.

Their role in the health care transition process should include:

- Provide preventative care and teach healthy lifestyle choices
- Identify and treat common medical conditions
- Assess the importance of medical problems and give proper direction for that care
- Provide information on insurance options as an adult

Where to find and how to search for additional resource materials

- Information you already have at home
- Internet based health resource websites
- Peer support (friends or support groups)
- School-based health center or school nurse
- Local family support agencies

Please see the **Resources Section** for more information.

Record keeping

While working with your youth's health care provider or pediatrician, it is important to keep records of your visits and conditions that are being treated. By keeping a record of your youth's important medical treatments, you can provide them with enough information to help them transition to the adult health care provider at the appropriate time.

Teaching your youth to maintain their own records will also support their success in the health care system as an adult.

Here are two ways to keep medical documentation and health records:

- Have a complete, current record of care coordination (Care Notebook, see page 22)
- Use a portable medical summary (see page 61)

Skill Building Activity

Suggested record-keeping methods: Care Notebook and Portable Medical Summary

Care Notebook

- Should be complete and current
- Keep multiple copies (in case another doctor needs the information)
- Includes medical history, disability information, past records (keep at home)

The following section includes information from a website page on how to build your own care notebook. By using the tools on this website, you will be able to pick and choose the pages that are important for your youth's specific needs.

Portable Medical Summary

- Current and important medical information you want others to know (physician appointments)
- One-page medical summary to carry with you, in case of emergency

A sample of a completed **portable medical summary** and a blank one for you to complete with your youth is included in the **Toolkit**. An electronic version can also be accessed at www.hrtw.org.

Take this opportunity to work together with your youth on each of the methods of record-keeping. This will strengthen your youth's knowledge about his or her history and condition but will also prepare him or her to become responsible for their own health information.

Building Your Own Care Notebook

Below is a list of downloadable forms that can be used to build your own *Care Notebook*. You may download a complete section's documents by clicking on the section's ZIP link, or select specific documents by clicking on the sub-category links below. All Care Notebook forms are made available in both **Microsoft Word** and **Adobe PDF** versions for your convenience.

Complete List of Forms Available: www.medicalhomeinfo.org/CareNoteBook

Care Notebook Cover Page

Personal Information

- Care Providers
- Insurance Information
- Family Information
- Family Support Resources
- Funding Resources

Pages to Keep Track of Appointments and Care

- Appointment Log
- Diet Tracking Form
- Equipment-Supplies
- Growth Tracking Form
- Hospital Stay Tracking Form
- Immunizations
- Information Needed by Emergency Care Providers
- Lab Work-Tests-Procedures
- Make-a-Calendar
- Medical Bill Tracking Form

- Medical-Surgical Appointments
- Medications
- Family and Child Medical History

Personal Notes

- Parent and Child Questions for Doctor
- Parent and Child Questions for Setting up Home Care

Care Needs of My Child's Abilities and Special Needs

- Activities of Daily Living
- Care Schedule
- Child's Page Now and Later
- Communication
- Coping-Stress Tolerance
- Mobility
- Nutrition
- Respiratory
- Rest-Sleep
- Social-Play
- Emergency Plan
- Baby-sitters Guide
- Information for Caregivers-Instructions for Care

Community Health Care-Service Providers

- Medical/Dental
- Public Health

- Home Care
- Therapists
- Early Intervention Services
- Child Care
- Respite Care
- Pharmacy
- Special Transportation

School Issues

- School: Making it work
- Home-School Worksheet
- School Communication Sheet
- Permission for Procedures-Medications at School
- Physical Education Activity Guide
- Insert your Individual Education Plan or 504 Plan
- Transitions-Looking Ahead

Roles of Care Coordinators

Care coordination helps link children and their families with appropriate services and resources in a coordinated effort to achieve good health.

The Care Coordination Process⁴

1. **Assess and Identify Needs** – Activities preformed by a care coordinator are based upon a comprehensive assessment that can sometimes include

a psychosocial assessment of the child and family. Identifying needs is the first step in the care coordination process. The development and use of an assessment tool will help in gathering the information needed to develop a plan of care.

- 2. Develop a Plan of Care After identifying the needs, a plan of care is developed with the family when goals and outcomes are discussed. The care coordinator may clarify with the family which action steps the family will address and which will be addressed by the care coordinator.
- **3.** Put the plan into action Following the plan, take actions to work towards the desired outcomes. Identified service providers and programs all work towards fulfilling the needs of the family. The care coordinator organizes the process and helps the family with resources, referrals, and coordinating care with specialty physicians, with schools and other agencies.
- **4. Evaluate** Periodic evaluations are performed to reassess the plan of care and to address new needs.

