

FAMILY HEALTH JOURNAL

This journal belongs to



Introduction

The Family Health Journal was developed to help families and youth keep track of important health information and prepare for appointments. Included are forms to record medical history, surgeries, clinic visits, important phone numbers, treatments, medications, resources, etc.

We encourage you to use this journal as a way to share information and communicate with members of your child's health care team. To download extra pages or the whole journal, go to:

http://fcrc.albertahealthservices.ca/publications/ journals/Family-Health-Journal.pdf

Here are some helpful hints on using this journal:

- Add or remove pages to customize the journal to meet your needs
- Take it with you to ALL healthcare appointments
- Use it to write down any questions you have before going to appointments
- Pass this journal onto your child to use when he/she gets older (see *Transition* sections)
- Keep your journal up to date

We wish to acknowledge and thank the many families and youth who helped with the development of this journal.



Alberta Children's Hospital

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| TRANSITION FOR PARENTS | For Parents Transition Readiness Checklist for Parents For Parents of Youth with Developmental Disabilities Transition Readiness Checklist-Parents of Dependent Youth My Plan - Dependent Youth Pediatric Transfer Plan | | | | | | |
| TRANSITION FOR YOUTH | For Youth My Skills and Goals Transition Readiness Checklist for Youth My Plan My Support Circle | | | | | | |



My Child's Information

My Child's Health Information

| My Child's Information | | | | | | | | |
|---|-----------------------------|--|--|--|--|--|--|--|
| Child's Name: | Preferred Name: | | | | | | | |
| Date of Birth: | Alberta Health Care Number: | | | | | | | |
| Hospital or Health Record Number: | | | | | | | | |
| Diagnosis/Medical Condition(s): | | | | | | | | |
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| ALLERGIES: | | | | | | | | |
| | | | | | | | | |
| Medications: (See <i>Medications</i> section of binder) | | | | | | | | |
| Blood Type: O A+ O A- O B+ O B- | 0 0+ 0 0- 0 AB+ 0 AB- | | | | | | | |
| Surgeries: | | | | | | | | |
| | | | | | | | | |
| | | | | | | | | |
| Goals of Care Designation: | | | | | | | | |
| | | | | | | | | |
| Most important things to know about my child in | an Emergency: | | | | | | | |
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This provides quick and easy access to important health information



My Child's Health Information

| Parent/Guardian Information | | | | | | | |
|------------------------------------|--------------------------|---------------------------------------|-----------------|--|--|--|--|
| Name: | | Relationshi | ip to child: | | | | |
| Address: | | Phone: | | | | | |
| Email: | | Language(| s) Spoken: | | | | |
| Name: | | Relationshi | ip to child: | | | | |
| Address: | | Phone: | | | | | |
| Email: | | Language(| s) Spoken: | | | | |
| Pediatrician/Family Doctor | | I | | | | | |
| Name: | | Phone: | | | | | |
| Address: | | L | | | | | |
| For other members of the healthcar | re team, go to Healthcar | e Team sec | tion of binder. | | | | |
| Pharmacy | - | | | | | | |
| Name: | | Phone: | | | | | |
| Address: | | L | | | | | |
| Insurance Information: | | | | | | | |
| Hospital | | | | | | | |
| Name of Hospital: | | | | | | | |
| Address: | | Phone Number: | | | | | |
| | | Phone Number of Emergency Department: | | | | | |
| Emergency Contact | | I | | | | | |
| Name: | | Relationship to child: | | | | | |
| Address: | | | | | | | |
| Home Phone: | Work: | rk: Cell: | | | | | |

This provides quick and easy access to important contact information



Childhood Illnesses/Immunizations

Childhood Illnesses: (chicken pox, measles, mumps, rubella, whooping cough, etc.)

| | Comments | | | | | |
|-----------|-----------------------|---|--|------|--|---|
| 4000 m (1 | | | | | | |
| | osis | D | | | | |
| | Date of Diagnosis | W | | | | |
| | Date | ٢ | | | | • |
| | Childhood Illness Age | | | | | - |
| | | | | | | |

| Immunizations: | Date Given: |
|---|-------------|
| DpT (Diphtheria, Pertussis, Tetanus) | |
| Polio | |
| HIB (Hemophilus Influenza - Type B) | |
| MMR (Measles, Mumps, Rubella) | |
| Varicella (Chickenpox) | |
| PCV13/Prevnar (Pneumococcal Conjugate) | |
| Hepatitis B | |
| Hepatitis A | |
| HPV (Human Papillomavirus) | |
| Meningitis (Meningococcal Conjugate – Groups A, C, W-135 & Y) | |
| Influenza (annual) | |
| Other | |



Appointments & Care Log

Care Log/Journal

Hospital Admissions, Clinic Visits, Surgery, Emergency Visits, etc



Appointments

| Date: | Appointment With: | | | | | | |
|--|--|--|--|--|--|--|--|
| Time: | Phone Number: | | | | | | |
| | | | | | | | |
| Reason for going (injury, check up, illness, prescription refill, therapy, etc): | | | | | | | |
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| Pomomhor to bring: | | | | | | | |
| Remember to bring: | Provincial Healthcare cord (Out of Province) | | | | | | |
| | Provincial Healthcare card (Out of Province) | | | | | | |
| \Box Health insurance card | Referral Letters (if needed) | | | | | | |
| ☐ Health Journal and Pen | \Box Transfer Summaries (if needed) | | | | | | |
| | | | | | | | |
| Notes: | | | | | | | |
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Next Appointment:



Use this sheet to write down questions you want to ask your healthcare team. Question Answer Answered by: Date: Question Answer Date: Answered by: Question Answer . . Answered by: Date: Question Answer . . Date: Answered by:



Measurements

If you prefer to have some of this information in a graph, ask your child's nurse for a growth chart.

| Date | Date Height Weight | | Head Circumference | Blood Pressure |
|------|--------------------|--|-----------------------|----------------|
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Bloodwork and Test Results

| Results & Comments | | | | | | |
|---|--|--|--|--|--|--|
| Test | | | | | | |
| Who ordered the test? (Name & Specialty) | | | | | | |
| Date | | | | | | |



Medications

Medication Log

Use this to keep track of both over-the-counter and prescription medications.

| | Date Stopped | | | | |
|---|---------------------------------|--|--|--|--|
| | Comments | | | | |
| | Dose and time(s) given | | | | |
| טאר וווא נט אפרף וומכא טו גטטוו טעפו-ווופ-נטטווופו מווט אופאכווףווטוו ווופטוכמווטווא. | What is the medicine for? | | | | |
| | Who prescribed the medicine? | | | | |
| Neep liack of boll ov | Name & Strength of Medicine | | | | |
| | Date Started | | | | |



Medication Log

Use this to keep track of both over-the-counter and prescription medications.

| | Date Stopped | | | | |
|---|---------------------------------|--|--|--|--|
| | Comments | | | | |
| | Dose and time(s) given | | | | |
| טאר וווא נט גנפף וומכג טו גטטוו טעפו-וופ-נטטווופו מווט אופאכוואווטוו ווופטוכמווטוא. | What is the medicine for? | | | | |
| | Who prescribed the medicine? | | | | |
| REED ILACK OF DOLL OVI | Name & Strength of Medicine | | | | |
| | Date Started | | | | |



Healthcare Team

My Child's Healthcare Team

Include your doctors, nurses, social workers, child life specialists, dietitians, occupational therapists, physical therapists, pharmacists, speech therapist, etc.

| Name: | Specialty/Role: | | | | | |
|-------------------|-------------------|--|--|--|--|--|
| Address/Location: | | | | | | |
| Phone: | Contact Person: | | | | | |
| Pager #: | Fax: | | | | | |
| e-mail: | I | | | | | |
| Name: | Specialty/Role: | | | | | |
| Address/Location: | | | | | | |
| Phone: | Contact Person: | | | | | |
| Pager #: | Fax: | | | | | |
| e-mail: | | | | | | |
| Name: | Specialty/Role: | | | | | |
| Address/Location: | | | | | | |
| Phone: | Contact Person: | | | | | |
| Pager #: | Fax: | | | | | |
| e-mail: | ! | | | | | |
| Name: | Specialty/Role: | | | | | |
| Address/Location: | | | | | | |
| Phone: | Contact Person: | | | | | |
| Pager #: | Fax: | | | | | |
| e-mail: | | | | | | |
| Name: | Specialty/Role: | | | | | |
| Address/Location: | Address/Location: | | | | | |
| Phone: | Contact Person: | | | | | |
| Pager #: | Fax: | | | | | |
| e-mail: | | | | | | |



