Transition from Paediatric to Adult Health Care

POND Family Day
Yona Lunsky
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camh
Through the Eyes of Patients and Caregivers: Crystal Chin

Redefining Health Care spoke to a number of former patients and caregivers to ask for their view about care transitions.

Crystal was diagnosed with a neuromotor condition at eight months. She moved to Canada from Taiwan in her late childhood and received care in paediatric hospitals until she transitioned to adult care. Crystal has made significant contributions to improving health care delivery by ensuring that the patient voice is heard. She has worked with organizations, such as Holland Bloorview Kids Rehabilitation Hospital, Health Quality Ontario, The Change Foundation and

1. Can you describe an experience when you transitioned from one health care setting to another?

Transitions occur on a daily basis in all areas of life, and not just in health care. This process can frequently pose as a time of uncertainty. Our advancements in medicine and technology have allowed all of us to live longer, including individuals with congenital conditions and medical complexities, as well as individuals with chronic conditions who acquire other illnesses through the aging process. It is not enough to prepare youth and their families for these transitions along with a scattered number of sub-specialists and a few clinics throughout the country. It is essential to incorporate fundamental knowledge of childhood-onset conditions to equip current and future adult care providers throughout the health care system in understanding the needs of this population in order to plan and best assist the families and young adults who will inevitably graduate and transition into their professional practice. Yet, from my experience, there seems to be a lack of holistic integration in the adult system, which saddles the patient with all the responsibilities of sorting out logistics and coordinating care. It is impossible to anticipate these needs.
Navigating Adult Health Care
Your Child’s Needs

• Health navigation skills
• Health literacy
• Familiarity with health procedures
• Health advocacy (ask questions, give answers)
• My health story (know it well)
  • Paperback, hardcover, Kindle, graphic novel
  • 1st, 2nd and 3rd edition
I am Aldene.

“I am a proud member of a self advocacy group. “One day I was eating a peanut butter sandwich for lunch. The next thing I remember was waking up in a hospital bed with a tube down my throat. I was on life support for three days. They diagnosed a peanut allergy. The staff at the hospital took the time to teach me how to make sure it never happens again.”

GET TO KNOW ME

FACEBOOK.COM/HCARDDD
@HCARDDD
WWW.HCARDDD.CA

I am more than my disability.

I am Andrew.

“I enjoy acting and writing songs in my spare time. I have a great sense of humour. “Every year I need to get an echogram of my heart. One year the person was pressing really hard on my chest and it hurt very badly. I told him to stop but he didn’t. I ended up having to take the test over again because the results did not come out correctly. This next time it was done correctly and without pain.”

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I am Francie.

“I am a drama queen that loves acting and sports.”

“I like getting lots of support at the hospital. Family, friends and nice nurses and doctors make me feel good.”

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I am more than my disability.
People with a Disability and Caregivers

Health Passports and Communication Tools

Today’s Health Care Visit

The *Today’s Health Care Visit* is a worksheet you can use to write information down before a health care visit. Click on the picture to print the worksheet.

Having trouble reading the *Today’s Health Care Visit* pamphlet? Try the Large Print version instead!

About Me

The *About Me* is a helpful worksheet where you can write down important information about yourself and you can show it to the hospital staff. This worksheet includes your favourite food and drinks; things that help you to feel safe and relaxed; things that you don’t like; people that support you; your health conditions. Click on the picture below to download and print the worksheet.

Watch a Video

**Getting a blood test.** In this video Francie gives some great tips on how you can make it easier to get a blood test done.

**Going to the doctor.** In this video Andrew explains what happens at a doctor’s visit and why it is important to get a health check.

See all videos for people with developmental disabilities
Why am I here today?

Mark an ‘X’ next to your reason(s):

- I feel sick: ☐
- Something is wrong, but I don’t know what: ☐
- I am sad about something: ☐
- I am very angry: ☐
- I am in pain: ☐
- I’m nervous about being here: ☐

Please fill out:

- What happened?
- When did this start?
- Where does it hurt, or not feel well?