Ask your child's provider if there is a care coordinator on staff. If there is not, find out if there is someone available who could fill that role in their office.

Chapter 4 Health Care Transition Planning



Chapter 4

Health Care Transition Planning

Health Care Transition Plans

A **health care transition plan** is different from a regular care plan, because the goals and objectives are specifically about how to address the health and medical needs of your youth as they enter adulthood.

Transition planning should at a minimum include the pediatric provider, the youth, the family, the care coordinator and, if appropriate, the adult health care provider. This plan should be written with specific goals and tasks for each member of the group.

An example of topics to consider include:

- Health condition management
- Health promotion/proactive wellness
- Increasing responsibility
- Health care funding options (e.g. insurance)
- High school goals/plans
- Post-secondary school plans
- Work plans
- Independent living issues
- Community inclusion
- Actual transfer of care

It is important that your child provides his/her **valuable input** during the creation and maintenance of this document.

Be sure to review and update the plan each year, or more frequently as needed, in case there are changes in needs, concerns, and/or priorities.

Additional Tips for Transition Planning:

- Have a plan for review and revision of the original document
- Decide if the plan should be reviewed annually or only if there is a change in your child's condition
- Periodically check in with the provider to evaluate progress
- Make sure everyone is on task
- Determine if there have been any unexpected outcomes or changes
- Be sure to include everyone should there be any revisions

Check the Toolkit for Sample Transition Care Plans!


Chapter 5 Health Care Coverage and Legal Issues

Chapter 5

Health Care Coverage and Legal Issues

Health Care Coverage for Adults with Disabilities

In many states, as soon as a youth becomes 18 years old, the eligibility requirements for health insurance change. As a result many young adults are unable to maintain adequate health care coverage. In fact, lack of adequate insurance is the main reason young adults with disabilities are not able to manage their own health needs.

Each state has different rules and regulations that determine age limits, parental continuation of coverage, dependency, and eligibility requirements. It is important to check the laws that govern these policies and determine options that may be possible for your youth, based on their health condition and medical necessity.

Best advice: Start early and plan ahead!

Age Restrictions for Private Insurance (North Carolina)

It is important to note that, in the state of North Carolina, health insurance coverage for your child with special health care needs can be maintained even after he or she reaches the age at which dependent child coverage usually terminates, usually age nineteen (19).

Your child's status as a student is **not** a consideration. In order to qualify for this continual insurance coverage, the child must be incapable of sustaining employment because of mental retardation or physical handicap and must be chiefly dependent on the policyholder (or subscriber) for support and maintenance.

The policyholder or subscriber (youth/young adult) must provide proof of incapacity (inability) and dependency to the insurer, hospital service plan, or medical service plan corporation within 31 days of the youth reaching the age limit.

You (parent or caregiver) may also be required to furnish proof of this incapacity or dependency as required by the insured (but not more frequently than annually) after the child has reached the age limit.

If you need to reference this information, it can be found under **N.C. General Statute 58:51:25**⁵.

Legal issues related to health care coverage Medical Power of Attorney

A Medical Power of Attorney is a document, signed by a competent adult; designating a person that she/he trusts to make health care decisions on their behalf should they become unable to make such decisions. We have provided a sample document in the Appendix for your review. Check the following websites for more information: www.legalhelpmate.com/power-of-attorney.aspx; www.expertlaw.com/library/estate_planning/power_of_attorney.html.

Health Insurance Portability and Accountability Act (HIPAA)

HIPAA is a federal law that covers both the privacy of your youth's medical information as well as issues related to the transfer and continuation of health insurance coverage. We have included a fact sheet in the Toolkit for your review. For more information check the US Department of Health and Human Services website at www.hhs.gov/ocr/hipaa.

Family Educational Rights and Privacy Act (FERPA)

FERPA is another federal law that deals with access to educational records, as well as health records held at educational institutions. Please review the fact sheet in the Appendix. A brochure for parents can be found on the US Department of Education website: www.ed.gov/policy/gen/guid/fpco/brochures/parents.pdf.

Guardianship

There are many factors to consider when deciding guardianship. A guardianship is the legal proceeding by which a capable adult (e.g. agent) can be appointed to manage the personal or financial affairs of an individual who is unable to do so on his or her own. As a parent, the best resource for obtaining more information is to visit the NC Guardianship Association at www.nc-guardian.org.