My Child's Healthcare Team

Include your doctors, nurses, social workers, child life specialists, dietitians, occupational therapists, physical therapists, pharmacists, speech therapist, etc.

| Name: | Specialty/Role: |
|-------------------|-----------------|
| Address/Location: | |
| Phone: | Contact Person: |
| Pager #: | Fax: |
| e-mail: | I |
| Name: | Specialty/Role: |
| Address/Location: | |
| Phone: | Contact Person: |
| Pager #: | Fax: |
| e-mail: | |
| Name: | Specialty/Role: |
| Address/Location: | |
| Phone: | Contact Person: |
| Pager #: | Fax: |
| e-mail: | |
| Name: | Specialty/Role: |
| Address/Location: | |
| Phone: | Contact Person: |
| Pager #: | Fax: |
| e-mail: | |
| Name: | Specialty/Role: |
| Address/Location: | 1 |
| Phone: | Contact Person: |
| Pager #: | Fax: |
| e-mail: | I |



PARENTS AS PARTNERS #1

Building a Relationship With Your Healthcare Team

You are a Partner In Your Child's Healthcare YOU KNOW YOUR CHILD BEST

Your experience and knowledge of your child + ,

the experience and knowledge of the healthcare professionals

the best decisions about your child's health

Key Pieces To A Collaborative Relationship

HONESTY

Be an open and honest partner. Let the healthcare professional know what is happening in your family and what else you have done to help your child. It is important for families and healthcare professionals to acknowledge and discuss openly any concerns or issues.

RESPECT

Being considerate of others shows respect. You can do this by introducing yourself and calling the healthcare team members by name. You also show respect by listening without interrupting and following through on what you have agreed to do.

TRUST

With honesty and respect as the base, trust will develop over time. Begin with the belief that the healthcare professional wants to help and has the knowledge and skills to do so. Consider each meeting as a new opportunity to work together.

APPRECIATION

Showing your appreciation goes a long way. People feel valued when their efforts are acknowledged.

I really appreciate you taking the time to answer my questions today.



Emotions Are Powerful

"When | first heard my child's diagnosis | was in shock. | had trouble taking anything in at first so | started writing down what people told me. Sometimes | was too upset to process anything and had to ask for time to think. Once | was so angry | yelled at the nurse - when | calmed down | apologized and we worked things out."

Prepare For Your Appointment

- Observe your child at home and bring notes of what you saw
- Bring information about your child's history
- Bring a list of questions
- Prioritize your concerns
- Bring list of medications with doses
- Remember your healthcare team has your best interests in mind

Share, Share, Share

As the constant in your child's life, you have valuable knowledge that will help your health care team understand and treat your child.

Talk about...

- Your observations of your child's symptoms and behaviours
 - What you have learned about your child's condition
- The impact on your family
- Important family beliefs and values
- Concerns that may be impacting your child's well-being
- Your intuition your gut feeling on what's going on
- Any difficulties you may have with carrying out the recommended treatment plan

Everyone has time pressures. Doctors get called away, you get stuck in traffic, children get sick...

To respect each other's time:

- Call if you are late or have to reschedule
- Talk about what is most important to you first
- Bring something to do while you wait
- Leave space in your day for potential delays

Communicating what you want to know...

Throughout your journey with your child's health there will be times you want to know every detail of your child's care and other times when you want to leave the care to the healthcare professionals and only be informed about decisions.

You can tell the healthcare professional how much you want to know and how you want to receive the information.

Created by parents who have years of experience partnering with their child's healthcare team. For more information visit the website of the Family and Community Resource Centre at the Alberta Children's Hospital.

http://fcrc.albertahealthservices.ca

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PARENTS AS PARTNERS #2

Building a Partnership – Sharing Information

You Are A Partner In Your Child's Healthcare YOU KNOW YOUR CHILD BEST

Your experience and knowledge of your child

the experience and knowledge of the healthcare professionals

the best decisions about your child's health

Giving Information...

Write it down... There's a lot to remember. Keeping a health journal will help you keep your child's healthcare information organized.

A Family Health Journal is available at the Family and Community Resource Centre at the Alberta Children's Hospital or at http://fcrc.albertahealthservices.ca

"My journal has helped me to remember names of people treating my son, to follow up with recommendations and tests, and to provide information to healthcare professionals quickly and accurately."

"Over the years, I have found it helpful to provide health care professionals a list of the major medical events in my child's journey. This helps to take the pressure off of me to remember dates and details of everything that has happened in the past. Being prepared for the "history question" allows me to focus on the current issue."

Help others to better understand about your child. Here are some ideas from experienced parents:

Create a top ten list of "Things You Need to Know About My Child".

Scrapbook a couple of pages with pictures and key information.

Prepare a "This is Me" book to share with caregivers.

Develop a package of information for school staff in non-medical language.

Share a story written by the child about their healthcare experiences.

Help the team see your child as a "person" not just a "patient"



Involve your child in the conversation, if possible

- Talk about your child's likes and dislikes
- Explain what comforts your child
 - Share photos

Describe how the treatment is impacting day to day life

Consider what your child is hearing ...

Your child is usually in the room when their medical condition is being discussed. Ensure your child is comfortable with the conversation and included whenever possible. Sometimes, you may want to request a private conversation without your child there.



Getting Information...

Learning More

- Ask your healthcare professional for information.
- Check out the Family Resource Centre at your Children's Hospital.
- Avoid random searches on the Internet.
- Ask a librarian for help with searching for information – at the Alberta Children's Hospital you can contact the Child Health Information Specialist in the Family and Community Resource Centre.
- Look for an organization that supports families with a related health condition.
- Talk to other parents who are in a similar situation. For example, Family to Family Connections at the Alberta Children's Hospital or the Glenrose Rehabilitation Hospital will help you connect to other families.

I've taught my child to say "I don't understand what you're saying. Can you use words I can understand?"

Get to Know Your Healthcare Team

It is helpful to learn the names and roles of the members of your healthcare team and to try to understand what they can and cannot do in their roles. In each clinic or unit look for a key contact person who will be able to answer your questions and pass on information to the other team members.

Asking Questions

Don't be afraid to ask lots of questions and to ask again if you don't understand or remember. There are no bad questions – keep asking until you feel comfortable.

Use open ended questions that encourages people to say more; not closed questions that can be answered with a yes or no.

What symptoms does a child with this condition usually experience?

Try probing for more detailed information if you want to know more.

Can you help me to understand why you think my child has this condition?

Explore possibilities rather than asking for a specific answer. It isn't always possible for your healthcare team to give you an exact answer or diagnosis.

How might this condition affect my child's day to day life?

ANOTHER OPINION

When you have a difficult decision to make, it may be helpful to explore options with another healthcare professional. It is okay to ask for another opinion.

There's a lot to think about to make this decision. I think it would be helpful to talk to another healthcare professional so I can feel confident with the choices we make. Created by parents who have years of experience partnering with their child's healthcare team. For more information visit the website of the Family and Community Resource Centre at the Alberta Children's Hospital.

http://fcrc.albertahealthservices.ca

Alberta Children's Hospital

Alberta Health Services



PARENTS AS PARTNERS #3

Working Together - Making Decisions

You Are A Partner In Your Child's Healthcare YOU KNOW YOUR CHILD BEST

Your experience and knowledge of your child

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the experience and knowledge of the healthcare professionals

the best decisions about your child's health

Becoming Part of the Team

- Get to know your child's healthcare team and let them know how you want to participate in decision making.
- Share with the team what is important to you and your child.
- Express your family's values, needs, and preferences.
- □ Share your observations about your child.
- Ask questions to improve your understanding.

"It takes time and energy to build a strong and effective team to support your child and family. Team members will change over time – it's a continuous process."

You need information to make informed decisions. It is okay to ask lots of questions. For ideas on how to get the information you need, see Tip Sheet 2.

I messages are a respectful way to help others understand what you are feeling and thinking.

