Pediatric to Adult Care Transition (PACT) Workbook

DOERNBECHER CHILDREN'S *Hospital*

OCCYSHN

Oregon Center for Children and Youth with Special Health Needs

OCCYSHN
Oregon Center for Children and Youth with Special Health Needs

t 503 494-8303
t 877 307-7070
f 503 494-2755
e occyshn@ohsu.edu
w www.occyshn.org

Mail code CDRC
707 SW Gaines St
Portland, OR 97239

DOERNBECHER CHILDREN'S Hospital
OHSU

General Pediatrics and Adolescent Health Clinic

Pediatric to Adult Care Transition (PACT)

You are nearing time to transition from our clinic. Our goal is to make sure your transition to adult care is coordinated and organized. This is a folder to help you gather information and resources to help make the transition process easier. You and your doctor will determine the exact date of transition *(write transition date here)*_____, and at that time, you will have to leave us. The good news is we can help you get ready for this big change. We will also help your new primary care provider get to know you so you don't have to go through the process alone.
-Your medical team at Doernbecher General Pediatrics and Adolescent Health Clinic

What questions or concerns do you have about the transition process?

OCCYSHN
Oregon Center for Children and Youth with Special Health Needs

t 503 494-8303
t 877 307-7070
f 503 494-2755
e occyshn@ohsu.edu
w www.occyshn.org

Mail code CDRC
707 SW Gaines St
Portland, OR 97239

Dear Family,

We write you as parents of young people with complex medical conditions, and welcome you to the process of transferring your son or daughter's care from a pediatric setting to an adult setting.

Ana's daughter is 16 and will be transitioning to adult care soon, and BranDee's son is 22 and recently went through the process. We know first-hand what it's like to make the move from pediatric to adult care, especially for youth who have lots of providers, medications, appointments, and/or surgeries. From talking with other parents, we know that our experience is not unusual; transition can be overwhelming, and it is hard to know where to start.

We work with the Oregon Center for Children and Youth with Special Health Needs and OHSU General Pediatrics to make transferring from pediatric to adult primary care easier for families. We are happy that you are now part of this project, too.

You are receiving this binder to help you organize the information and steps needed to find adult health care providers for your son or daughter. Although this project focuses on helping you find an adult *primary care* provider, the binder will be helpful as you transition your specialty care as well.

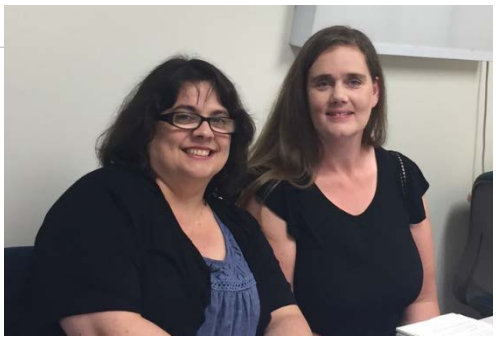
We've learned that a good plan, started early, will help ease any of the stress or anxiety you or your young person might be experiencing. Participating in this project is a great step toward a successful transition to adult care!

One request: you will be asked to complete two surveys during this project. We know it's difficult to find time, but please complete and return them. Your feedback will teach our team what works and what doesn't for medically complex young adults. And our team will send you a $25 gift card for each completed survey.

Best wishes to you and your family,

Ana Valdez

BranDee Trejo



Transition of Care Checklist

Meeting 1: Introduction & Start Health Passport	☑ *Today!*	
Complete Survey by Email	☐	
Meeting 2: Review Health Passport & Find Adult Provider	☐	
Complete Follow-Up Survey by Email	☐	

NOTES:

DOERNBECHER CHILDREN'S Hospital OHSU

Health Passport

OCCYSHN
Oregon Center for Children and Youth with Special Health Needs

My medical team (include MD, DO, PA, NP, PT, SLP, Psychologist, etc)

Name	Specialty	Phone	What condition does this provider manage?

Medical conditions and medications summary

My Active Medical Conditions

Surgeries (year)

Allergies

Equipment/Supplies

Significant past medical events

Things to know

Daily medications

Name	Dose	# times/day	Reason for taking

As-needed medications

Name	Dose	# times/day	Reason for taking

Emergency medications

Things to consider when choosing a new provider

What clinics are close to my/our home?

Which clinics accept my/our insurance?

Which clinics and providers are taking new patients?

What is important to me/us in a new provider?

What other things am I/are we considering when looking for a new provider?