What do you think will help you feel better?

For Health Provider:

Commonly missed diagnoses in DD:
- Dental pain
- Constipation
- GERD
- Polypharmacy & side effects
- Sensory issues
- Ear infection

Common Social Stressors:
- Change in routine
- Change in worker
- Change in roommate
- Change in living situation
- Past trauma or abuse

Remember ABC:
All
Behaviour is
Communication
What is the behaviour trying to tell you?

How can you help me today?

My biggest fear about seeing Doctors and Nurses is:

- [Blank]

If I’m in pain, I show it by:

- [Blank]

If I get upset, I show it by:

- [Blank]

The best way to help me if I get upset is to:

- [Blank]

If you have to do a medical procedure (e.g., needle, x-ray), these things might help:

- [Blank]

Things that you can do to help me communicate:

Mark an ‘X’ next to the things that help.

- Speak Slowly: ☐
- Repeat things: ☐
- Let my caregiver explain: ☐
- Use Pictures: ☐
- Write it down: ☐
- Use simple language: ☐

Things I like:

- [Blank]

Things I don’t like:

- [Blank]

I have a crisis plan: yes ☐ no ☐

A crisis plan may include de-escalation techniques and interventions. Ask caregivers for this information.
The MedicAlert Autism Program
A new national program in partnership with Autism Canada.

AASPIRE Healthcare Toolkit for Patients & Supporters

Make a Personalized Accommodations Report for your healthcare provider.

This section also has information on:
- Healthcare
- Staying Healthy
- Your Rights in Healthcare
- Autism Information
- Medical Information
- Checklists and Worksheets
https://www.ambitiousaboutautism.org.uk/know-your-normal
What is ‘NORMAL’?

We want to help young people with autism identify their normal and understand when feeling different could be a sign of a mental health problem.

Visit ambitiousaboutautism.org.uk/nowyourownnormal for an invite to our launch keynote event.

#knowyourownnormal

https://www.ambitiousaboutautism.org.uk/now-you-your-normal
Your “Parent” Needs

• New model, get ready
• New role as support
• Onset of new problems
• New types of environments
• PLANNING SKILLS
• Sharing different editions of Health Story
• Parent support
Pay attention and be prepared....
Developmental Services Ontario: What you and your patients need to know

What is DSO?
- DSO helps adults with developmental disabilities and their caregivers connect with services and supports
- There are nine DSO agencies in Ontario
- Completes an application package and needs assessment
- Makes referral to adult developmental services and programs on your behalf

Developmental Services and Supports Access and Organized through DSO
- Community participation supports (e.g., work, recreation, passport funding)
- Residential supports (e.g., group homes, supported independent living)
- Caregiver respite services (in home and out of home)
- Person-directed planning supports (help adults with developmental disability develop their own vision and goals for their future)
- Specialized supports (e.g., service coordination, clinical services, case management)

These supports can be delivered one-on-one or in groups. More information may be found at http://www.developmental.ca/ (under “Developmental Services in Ontario”)

What will happen when your patient or their caregiver calls DSO?
- The call will be answered by a DSO worker who will talk about the supports and services needed. The DSO worker will:
  - Ask about the person with a developmental disability and their current situation
  - Provide information about services that might be of interest
  - Explain the process to go through that is required to be eligible for services funded by the Ministry

Who is eligible for DSO?
- Age: 18+ years to receive services, but can apply between 16-17 years
- Documentation confirming age (e.g., government issued ID like a health card, passport, birth certificate)
- Resident of Ontario
- Documentation confirming residency in Ontario (e.g., government issued ID like a health card, passport, birth certificate)
- Have a developmental disability
  - Documentation by a psychologist confirming adult eligibility criteria. Typically, this is the most recent psychological assessment you have available (e.g., psychological assessment completed during school years).
Mindfulness means putting the oxygen mask on yourself first: study

'We have to take care of ourselves,' says Toronto mother of son, 25, with autism

Muriel Draisma - CBC News - Posted: Apr 04, 2017 6:03 PM ET | Last Updated: April 5, 2017

Lee Steel, mother of a 25-year-old son with autism, says mindfulness taught her to put the focus back on herself. (CBC)

Before Lee Steel took mindfulness training, she sometimes felt like a cup filled to the brim.