I feel helpless when I see my child like this and I can't do anything.

I feel more confident trying this at home now that I've done it with you.

I am confused because I am hearing many different opinions.

I am overwhelmed by the number of therapy exercises we are supposed to do everyday.

 $oldsymbol{I}$ feel more in control when I have all the information.

Find Support For Your Participation

As a parent, it can sometimes be a challenge being part of a healthcare team. Consider finding an individual on the team who will help you participate. This would be someone you feel comfortable with who understands your situation well.



"I found it helpful to connect with another family who has lived through making a similar decision. They understood the challenge we faced."

"I talked to my community physiotherapist to get her opinion on the impact that surgery would have on my son's day-to-day activities."

Making a Decision

- 1. Work together with your healthcare team to clarify the main concern. Members of the team may have different perspectives so some discussion may be required.
- 2. State what decision has to be made.
- 3. Explore the options together. What are the expected outcomes and the risks for each option?
- 4. Decide on the timeframe to make the decision. Ask for time to think about the options and consult with others.
- 5. Make the decision.

Waiting for Decisions

Your healthcare team may suggest a "wait and see" approach before further decisions are made. This may be suggested because your child needs time to heal or more needs to be learned about your child's condition. Determine your next steps:

What should I look for? At what stage should I be concerned? When will we re-evaluate? Do I make the appointment?

When you are concerned about the wait time, you may want to ask for further action. Explain your concerns and discuss possible options.

I already see a significant difference between Jane's speech and that of her peers. I've heard that it takes a while to get into see a speech language pathologist. If we wait before booking an appointment it could be a year before she is assessed. Could we start the process now?

Assumptions can create misunderstandings

"I have learned that it is important to check out my assumptions with the healthcare professionals to avoid misunderstandings."

I'm assuming you set this appointment up – is that correct?

Am I right in thinking you will be the person who follows up on this?

Summarize any decisions that have been made to confirm your understanding.

Just let me summarize our decisions today. We are going to try the new medication for six months. I will let you know if there are any side effects. You will schedule an appointment for six months from now to discuss how well the medication is working. At that time, we'll decide whether we need to pursue the new treatment.

TOUGH DECISIONS

When crisis situations happen, it can be difficult to make decisions.

It may help to seek out others who can help you clarify your thoughts and values. In the hospital, you can find a social worker, hospital chaplain, or medical staff who will help you with this process.

Sometimes, you may decide you do not want to make the decision. That's okay. You can focus on supporting your child and ask the healthcare team to decide what to do. They will ask for your agreement. Created by parents who have years of experience partnering with their child's healthcare team. For more information visit the website of the Family and Community Resource Centre at the Alberta Children's Hospital.

http://fcrc.albertahealthservices.ca

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PARENTS AS PARTNERS #4 When We Disagree - Developing a Shared Understanding

You Are A Partner In Your Child's Healthcare YOU KNOW YOUR CHILD BEST

Your experience and knowledge of your child th ar of

the experience and knowledge of the healthcare professionals

the best decisions about your child's health

As a partner in your child's healthcare, you are encouraged to participate in decisions about your child.

At times, this may involve differences of opinion and challenges in communication. The way you deal with these situations is important for building and maintaining a strong relationship with your healthcare team. The key pieces of a collaborative relationship are honesty, respect, trust and appreciation (see Tip Sheet 1). "I try to remember that my body language can say as much as my words."

Set The Tone

You can encourage positive communication by acknowledging any difference of opinion or conflict. State your desire to move forward.

We seem to have a difference of opinion. Can we clarify options and create a plan to move forward?

Keep an Open Mind

You may not have all the information. There may be possibilities you have not considered. Be willing to reconsider your position after you have gathered information and considered all the options.

ASK FOR HELP FROM OTHERS

You may be tired, emotional, or uncomfortable with conflict. Consider asking someone to help you work through a difference of opinion you have with a healthcare professional. You could ask a trusted family member, friend, Elder, or another professional such as a social worker or chaplain. "When my child was in ICU, I was overwhelmed and exhausted. I found it difficult to participate in decision making. I talked with a social worker and she was able to support me and help me express my concerns."



"My child's doctor and I did not agree on the need for a referral for my son. She wanted me to wait and I wanted to get it done right away. As we discussed it further we came to understand the reasons for each of our positions. My doctor was concerned she wouldn't be able to follow through because she was leaving her position while I was concerned about the long wait to get in. We decided she would put in the referral and I would make sure my son's new doctor followed up on it. Exploring the reasons behind each of our positions helped us to resolve our difference of opinion."

Respectful Ways To Ask For Clarity:

Help me to understand why... So if I understand you correctly, you are saying...

"Making important decisions for your child can be very emotional; especially when the whole team does not agree! I have found that when I have an emotional reaction, it is often because of my fear and worry. Taking a moment to breathe deeply and calm myself helps to turn my focus back to the needs of my child. I know that my healthcare team has the best interests of my child in mind and that together, we can create a plan that everyone can agree on."

Working Towards a Shared Understanding

When you have a difference of opinion, the following steps will help you work together to come up with a solution:

- 1. Plan ahead. Consider what you will say and what questions you need to ask. Set up a time to talk.
- 2. Start the conversation by indicating your desire to understand the other person's point of view and to work together in the best interests of your child.
- 3. Listen to the other person without interrupting. Allow them to explain their position.
- 4. Ask open ended, probing questions to clarify and get the information you need.
- 5. If necessary, explore the reasons behind each of your positions. Ask "why" questions to get a better understanding.
- 6. State your understanding of each position.
- 7. Discuss possible solutions and form an agreement on next steps.
- 8. Restate the agreement you have made.

If you can't reach a shared understanding...

- Ask to speak with a manager to help resolve the difference.
- Get a second opinion.
- Seek out a different professional for your child's care.
- Express your concern to the AHS Patient Relations
 Department.
- Consult a Clinical Ethicist at your hospital if it is a medical ethics decision.

When I have lost control I apologize for any inappropriate words or actions and acknowledge my emotional response – "I'm sorry, it is difficult for me to separate my emotions from this situation."

Created by parents who have years of experience partnering with their child's healthcare team. For more information visit the website of the Family and Community Resource Centre at the Alberta Children's Hospital.

http://fcrc.albertahealthservices.ca

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Alberta Health Services



Resources & Services

Resources / Services

Use this to record contact information for Homecare, Transportation, Childcare, Respite, etc

| Resource / Service | Contact person(s), Phone, Fax, Email, Contract #, Intake #, etc. | | | | | | | |
|--------------------|---|--|--|--|--|--|--|--|
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Equipment and Supplies

| Record information about your child's medical equipment and | supplies | | | | | | | | |
|---|----------|--|--|--|--|--|--|--|--|
| Item (brand name, size, model, serial #, etc): | | | | | | | | | |
| Supplier: | | | | | | | | | |
| Contact Person: | Phone: | | | | | | | | |
| Address: | | | | | | | | | |
| Email/Fax: | Cost: \$ | | | | | | | | |
| Item (brand name, size, model, serial #, etc): | | | | | | | | | |
| Supplier: | | | | | | | | | |
| Contact Person: | Phone: | | | | | | | | |
| Address: | | | | | | | | | |
| Email/Fax: Cost: \$ | | | | | | | | | |
| Item (brand name, size, model, serial #, etc): | | | | | | | | | |
| Supplier: | | | | | | | | | |
| Contact Person: | Phone: | | | | | | | | |
| Address: | | | | | | | | | |
| Email/Fax: | Cost: \$ | | | | | | | | |
| Item (brand name, size, model, serial #, etc): | | | | | | | | | |
| Supplier: | | | | | | | | | |
| Contact Person: | Phone: | | | | | | | | |
| Address: | ! | | | | | | | | |
| Email/Fax: | Cost: \$ | | | | | | | | |
| Item (brand name, size, model, serial #, etc): | | | | | | | | | |
| Supplier: | | | | | | | | | |
| Contact Person: | Phone: | | | | | | | | |
| Address: | | | | | | | | | |
| Email/Fax: | Cost: \$ | | | | | | | | |



Family Medical History Include important medical information about the child's mother and father.