Worksheet for Primary Care Medical Home Transfer

Insurance information:

Name: _____ Policy number: _____

	Clinic/Provider name, Location	*Phone number*	*Date called*	*Accepts insurance?*	*Takes new patients?*	*Earliest available appointment*
1				☐	☐	
2				☐	☐	
3				☐	☐	
4				☐	☐	
5				☐	☐	
6				☐	☐	

Transferring care

My new doctor (Name, Address, Phone number)

_____

_____

_____

Date of first appointment with new doctor

Things to bring to first appointment

- ☐ I have my Health passport
- ☐ I have my Medical Summary (from my pediatric PCP)

Things I still need

_____

_____

_____

Questions for my new doctor

_____

_____

_____

_____

Sample One Page Profile

Date: (Keep this document updated)_____

Photo here:

Photo should be showing your child at their best, doing something that is important to them, and it should be a picture your child likes.

"I feel at my best" or "I feel healthy" when:

List things that are examples of your child at their healthiest and feeling good. For children/youth with chronic conditions, give examples of a "good day."

What works for me in a health care setting:

List specific items that make for a good or easy doctor/dental/therapy visit.

What doesn't work for me in a health care setting:

List of issues that have been difficult in the health care setting, if any:

What I want my medical home to know:

List other things that the provider might need to know about health habits or family life:

- Foods I like, foods I dislike
- How I feel about exercise
- How I get to and from medical appointments
- Dental problems, if any
- How I work with the school nurse, if applicable
- What people like or admire about me
- Our family's preferences about when to start medications

Oregon Family to Family Health Information Center (2019)
www.oregonfamilytofamily.org

_____'s One Page Profile

Date: (keep this document updated)____

Photo here:

"I feel at my best" or "I feel healthy" when:

What works for me in a health care setting:

What doesn't work for me in a health care setting:

What I want my medical home to know:

List other things that the provider might need to know about health habits or family life:

Oregon Family to Family Health Information Center (2019)
www.oregonfamilytofamily.org

Examples of providers to include on Health Passport

Specialty Care

- Speech, Occupational or Behavioral Therapies
- Medical Specialty

Payers

- Health Plan(s)
- Care Coordinator(s) at Health Plan(s)

Community

- Developmental Disabilities Case Manager
- Children's Intensive In-Home Services Manager
- Brokerage
- Vocational Rehabilitation
- Post-Secondary Education/Job
- Center for Independent Living

Mental Health

- Psychologist
- Counselor/Therapist
- Wraparound Coordinator

Education

- School Nurse
- Special Education Coordinator
- Teacher
- School Counselor
- Transition Specialist

Other Health-Related Services

- Durable Medical Equipment/Vendor
- Pharmacist(s)

Oral/Dental Care

Resource Needs Checklist

o I would like some support to make sure I fully understand this information.

Health Care	
☐	On-going health care needs
☐	Medication Management
☐	Health insurance
☐	Vision/Dental Care
☐	Medication Payments
☐	Other:

Mental Health	
☐	Depression
☐	Anxiety
☐	Behavioral Concerns
☐	Emotional Support Animal
☐	Interested in therapy/counseling
☐	WRAP-around Services
☐	Other:

Healthy Living	
☐	Physical activity/Recreation/Sports
☐	Nutrition/Meal Planning
☐	Sexual/Reproductive Health
☐	Substance use/abuse
☐	Stress Management
☐	Sleep Issues

Support	
☐	Respite Care
☐	Community support groups
☐	Financial Assistance/Support
☐	Community Referrals/Assistance
☐	Youth Camps/Classes/Activities
☐	Other:

Legal	
☐	Guardianship options
☐	Supported decision-making
☐	Juvenile Justice
☐	Custody Family Law
☐	Legal Status/immigration
☐	Other:

Transportation/Housing	
☐	Public Transportation
☐	Medical Transportation
☐	Affordable Housing
☐	Youth Transitional Housing Programs
☐	Other:

Jobs/Education/Career	
☐	Diploma/GED planning
☐	College questions/planning
☐	Jobs
☐	Volunteering
☐	College Disability Support

Disability Specific Concerns	
☐	Disability Community Resources
☐	Information on Social Security (SSI) Benefits and Services
☐	Guardianship Handbook copy
☐	Referrals/Advocacy for county services
☐	Group Homes/Supervised Housing
☐	Independent Living Programs
☐	Adaptive/Medical Equipment
☐	Medical ID Bracelet
☐	Vocational Rehab/Training
☐	Service Animal

DOERNBECHER CHILDREN'S Hospital OHSU

Health Passport

(expanded format)

OCCYSHN
Oregon Center for Children and Youth with Special Health Needs

Part 1: My medical team (include MD, PA, NP, PT, SLP, Psychologist, etc)

Name	Specialty	Phone	What condition does this provider manage?