> Check the Toolkit for more Information on Insurance Tips and Resources !

Chapter 6 Cultural Competence and Transition

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Chapter 6

Cultural Competence and Transition

Cultural Competence

Cultural beliefs about health, parenting, and child development can vary according to one's ethnicity, and these beliefs can influence you and your child's interaction with the health care system.

As a parent, it is important to inform your youth's doctor if there are any customs that your family observes that could affect medical decisions and treatments. The physician should be willing to provide support and encouragement for you to express your families' beliefs about health and wellness, as well as work with you to assure access to needed services.

Cultural competence is related to the ability of professionals to work cross-culturally. It can contribute to better health by improving communication and building trust.

When selecting an adult health care provider, your

youth may want to find out if the physician has experience addressing the health needs of patients from different cultures. As a starting point, the family member or youth can ask the following questions:

- How are cultural differences valued and recognized by the health provider and their staff?
- Does the health care provider have interpreter services or materials in different languages for individuals who speak little or no English?
- Does the health care provider have policies and procedures for how to serve individuals with communication difficulties (e.g. hearing impairment and/or literacy issues)?

Health Literacy

Health literacy is the ability to obtain, process, and understand basic health information and services needed to make appropriate health decisions and follow instructions for treatment. Culture contributes to health literacy because it affects the way people understand and communicate health information.

Families of all youth, particularly those with disabilities and complex chronic conditions, need health literacy skills in order to be able to manager their youth's health condition.

Being able to ask questions is necessary to having healthy behaviors and is the key to informed decision making. You and your child's health depends largely on whether you can understand and remember the health information you receive.

A recent government study estimates that over 93 million American adults have limited health literacy skills. This number may be somewhat higher because most patients often hide their confusion from their doctors because they are too ashamed and intimidated to ask for help.⁶

Health literacy skills have little to do with a person's education, income, race, or age. People of all ages and educational levels often find it difficult to understand health or medical information. Medical professionals seem to have a "medical language" that can be confusing to the average person.

- Do not be afraid to ask questions if the medical provider says something that you do not understand
- Be a good role model for your child by asking questions but also by encouraging them to ask for themselves

Check the Toolkit for more information about Health Literacy!

Chapter 7 Advocacy, Support and Mentoring

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Chapter 7

Advocacy, Support and Mentoring

Advocacy Skills for Parents

An **advocate** is someone who speaks out for a person or a cause. How you advocate for your children's health care needs when they are young, teaches them to advocate for themselves as they become teenagers or young adults.

Advocacy starts with knowledge: knowledge of medical history (diagnosis), medical needs, patient rights, and personal desires. One of the best ways to provide your child with the skills necessary for transitioning is practice, practice, practice!

Watch for opportunities to talk about advocacy and speaking up for what they need. Be a good advocacy model. Some examples of ways to involve your child in her or his own health care include having the child:

- Write letters (drafting what needs to be said or asked)
- Schedule his or her own medical appointments
- Arrange for her or his own transportation needs
- Request medication refills from his or her provider
- Complete a list of questions before a medical appointment

Let youth try to advocate for themselves with you there to support. Encourage them to talk about their health conditions and how they feel. Teach them to communicate with medical providers; redirect questions from the provider to your child.

Advocating goes beyond one's personal and immediate needs. It also includes being involved in system-wide changes through legislation.

- Are you aware/involved/active in local/state/national system change advocacy?
- Has your youth been given an opportunity to experience this kind of advocacy?

Finding Support through the Health Care Transition Process

One of the best ways to find support for your family as your child begins health care transition is to reach out to other families who have already experienced this process. There are agencies in North Carolina that can link you with parents with similar backgrounds (same diagnosis, etc.) to share your experiences and provide support for each other.

Support agencies include:

Arc of NC (800) 662-8706 Exceptional Children's Assistance Center (800) 962-6817 Family Support Network (800) 852-0042

Mentoring: Providing Support for Other Families

Once your family is well into the transition process with your child, you may consider offering your valuable experience to other families who are just starting out. By mentoring other families you will have the opportunity to share your knowledge, provide support, and help a family much like yours.

- Remember while you are building supports for yourself to also seek out support networks for your child
- Included are some useful websites for this purpose in the **Resources** section of the toolkit

Check the Toolkit for information about building a Circle of Friends and other support networks!

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