Mother's Name:

| Health Concern | History |
|----------------|---------|
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Father's Name:

| Health Concern | History |
|----------------|---------|
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Include important medical information about the child's siblings.

Name of sibling:

| Health Concern | History |
|----------------|---------|
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Name of sibling:

| Health Concern | History |
|----------------|---------|
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Include important medical information about other relatives, including distant aunts and uncles.

Maternal (Mother's) Side:

| Relation | History |
|----------|---------|
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Paternal (Father's) Side:

| Relation | History |
|----------|---------|
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School Information

Daycare / Preschool / School

| Comments | | | | | | |
|--------------------------|--|--|--|--|--|--|
| Phone Number | | | | | | |
| Contact Person | | | | | | |
| Grade | | | | | | |
| Daycare/Preschool/School | | | | | | |


Other

Transition for Parents

For Parents

As a parent, you have been responsible for arranging appointments, filling prescriptions, and talking to your child's healthcare team for many years. Soon it will be time to think about passing these responsibilities over to your child so they will be prepared for the transition (move) to adult medical care.

The final sections of the binder were created to help youth develop the skills needed to learn how to manage their own healthcare. The tools will help them understand their medical condition, learn how to prepare for medical appointments, and keep track of important health information.

Start by discussing this with your child and encouraging them to gradually take on more responsibility. We suggest starting as young as age 12. The earlier youth start practicing these skills, the easier it will be for them to transition to adult care.

Remember, transition is a process and mastering these new skills takes time. It starts with your child acquiring new knowledge or skills, then practicing them, and finally taking on full responsibility.

For more information visit the **Youth to Adult Health Care Transition** section of the Family and Community Resource Centre (FCRC) website:

http://fcrc.albertahealthservices.ca/transition/

To keep track of where your child's healthcare is being transferred, use the *Pediatric Transfer Plan* on page 50.





Transition Readiness Checklist for Parents

Your child is growing up and will be moving to adult care at 18. Are you and your child well on your way to being ready for this change? This checklist can help you learn if there are areas where you could be better prepared and your child more independent.

If there is an area you would like to work on with your child, put a \checkmark in the box to the left, click the **blue** links within that area for information about where to start, and use **My Plan** (page 59) to keep track of your goals. An electronic version of this document is available at:

https://www.albertahealthservices.ca/assets/info/trt/if-trt-readiness-checklistparents-independent-youth.pdf

| ✓ | | Yes | In Progress | N/A |
|---|---|-----|----------------|-----|
| | My child knows or has a summary of their condition, medication & treatment plan in case of an emergency (such as MyHealth Passport) – <u>Keeping Track of Health Information; Understanding Your Medical</u> <u>Condition; MyHealth Passport</u> | | | |
| | My child knows or carries their personal health insurance information and/or health benefits card – <u>Health Insurance</u> | | | |
| | My child knows how to prepare for a natural disaster or emergency – AHS Disaster Resources | | | |
| | When needed, my child has an advocate who can speak up for them – <u>Making Your Own Decisions</u> | | | |
| | My child has someone who will help with health management if family is not available – <u>A Health Care Advocate</u> | | | |
| | My child has a family doctor or nurse practitioner that they like and will continue seeing as an adult – Finding a Family Doctor | | | |
| | My child sees their family doctor or nurse practitioner at least once a year for checkups – Finding a Family Doctor | | | |
| | My child is comfortable talking with healthcare providers and asking them questions – <u>Talking with Your Healthcare Providers</u> ; <u>Questions to Ask</u> <u>Your Doctor</u> | | | |
| | My child meets with healthcare providers on their own – <u>Talking with</u> Your Healthcare Providers; <u>Supported Decision Making</u> | | | |
| | I know the types of doctors and other healthcare providers my child will need to see as an adult – <u>Healthcare as an Adult</u> ; <u>Keeping Track of</u> <u>Health Information</u> | | | |

Managing Your Child's Health



| | I know how to access support if my child is feeling anxious, depressed or has other mental health concerns – Youth Addiction and Mental Health Help4Me; Anxiety Canada; Teen Mental Health. | | |
|----|---|--|--|
| | I know how my child's health benefits or insurance will change after they | | |
| | become an adult – <u>Health Insurance</u> | | |
| Co | mments: | | |
| | | | |
| | | | |

Independent Living

| ✓ | | Yes | In Progress | N/A |
|----|--|-----|----------------|-----|
| | I know what resources and supports are needed and available for my child to move out on his or her own – <u>Moving Out</u> ; <u>Applying for Funding</u> <u>& Supports</u> | | | |
| | I am aware of independent transportation options available for my child – <u>Getting Around</u> ; <u>Driving</u> | | | |
| | My child knows how get specialized equipment and supplies when needed for their health condition – Equipment & Supplies | | | |
| | My child knows how to get their medication – <u>How to Fill a Prescription</u> | | | |
| | My child knows how to maintain their equipment – <u>Equipment &</u> <u>Supplies</u> | | | |
| | My child and I know what we need to do to take care of their health if we want to travel – $\frac{\text{Travelling}}{\text{Travelling}}$ | | | |
| | My child knows if they are eligible for adult Home Care services, as well as how to arrange access and direct their care – <u>Applying for</u> Funding & <u>Supports</u> | | | |
| Со | mments: | | · | |

Parent/Guardian/Family

| ✓ | | Yes | In Progress | N/A |
|----|---|-----|----------------|-----|
| | I understand my child's right to confidentiality and to informed consent – <u>Confidential Healthcare for Youth</u> | | | |
| | I know who can help me cope with personal life changes during my teen's transition – Parent Well-Being | | | |
| | I'm working with my child on goals for the future – Getting Your Child Ready for Adult Healthcare | | | |
| Co | mments: | | | |

Sexual Health

| ✓ | | Yes | In Progress | N/A |
|----|---|-----|----------------|-----|
| | I understand how my child's condition may be affected by puberty – <u>Sexual & Reproductive Health; Who To Ask About Sex; Ready or Not</u> <u>Alberta</u> | | | |
| | My child has been given information on sexual health to meet their level of understanding – <u>Teaching Sexual Health</u> ; <u>Talking With Your</u> <u>Child About Sex</u> | | | |
| Co | mments: | | | |
| | | | | |

Recreational and Social Supports

| ✓ | | Yes | In Progress | N/A |
|----|---|-----|----------------|-----|
| | My child understands what a good friend is – <u>Relationships: What</u> <u>is Healthy and What is Not</u> | | | |
| | My child has at least one good friend | | | |
| | My child is involved in activities that they like and will continue to do as an adult | | | |
| | I know about resources that can support my child's and my understanding of what is available in adult services – <u>Local Resources</u> ; <u>Events</u> | | | |
| Co | mments: | | | |

Financial & Legal Supports

| ✓ | | Yes | In Progress | N/A |
|----|---|-----|----------------|-----|
| | My child understands how to set up decision making support if they want additional help as an adult – <u>Making Your Own Decisions</u> | | | |
| | I know what sources of funding and financial supports are available for when my child turns 18 – <u>Applying for Funding & Supports</u> | | | |
| | I know about the <u>Disability Tax Credit & Registered Disability Savings</u> <u>Plan</u> | | | |
| | My child knows how to manage money – Managing Your Money | | | |
| Co | mments: | | | |

Healthy Lifestyle

| ✓ | | Yes | In Progress | N/A |
|----|---|-----|----------------|-----|
| | My child is involved in physical activities that will help them stay strong and flexible – <u>Design Your Own Exercise Routine</u> ; <u>I'm Bored-There Is</u> <u>Nothing To Do</u> | | | |
| | I encourage a balanced diet to support growth, development and activities – <u>Healthy Weights for Teens;</u> <u>Tips for healthy eating</u> ; <u>How to</u> <u>Raise Kids with a Healthy Body Image</u> | | | |
| | My child is able to grocery shop and prepare healthy meals – <u>10 easy</u> ways to get teens cooking; <u>Inspiring Healthy Eating</u> | | | |
| | I am concerned about my child because they are participating in risky behaviour such as smoking, alcohol, drugs – <u>Teen Risk Taking: Tips</u> <u>for Parents;</u> <u>Information for Parents: Getting Help with Addiction;</u> <u>Family Talk About Drinking</u> | | | |
| Co | mments: | | | |

Education and Vocation

| ✓ | | Yes | In Progress | N/A |
|----|--|-----|----------------|-----|
| | My child goes to a school that meets their needs – <u>Alberta Education:</u> <u>Diverse Learning Needs</u> | | | |
| | I know how my child's health condition may impact plans for future education and/or employment – <u>Understanding Your Medical Condition</u> | | | |
| | I know what choices for education or employment my child has after high school – Education; Finding a Job | | | |
| | My child knows why and how to register for accessibility and support services at post-secondary school – <u>Education</u> | | | |
| | I know how to help my child find suitable volunteer or work opportunities – <u>Finding a Job</u> | | | |
| | I know what resources and supports are available in the community to help my child prepare for and/or maintain employment – <u>Finding a Job;</u> Local Resources | | | |
| Co | mments: | | | |
| | | | | |

For Parents of Youth with Developmental Disabilities

Transitioning youth with developmental disabilities to adulthood can be very challenging. Information, education, and support can help make the journey easier. Included here is information about changes that lie ahead, as well as some tools to help you prepare.