Part 2: Medical conditions and medications summary

My Active Medical Conditions	Surgeries (year)	Allergies	Equipment/Supplies

Significant past medical events

Things to know

Daily medications

Name	Dose	#times/day	Reason for taking

As-needed medications

Name	Dose	#times/day	Reason for taking

Emergency medications

Name	Dose	Reason for taking

OREGON FAMILY TO FAMILY HEALTH INFORMATION CENTER

Me gustaría hablar con un/a Compañero/a de Padres de Familia

NECESITO INFORMACION SOBRE:

___ La condición o discapacidad e mi hijo/a

___ Que servicios están disponibles para él /ella ahora o en el futuro

___ Cómo conseguir servicios específicos para él/ella como terapias, cuidado dental, cuidado de salud menta

___ Como manejar la transición cuando mi hijo/a sea adolescente o cuando cumpla 18 años

___ Información sobre algo más: _____

APOYO:

___ Para comunicarme mejor con los terapeutas y proveedores de cuidados de salud

___ Para hablar con un padre/madre de un niño/a similar al mío/a, por teléfono

___ Para encontrar un grupo de apoyo en _____ (Código Postal)

___ Para explicar la discapacidad de mi hijo/a a los doctores, familiares, profesores o otras personas

___ Para saber cómo contestar cuando me hacen preguntas acerca de su condición

___ Apoyo para otra cosa: _____

SERVICIOS DE LA COMUNIDAD

___ Encontrar a un doctor, especialista o dentista que entienda nuestras necesidades

___ Encontrar recreación en la comunidad para mi hijo/a

___ Encontrar cuidado de niños seguro, una oportunidad de descanso para mí con su cuidado

___ O a encontrar algo más: _____

AYUDA ECONOMICA:

___ Pagar gastos tales como comida, alquiler, ropa, transporte o gastos médicos

___ Seguro médico, OHP (Plan de salud de Oregón), u otros asuntos financieros de salud

___ Gastos de equipo especial para las necesidades de mi hijo/a

___ Pagar por terapia, cuidado infantil u otros servicios que mi niño/a necesite

___ Pagar por alguna otra cosa: _____

Por favor contáctenme vía: (Marque todas las opciones válidas)

Llámenme al número: _____

La mejor hora para encontrarme es: Mañana Tarde Noche Sábado Domingo

Mándenme un texto al número: _____

Mándenme un e-mail al correo electrónico: _____

Devuelva este formulario a: OR F2F HIC, 707 SW Gaines, Portland, OR 97239

El Centro de Información de Salud Familiar de la Familia de Oregón es un proyecto del Centro de Niños y Jóvenes de Oregon con Necesidades Especiales de Salud. Departamento de Salud y Servicios Humanos de los EE.UU. (Subvención # H84MC21658 / $ 94,800). Este contenido no debe ser interpretado como la posición o política oficial de, ni deben ser inferidos por la Universidad de Salud y Ciencias de Oregon, HRSA, HHS o el Gobierno de los Estados Unidos.

OHSU

Oregon Family to Family Health Information Center

Oregon Center for Children and Youth with Special Health Needs

I WOULD LIKE TO TALK WITH A PARENT PARTNER

I NEED INFORMATION ABOUT:

- ☐ my child's condition or disability
- ☐ what services are available for my child now or in the future
- ☐ how to get my child specific health services, such as therapies, dental care, mental health care
- ☐ managing transition when my child becomes a teenager or turns 18
- ☐ something else: _____

SUPPORT:

- ☐ to better communicate with my child's health care providers and therapists
- ☐ to speak one to one with another parent who has a child that is similar to mine
  - ☐ On the phone
  - ☐ At a support group in _____ zip code
  - ☐ Online
- ☐ to explain my child's disability to health care providers, family members, teachers or the community
- ☐ to know how to respond when others ask questions about my child's condition
- ☐ support for something else: _____

COMMUNITY SERVICES:

- ☐ locating a doctor, specialist, or dentist who understands my child's needs and our family
- ☐ finding community recreation for my child
- ☐ finding safe child care or respite for my child
- ☐ finding something else: _____

FINANCIAL HELP:

- ☐ paying for expenses such as food, housing, medical care, clothing, or transportation
- ☐ insurance, Oregon Health Plan, or other health care financing issue
- ☐ getting special equipment for my child's needs
- ☐ paying for therapy, day care, or other services my child needs
- ☐ paying for something else: _____

Please contact me/us via: (check all that apply)

- ☐ Call/text me at: _____

  Best time to reach me is: Morning | Afternoon | Evening | Saturday | Sunday

- ☐ Email me at: _____

Name: _____

FAX to: 503 494-2755 **OR** Scan and email to: _____ or contact@oregonfamilytofamily.org

OR mail to: *Oregon Family to Family Health Information Center c/o OCCYSHN –707 SW Gaines –Portland, OR 97239*

Please feel free to call us with any questions: 1-855-323-6744

The Oregon Family to Family Health Information Center is affiliated with the Oregon Center for Children and Youth with Special Health Needs, Oregon Health & Science University, and supported by the Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services (HHS). (Grant #H84MC21658/Family Professional Partnership/$95,700). This form is adapted from Milestones, Waltham, Massachusetts. (www.advancingmilestones.com)