If one more thing happened — one extra drop — the Toronto mother of an adult son with autism said she felt she would spill over.
Health care provider needs (in adult based care)

- “You’ve got this…”
- Think physical disability
- Think child
- Think geriatrics

And think about how different at the same time!

- Open learning attitude
- Know how to be part of a family-centered team
A Guideline for Transition from Paediatric to Adult Health Care for Youth with Special Needs
Primary care of adults with intellectual and developmental disabilities

2018 Canadian consensus guidelines

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Abstract

Objective To update the 2011 Canadian guidelines for primary care of adults with intellectual and developmental disabilities (IDD).

Methods Family physicians and other health professionals experienced in the care of people with IDD reviewed and synthesized recent empirical, ecosystem, expert, and experiential knowledge. A system was developed to grade the strength of recommendations.

Recommendations Adults with IDD are a heterogeneous group of patients and have health conditions and factors affecting their health that can vary in kind, manifestation, severity, or complexity from those of others in the community. They require approaches to care and interventions that are adapted to their needs. These guidelines provide advice regarding standards of care. References to clinical tools and other practical resources are incorporated. The approaches to care that are outlined here can be applied to other groups of patients that have impairments in cognitive, communicative, or other adaptive functioning.

Conclusion As primary care providers, family physicians play a vital role in promoting the health and well-being of adults with IDD. These guidelines can aid their decision making with patients and caregivers.
Life Transitions

ANTICIPATE TRANSITIONS
Proactively discuss the effects of anticipated transitions with patients, their caregivers, and other members of the health care team.\(^{44, 105, 106}\)

Strongly Recommended

RECOMMENDATION STRENGTH

TYPES OF KNOWLEDGE

BACKGROUND

PROACTIVELY ENGAGE SUPPORTS
Proactively engage psychosocial and spiritual supports (e.g., meditation, participation in a support group or faith community) to enhance resilience and coping skills of patients. Refer to a behaviour therapist or psychologist for interventions such as social skills training (see Psychosocial Context and Mental Well-being).\(^{108, 109}\)

Promote friendships and positive social networks.\(^{110}\)

Strongly Recommended

DDPCP website (Surrey Place)
Today’s Visit:

Problem that brought me to hospital:

Tests that hospital staff did:

What hospital staff found out:

What hospital staff did to help me:

Name(s) of ED staff member that I saw today: (MD, NP, SW, RN, etc.)

Additional Information for Primary Care:

Medications and Follow-up instructions:

Was a new medication prescribed? YES or NO

If Yes:
Medication: _______________________
I am to take this ___ times per day.  
I am to stay on this for ___ days
Reason prescribed: _______________________

Medication: _______________________
I am to take this ___ times per day.  
I am to stay on this for ___ days
Reason prescribed: _______________________

I should come back to hospital if:

This is someone at the hospital that me, or my caregivers can speak with to plan for any future emergencies:
Name: _______________________

Appointments

Were any other appointments made? YES or NO

If Yes,  
Name: _______________________
Appointment Location: _______________________
Reason for the referral: _______________________

Will they call me? YES or NO
If I should call them, their number is: _______________________
I should try to see my Family Doctor within ___ days.
FINAL THOUGHTS

Invest in the relationship with the primary care provider
Annual Health Checks
Team meetings
Different versions of the book, regularly updated
Mental health is health
Caring for the caregiver
Prepare for emergencies
Be open to learning together
A problem to be solved? Or a sunset to be appreciated?
Thank You

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H-CARDD program is www.hcardd.ca