The *Transition Guideline for Youth who will continue to be Dependent Adults* is a good place to start. It can be found on the Family and Community Resource Centre (FCRC) website:

http://fcrc.albertahealthservices.ca/transition/ getting-ready

As well, the *Transition Readiness Checklist for Parents of Dependent Youth* (pages 45-48) and the *Parents* section of the website may help answer some of the questions you have about adult funding, housing, transportation, and employment or education options after high school.

http://fcrc.albertahealthservices.ca/transition/

To keep track of where your child's healthcare is being transferred, use the *Pediatric Transfer Plan* on page 50.





Transition Readiness Checklist – Parents of Dependent Youth

Your child is growing up and will be moving to adult care at 18. Are you and your child well on your way to being ready for this change? This checklist can help you learn if there are areas where you could be better prepared and your child as independent as possible. Some children with a developmental disability will be able to live independently with support. Others may be more dependent on guardians or caregivers. Every child is different. If your child is completely dependent some of the questions in this checklist may not apply.

If there is an area you would like to work on, put a \checkmark in the box to the left, click the **blue** links within that area for information about where to start, and use **My Plan for Dependent Youth** (page 49) to keep track of your goals. An electronic version of this document is available at:

https://www.albertahealthservices.ca/assets/info/trt/if-trt-readiness-checklistparents-dependent-youth.pdf

In N/A Yes Progress My child carries a summary of their condition, medication & treatment plan in case of an emergency (such as MyHealth Passport) - Keeping Track of Health Information; Understanding Your Medical Condition; **MvHealth Passport** My child carries their personal health insurance information and/or health benefits card - Health Insurance I know how to prepare for a natural disaster or emergency – AHS Natural **Disaster Resources** My child has an advocate who can speak up for them – A Health Care Advocate; Making Your Own Decisions My child has a family doctor or nurse practitioner that they like and will continue seeing as an adult - Finding a Family Doctor My child sees their family doctor or nurse practitioner at least once a year for checkups - Finding a Family Doctor I know the types of doctors and other healthcare providers my child will need to see as an adult - Healthcare as an Adult; Keeping Track of Health Information I know how to access mental health support when needed – AHS Addiction & Mental Health; Youth Addiction and Mental Health -Help4Me: I know how my child's health benefits or insurance will change after they become an adult - Health Insurance. Comments:

Managing Your Child's Health



Sexual Health

| \checkmark | | Yes | In Progress | N/A |
|--------------|---|-----|----------------|-----|
| | I understand how my child's condition may be affected by puberty – Important Conversations – Sexual Health | | | |
| | My child has been given information on sexual health to meet their level of understanding – <u>Teaching Sexual Health - Differing Abilities</u> . | | | |
| Со | mments: | | | |
| | | | | |
| | | | | |

Recreational and Social Supports

| ✓ | | Yes | In Progress | N/A |
|----|---|-----|----------------|-----|
| | My child understands what a good friend is – <u>Relationships: What</u> is Healthy and What is Not | | | |
| | My child has at least one good friend or a supportive relationship | | | |
| | My child is involved in activities that they like and will continue to do as an adult | | | |
| | I know about resources that can support my understanding of what is available in adult services – Local Resources; Events | | | |
| Co | mments: | | | |
| | | | | |

Financial & Legal Supports

| ✓ | | Yes | In Progress | N/A |
|----|---|-----|----------------|-----|
| | I understand when or if my child needs a legal guardian – <u>Making Your</u> <u>Own Decisions</u> | | | |
| | I understand when or if my child needs a trustee – <u>Making Your Own</u> <u>Decisions</u> | | | |
| | I know what sources of funding and financial supports are available for when my child turns 18 – <u>Applying for Funding & Supports</u> | | | |
| | I know about the <u>Disability Tax Credit & Registered Disability Savings</u> Plan | | | |
| | Based on their ability, my child understands how to manage money – <u>Managing Your Money</u> | | | |
| Co | mments: | | | |

Parent/Guardian/Family

| ✓ | | Yes | In Progress | N/A | | |
|----|---|-----|----------------|-----|--|--|
| | I understand my child's right to confidential healthcare – <u>Making Your</u> <u>Own Decisions;</u> <u>Confidential Healthcare for Youth</u> | | | | | |
| | I know who can help me cope with personal life changes during my child's transition – Parent Well-Being | | | | | |
| | I'm working with my child to become as independent as possible – Getting Your Child Ready for Adult Healthcare | | | | | |
| Со | Comments: | | | | | |

Healthy Lifestyle

| ✓ | | Yes | In Progress | N/A |
|----|---|----------|----------------|-----|
| | My child is involved in physical activities that will help him or her stay strong and flexible – <u>Design Your Own Exercise Routine</u> | | | |
| | My child eats the amount and types of healthy food needed to support growth, development and activities – <u>Healthy Eating</u> ; <u>Tips for healthy</u> <u>eating</u> | | | |
| | I am concerned about my child because they are participating in risky behaviour like smoking, alcohol, drugs – <u>Teen Risk Taking: Tips for</u> <u>Parents; Information for Parents: Getting Help with Addiction</u> | | | |
| Co | mments: | <u>.</u> | | |

Education and Vocation

| ✓ | | Yes | In Progress | N/A |
|----|--|-----|----------------|-----|
| | My child goes to a school that meets their needs – <u>Alberta Education:</u> <u>Diverse Learning Needs</u> ; <u>Inclusive Education</u> | | | |
| | I know what activities or day programs my child can go to once they have finished school – <u>Persons with Developmental Disabilities (PDD)</u> ; <u>Applying for Funding & Supports</u> | | | |
| | I know what choices for education or employment my child has after high school – <u>Education;</u> Finding a Job | | | |
| | I know how to help my child find suitable volunteer or work opportunities – Finding a Job | | | |
| | I know what resources and supports are available in the community to help my child prepare for and/or maintain employment – Finding a Job | | | |
| Со | mments: | | | |

Independent Living

| ✓ | | Yes | In Progress | N/A |
|----|--|-----|----------------|-----|
| | I know what resources and supports are needed and available for my child to live as independently as possible – <u>Applying for Funding &</u> <u>Supports;</u> <u>Moving Out</u> | | | |
| | I am aware of independent transportation options available for my child – <u>Getting Around</u> | | | |
| | I know how get specialized equipment and supplies when needed for my child's health condition – <u>Equipment & Supplies</u> | | | |
| | I know what I need to do to take care of my child's health if we want to travel – <u>Travelling</u> | | | |
| | I know if my child is eligible for adult homecare services and how to arrange access when needed – <u>Applying for Funding & Supports</u> | | | |
| Со | mments: | | | |



My Plan – Dependent Youth

Are there things you are doing for your child that they could be doing for themselves?

If so, think about what your child could learn to do for themselves in the next week, month, or year and make a plan on how you will help your child learn this skill!

| | This (insert week/month/year) | | | | |
|--|----------------------------------|--|--|--|--|
| My child will learn to: | (moor wookmonk) | | | | |
| How will my child learn this? | | | | | |
| Who can help or support me or my child to do this? | | | | | |

| | This (insert week/month/year) |
|--|----------------------------------|
| My child will learn to: | |
| How will my child learn this? | |
| Who can help or support me or my child to do this? | |





Pediatric Transfer Plan:

1. Transition to a Family Doctor:

You may be seeing a pediatrician (a doctor who cares for children). When you transfer to adult healthcare, you will need to see a family doctor instead. Use this form to help plan your transition to a family doctor.

| Pediatrician: Name, Address & Contact Information | |
|--|--|
| Family Doctor: Name, Address & Contact Information | |
| How will information be transferred and knowledge about your condition exchanged with the new family doctor? | |

2. Transfer of Care to Adult Provider/Clinic/Program:

For each of the pediatric clinics/programs you attend, ask your healthcare team about the type of doctor(s) and/or healthcare provider(s) you will need to see as an adult and how your care is going to be transferred to them.

It's good to ask early so you'll know what to expect and can prepare for the changes ahead! Some key things to discuss:

- □ Where your care is being transferred
- □ When this will occur
- □ How the transfer process works
- □ What information is being sent to your new specialist(s)

Use the following page to record contact information and each clinic's transfer plans.

Note: If you attend more than one pediatric clinic, use one page for each clinic you attend.





Transition to Adult Provider/Clinic/Program

| Pediatric Clinic | |
|---|--|
| Name & Location/Address of Adult Clinic | |
| Contact Name & Phone Number for Adult Clinic | |
| Emergency Contact Information for Adult Clinic | |
| When will my care be transferred? At what age? When will my last pediatric appointment be? | |
| How does the transfer process work? Does the adult clinic call me to book an appointment or do I need to call them? | |
| What health information is transferred? And how? | |
| When will my first appointment with the adult clinic be? How long after my last pediatric appointment? | |
| Additional information | |



Transition for Youth

For Youth

As you get closer to becoming an adult, you're likely thinking about getting a driver's license, going to university or trade school, or applying for a job. It's also a good time to start thinking about taking on more responsibility for your healthcare because once you turn 18, you'll transition or move to adult medical care.

This *Transition for Youth* section will get you started on this journey. Use the tools to determine what your family is doing, that you could be doing instead. The final sections make up your own health journal. It will help you learn new skills as you start to manage your own healthcare.

We encourage you to keep this journal up to date and use it to share information and communicate with your healthcare team. You can use all of the pages, or only those that meet your needs. It's totally up to you. You may even prefer to use your own binder. For extra pages, go to the Family and Community Resource Centre (FCRC) website:

http://fcrc.albertahealthservices.ca/ publications/journals/Family-Health-Journal.pdf

As well, visit the *Youth* section of the website for information on how you can prepare for transition, what to expect in adult care and resources available in the community.

http://fcrc.albertahealthservices.ca/transition/



My Skills and Goals

To help you get started on this journey, think about some of the things that your family is doing that you could learn to do.



Complete the *Transition Readiness Checklist for Youth* (pages 55-58). This will help you identify areas where you could be more independent.



Think about the things you want to learn in the next week, month, or even year and make a plan for how you will learn them! Use *My Plan* (page 59) to set some goals and keep track of your progress.



Continue to work towards independence by going over your checklist every 6-12 months to help you review your current goals and set new ones.



For more copies of the checklist or plan go to: http://fcrc.albertahealthservices.ca/transition/getting-ready/





Transition Readiness Checklist for Youth

How well do you know yourself? Are you well on your way to take care of your own medical needs? This tool can help you (and your parents) think about the areas where you could be better prepared.

If there is an area you would like to work on, put a \checkmark in the box to the left of the statement, click the **blue** links within that area for information about where to start, and use **My Plan** (page 59) to keep track of your goals. An electronic version of this document is available at:

https://www.albertahealthservices.ca/assets/info/trt/if-trt-readiness-checklistyouth.pdf

Managing My Health

| \checkmark | | Yes | In Progress | N/A |
|--------------|--|-----|----------------|-----|
| | I have a family doctor that I like and see yearly for physical examinations – Finding a Family Doctor | | | |
| | I know who to ask for help if I have depression, anxiety or other mental health concerns – <u>Youth Addiction and Mental Health –</u> <u>Help4Me</u> ; <u>Anxiety Canada</u> ; <u>Teen Mental Health</u> | | | |
| | I can describe my health condition to others – <u>Understanding Your</u> Medical Condition; <u>Talking with Your Healthcare Providers</u> ; <u>Advocating for Yourself</u> | | | |
| | I can explain my medical history or have access to a summary – <u>Talking with Your Healthcare Providers;</u> <u>Understanding Your Medical</u> <u>Condition;</u> <u>Keeping Track of Health Information</u> | | | |
| | I know what my long-term health problems may be – <u>Understanding</u> Your Medical Condition | | | |
| | When my symptoms are getting worse I know who to contact and/or what to do – <u>Understanding Your Medical Condition</u> | | | |
| | I know what medical tests I need and the reasons for them – Understanding your Medical Condition | | | |
| | I wear a <u>Medic Alert</u> if recommended by my health care provider – <u>Understanding Your Medical Condition</u> | | | |
| | I know the names of my medications and dosages– <u>Managing</u> <u>Medications & Treatment Plans;</u> <u>Know Your Medications</u> | | | |
| | I know what each of my medications and/or treatments are for – <u>Managing Medications & Treatment Plans</u> ; <u>New Medicines</u> : <u>Questions to Ask the Doctor</u> | | | |
| | I know the side effects of the medications I take – <u>Managing</u> <u>Medications & Treatment Plans</u> ; <u>New Medicines: Questions to Ask</u> <u>the Doctor</u> | | | |
| | I prepare and/or take my own medications and/or treatments – Managing Medications & Treatment Plans | | | |



| | I know how to fill my own prescriptions – <u>Managing Medications &</u> <u>Treatment Plans</u> ; <u>How to Fill a Prescription</u> | | |
|----|---|--|--|
| | I know how to get specialized equipment and supplies that I need – Equipment & Supplies | | |
| | I know how to maintain my equipment – Equipment & Supplies | | |
| | I keep track of my health care visits, treatment plan, and medications – Keeping Track of Health Information | | |
| | I know how to get my medical records – <u>Keeping Track of Health</u> Information | | |
| | I can make and get to clinic appointments on my own – <u>Booking</u> <u>Medical Appointments;</u> <u>Getting Around</u> | | |
| | I know who my adult care providers will be, how often to see them and for what – <u>Healthcare as an Adult; Keeping Track of Health</u> Information | | |
| | I know how to be prepared for a natural disaster or emergency – <u>AHS</u> <u>Disaster Resources</u> | | |
| Co | mments: | | |

Health, Recreation and Social Supports

| \checkmark | | Yes | In Progress | N/A |
|--------------|---|-----|----------------|-----|
| | My family supports me in managing my health, or I have people to help if family cannot – <u>Making Your Own Decisions</u> ; <u>A Health Care</u> <u>Advocate</u> | | | |
| | I participate in clubs, groups, sports, or activities | | | |
| | I have at least one good friend | | | |
| | I talk to my family or friend(s) about my problems, sad feelings and/or worries | | | |
| | I know who to talk to if I am feeling anxious or depressed (For example: friends, family, healthcare provider, counsellor or another support person) – Youth Addiction and Mental Health – Help4Me; Anxiety Canada; Teen Mental Health | | | |
| Co | mments: | | | |
| | | | | |
| | | | | |

Sexual Health

| ✓ | | Yes | In Progress | N/A |
|----|---|-----|----------------|-----|
| | I know how my condition might affect my sexual health – <u>Sexual &</u> <u>Reproductive Health; Who To Ask About Sex</u> | | | |
| | I know how to prevent an unplanned pregnancy and/or sexually transmitted infections (STIs) – <u>Sexual & Reproductive Health</u> | | | |
| | I know about my need for genetic counselling before planning a family – <u>AHS Clinical and Metabolic Genetics Program;</u> <u>Ready or Not Alberta</u> | | | |
| | I know how my health and medications may affect future pregnancies – <u>Who To Ask About Sex</u> ; <u>Ready or Not Alberta</u> | | | |
| Со | mments: | | | |

Becoming Independent – School, Work, Travel, Money...

| ✓ | | Yes | In Progress | N/A |
|----|--|-----|----------------|-----|
| | I know how my health condition may limit my career choices – Understanding Your Medical Condition | | | |
| | I think about what I would like to do after high school and have ideas for my future – <u>Education</u> ; <u>Finding a Job</u> | | | |
| | I am setting and working on goals for the future – <u>ALIS: Set SMART</u> Goals | | | |
| | If I am unable to support myself financially, I know about resources that can help me – <u>Applying for Funding & Supports</u> | | | |
| | I know how to budget and manage my money – <u>Managing Your</u> <u>Money</u> | | | |
| | I know about funding options for college/university (For example: scholarships and bursaries) – <u>Education</u> | | | |
| | I know why and how to register for accessibility and support services at my post-secondary school – <u>Education</u> | | | |
| | I know what I need to do to take care of my health if I want to go away to school or live away from home – <u>Moving Out</u> ; <u>Education</u> ; <u>Applying for Funding & Supports</u> | | | |
| | I know what resources and supports are available to help me live on my own and/or be as independent as possible – <u>Moving Out</u> | | | |
| | I know what I need to do to take care of my health if I want to travel – Travelling | | | |
| | I am independent with transportation – Getting Around; Driving | | | |
| Со | nments: | | | |

Speaking Up For Myself (Self-Advocacy)

| ✓ | | Yes | In Progress | N/A |
|----|--|-----|----------------|-----|
| | I am comfortable asking questions of my healthcare providers – Talking with Your Healthcare Providers; Questions to Ask Your Doctor | | | |
| | I am able to meet with my healthcare providers on my own but understand I have the right to have a support person attend if I want – Talking with Your Healthcare Providers; Supported Decision Making | | | |
| | I know what patient confidentiality means – <u>Confidential Healthcare</u> for Youth | | | |
| | Before consenting to treatment, I fully understand the risks and benefits- Making Your Own Decisions; Shared Decision Making | | | |
| | I carry a copy of my Alberta Health Care card | | | |
| | I know what kind of health insurance I have and carry my own insurance card – <u>Health Insurance</u> | | | |
| | I know what my rights and responsibilities are as an employee – <u>Finding a Job</u> | | | |
| | I know what my rights and responsibilities are as student | | | |
| | I know how to ask for what I need – Advocating for Yourself | | | |
| Co | mments: | | | |
| | | | | |

Healthy Lifestyle

| \checkmark | | Yes | In Progress | N/A |
|--------------|--|-----|----------------|-----|
| | I know how alcohol, drugs and tobacco can affect my health condition and interact with my medications – <u>Managing Medications</u> <u>& Treatment Plans</u> | | | |
| | I eat the amount and types of healthy food needed to support growth, development and activities – <u>Learning About Healthy Eating for</u> <u>Teens</u> ; <u>Tips for Healthy Eating</u> | | | |
| | I know how my health condition affects my physical activities – <u>What</u> <u>Are My Activity Restrictions</u> ; <u>Understanding Your Medical Condition</u> | | | |
| | To stay healthy, I participate in activities/exercise that are safe for me – <u>Design Your Own Exercise Routine</u> ; <u>I'm Bored-There Is</u> Nothing To Do | | | |
| Co | mments: | | | |



My Plan

Are there things your family is doing for you that you could be doing for yourself?

If so, think about what you could learn to do for yourself in the next week, month, or year and make a plan on how you will do it!

| This (insert week/month/year) | | | | | | | |
|---|--|--|--|--|--|--|--|
| I will learn to: | | | | | | | |
| How will I learn this? | | | | | | | |
| Who can help me or support me to do this? | | | | | | | |

| This (insert week/month/year) | | | | | | | | |
|---|--|--|--|--|--|--|--|--|
| I will learn to: | | | | | | | | |
| How will I learn this? | | | | | | | | |
| Who can help me or support me to do this? | | | | | | | | |



There are many people in your life who can support you as you prepare for the move to adult care:

Parents/Guardians Aunts/Uncles/Cousins Grandparents Doctors Siblings School Aides/Assistants Social Workers Community Church Friends Support Workers Teachers

We suggest you create a support circle, so you can see who's there for you! The center of the wheel represents **YOU**. The light grey circle is for people who are close to you, and the darker grey circle is for people who are not as close but may still support you in some way. If there are other people not listed here who can help you learn the skills you need to become an adult, be sure to include them.





| YOUTH HEALTH JOURNAL CONTENTS | | | | | | | | |
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| APPOINTMENTS & CARE LOG | Care Log Preparing for an Appointment Questions & Answers Bloodwork and Test Results | | | | | | | |
| MEDICATIONS | Medication Log | | | | | | | |
| MY HEALTHCARE TEAM | My Healthcare Team | | | | | | | |
| RESOURCES & SERVICES | Resources & Services Equipment & Supplies Pouch for Vendor Information | | | | | | | |



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My Medical Condition



My Health Passport

Having a health passport provides a snapshot of your medical condition and history. It is handy to have when you see new healthcare providers or in an emergency. Making a passport will help you learn more about your medical condition, as well as provide a way of keeping track of your health information. You can create a wallet-sized passport at <u>www.sickkids.on.ca/myhealthpassport</u>.

| Name | |
|--|---|
| Date of birth | |
| Address and postal code | |
| Phone number | |
| Social insurance number (SIN) | |
| Alberta healthcare number | |
| Alberta health record number | |
| What are your medical condition(s) & when were they diagnosed? | |
| | |
| Do you wear a medic alert bracelet? | □Yes □No |
| Are you on any medications? | |
| (Don't forget about contraceptive pills/patches/ IUCDs, as well as vitamins and other supplements) | To learn about your medication(s), go to: <u>https://medlineplus.gov/</u> |
| Have you had any operations? What for and when? | |



My Health Passport Continued

| Bone Status | | | | | | | | |
|--|---------------|---|---|--|---|---------------|-------|--------------------|
| | | | | | | | | |
| Blood Type | □ A+ | □ A- | □ B+ | ⊔ В- | □ 0+ | □ 0- | □ AB+ | □ AB- |
| Check all of the | | | | | | | | |
| Check all of the immunizations that are up to date | | Polio HIB (Her MMR (M Varicella PCV13/F Hepatitis HPV (Hu Meningit | uman Pap is (Menin a (annual s A | Influenza Iumps, F npox) ^D neumoc billomavir gococca | a-Type B) Rubella) coccal Co us) |) njugate) | | <i>N</i> -135 & Y) |
| /info/Page16565.aspx | | | | | | | | |
| ALLERGIES | | | | | | | | |
| | | | | | | | | |
| How do you pay for medications, supplies and health care needs, not covered by Alberta Health Care (e.g. dental, eyeglasses, physiotherapy, etc.)? | | | | | | | | your plan Iber? |
| Where do you usually buy | Pharm | acy name | e: | | | | | |
| your prescriptions? | Phone number: | | | | | | | |
| Who should be called in | Name: | | | | | | | |
| case of an emergency? | Relationship: | | | | | | | |
| | Phone | number: | | | | | | |
| Where do you go to school? | Schoo | I name: | | | | | | |
| | Phone | number: | | | | | | |
| Special needs? | | | | | | | | |
| Other information? | | | | | | | | |





Understanding My Medical Condition

Knowing about your medical condition will help you understand how to stay healthy. It will also help you be more involved in decisions about your healthcare. To get started, fill in the boxes below. It's important that you go to reliable sources for information – see *Choosing Reliable Websites.*

Please fill in one form for each medical condition.

| What is the name of your medical condition? | |
|---|--|
| How is it diagnosed? | |
| What are some signs & symptoms of your medical condition? | |
| What causes it? | |
| How is it treated? | |
| What are some things you can do to take care of yourself? | |
| If I have any of these signs and symptoms, I should see the doctor: | |





Choosing Reliable Websites



Is what I read on the Internet always true?

No. Just because the information is on a website doesn't mean it's right or correct. This is especially true when it comes to health information.

How do I know if health information is true on a website?

You should always do your research first when looking at any new website! To help you do that, make sure to ask yourself the following questions when looking at any website.

1. Who manages the site?

The address that is in the bar at the top of the page tells you who manages the site:

- .gov is a government agency.
- .org is a not-for profit agency.
- .edu is an educational Website.
- .com is a commercial Website.
- .ca is a Canadian Website

2. Who writes the information for the site?

For <u>health information</u> make sure you know who is writing the information. A health professional such as a doctor, nurse, psychologist, etc. can be trusted to have accurate information on a disease or condition. You can usually do this by reading the "About Us" button or the "Contact Us" button; sometimes the contact information might be at the bottom of the page.

3. What if it is somebody's personal webpage?

If you find out it is somebody's personal webpage, know that you can read their story but do not take any personal health advice. It is their personal opinion and your own health story is unique to you.

4. Is the information up-to-date?

Check to see how "up to date" the information on the website is. On good websites you can usually find a "last updated" date on the bottom of the page or somewhere on the website you are looking at. This makes sure the webpage is constantly being updated and reviewed.

5. If the website links to new websites, can that new information be trusted or do I have to look at researching each new website?

You have to look at each new website you are on. Once you have done it a few times you will be able to spot a good website more quickly!

Great Health Information Websites to Get You Started:

- <u>http://kidshealth.org/</u> From the trusted Nemours Foundation. Parent's, Kid's & Teen's site. A top choice for all Health Information.
- <u>http://www.aboutkidshealth.ca/En/Pages/default.aspx</u> Trusted answers from the Hospital for Sick Children – AboutKidsHealth.
- <u>http://www.nlm.nih.gov/medlineplus/</u> Includes Health Topics with 750 topics on conditions, diseases and wellness, Drugs & Supplements, Medical Encyclopedia, Interactive Tutorials, etc.



Appointments & Care Log





Care Log (Surgery, Hospital Admissions, Clinic, Emergency Visits, Therapy, etc)

| Plans / Instructions / Comments | | | | | | |
|---------------------------------|--|--|--|--|--|--|
| Reason for Treatment or Visit | | | | | | |
| Place/Location | | | | | | |
| Doctor's Name | | | | | | |
| Date | | | | | | |

If you are having surgery go to Just For Teens - Tips for Surgery at www.albertahealthservices.ca/assets/hospitals/ach/ach-surgery-teen-tips.pdf





Preparing for an Appointment

 Date:

 Time:

 Appointment with:

Reason for going (injury, check up, you are ill, prescription refill, therapy, etc)

What to bring:

Alberta Healthcare card

Health insurance card

Health journal and a pen

For information on what to bring if this is your FIRST appointment with this doctor or specialist, visit *Preparing for Medical Appointments* at <u>https://www.albertahealthservices.ca/y2a/Page16156.aspx</u>

What the doctor said:

What I need to do:





Questions & Answers

This page is for any questions you may want to ask your healthcare team. It helps to write your questions down ahead of time.

| Question | | |
|---------------|--------------|-------|
| 0 | | |
| | | |
| Answer | | |
| Я | | |
| | | - |
| | Answered by: | Date: |
| Question | | |
| 0 | | |
| ×. | | |
| Answer | | |
| \mathcal{A} | | |
| | | |
| | Answered by: | Date: |
| Question | | |
| 0 | | |
| X | | |
| Answer | | |
| Я | | |
| | | |
| | Answered by: | Date: |





Bloodwork and Test Results



| | Results & Comments | | | | | | |
|---|--------------------|--|--|--|--|--|--|
| a de la compañía de l | Test | | | | | | |
| Who ordered the test? | (Name & Specialty) | | | | | | |
| | Date | | | | | | |

Medications



Medication Log

| Finish Date | | | | |
|---|--|--|--|--|
| Start Date | | | | |
| Comments (Where do you get it, how do you pay for it, any reactions, etc) | | | | |
| When do I take it? | | | | |
| Amount given at each dose | | | | |
| How do I take it? | | | | |
| What is the medicine for? | | | | |
| Name of Medicine | | | | |

My Healthcare Team



My Healthcare Team



Include your doctors, nurses, social workers, child life specialists, dietitians, occupational therapists, physiotherapists, pharmacists, etc.

| Name: | Specialty/Role: |
|-------------------|-----------------|
| Address/Location: | |
| Phone: | Contact Person: |
| Pager Number: | Fax: |
| Email: | |
| | |
| Name: | Specialty/Role: |
| Address/Location: | |
| Phone: | Contact Person: |
| Pager Number: | Fax: |
| Email: | |

| Name: | Specialty/Role: |
|-------------------|-----------------|
| Address/Location: | <u> </u> |
| Phone: | Contact Person: |
| Pager Number: | Fax: |
| Email: | |

| Name: | Specialty/Role: |
|-------------------|-----------------|
| Address/Location: | I |
| Phone: | Contact Person: |
| Pager Number: | Fax: |
| Email: | · |



My Healthcare Team continued...



| Name: | Specialty/Role: |
|-------------------|-----------------|
| Address/Location: | |
| Phone: | Contact Person: |
| Pager Number: | Fax: |
| Email: | |

| Name: | Specialty/Role: |
|-------------------|-----------------|
| Address/Location: | I |
| Phone: | Contact Person: |
| Pager Number: | Fax: |
| Email: | |

| Name: | Specialty/Role: |
|-------------------|-----------------|
| Address/Location: | I |
| Phone: | Contact Person: |
| Pager Number: | Fax: |
| Email: | |

| Name: | Specialty/Role: |
|-------------------|-----------------|
| Address/Location: | |
| Phone: | Contact Person: |
| Pager Number: | Fax: |
| Email: | • |



Resources & Services



Equipment and Supplies



Record where you buy or rent your medical equipment and supplies

| Item (brand name, size, model, serial #, etc.): | | |
|---|----------|--|
| Where to get it: | | |
| Contact person: | Phone: | |
| Address: | I | |
| Email/Fax: | Cost: \$ | |
| Item (brand name, size, model, serial #, etc.): | | |
| Where to get it: | | |
| Contact person: | Phone: | |
| Address: | | |
| Email/Fax: | Cost: \$ | |
| Item (brand name, size, model, serial #, etc.): | | |
| Where to get it: | | |
| Contact person: | Phone: | |
| Address: | I | |
| Email/Fax: | Cost: \$ | |
| Item (brand name, size, model, serial #, etc.): | | |
| Where to get it: | | |
| Contact person: | Phone: | |
| Address: | I | |
| Email/Fax: | Cost: \$ | |





Resources & Services



| Resources/ Service | Contact person(s), Phone, Fax, Email |
|--------------------|--------------------------------------|
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YOUTH Health Journal Evaluation Form

| We welcome any feedback you may have on how we can improve this journal. | | | | | | | | |
|--|---|-----------|-----------|---------|---------|------------------------------------|--|--|
| 1. | Overall, how useful did you find the Journal? | | | | | | | |
| | 1 | 2 | 3 | 4 | 5 | | | |
| | Not useful | | | | Ve | ry useful | | |
| 2. | What did ye | ou find v | vas the r | most us | seful? | Why? | | |
| | | | | | | | | |
| | | | | | | | | |
| 3. | What did y | ou find v | vas the l | east us | seful? | Why? | | |
| | | | | | | | | |
| | | | | | | | | |
| 4. | Do you hav | ve any io | leas or s | sugges | tions o | n how we can improve this Journal? | | |
| | | | | | | | | |
| | | | | | | | | |
| 5. | Additional | Commei | nts: | | | | | |
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Please return this form by mail or in person to the:

Family & Community Resource Centre (FCRC) Alberta Children's Hospital (2nd Floor) 28 Oki Drive NW Calgary, AB T3B 6A8



FAMILY Health Journal Evaluation Form

| We welcome any feedback you may have on how we can improve this journal. | | | | | | | |
|--|---|-----------|-----------|----------|---------|-------------------------------------|--|
| 1. | Overall, how useful did you find the Journal? | | | | | | |
| | 1 | 2 | 3 | 4 | 5 | | |
| | Not useful | | | | Ve | ry useful | |
| 2. | What did yo | ou find \ | was the | most us | seful? | Why? | |
| | | | | | | | |
| | | | | | | | |
| 3. | What did yo | ou find v | was the | least us | seful? | Why? | |
| | | | | | | | |
| | | | | | | | |
| 4. | Do you hav | e any io | deas or s | suggest | tions o | on how we can improve this Journal? | |
| . <u> </u> | | | | | | | |
| | | | | | | | |
| 5. | Additional C | Comme | nts: | | | | |
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