Improving Emergency Care for adults with Developmental Disabilities:

A Toolkit for Providers

2016

www.hcardd.ca
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About this Toolkit

This Toolkit is an opportunity to share implementation tools with emergency providers who are interested in improving the care provided to patients with developmental disabilities (DD).

The resources included in this Toolkit can be used together, or as stand alone materials, depending on the needs, goals and existing resources in your hospital. We encourage you to use whichever pieces of this Toolkit feel appropriate for your site. We have made electronic versions of all materials available (www.hcardd.ca). Where available, we have included a modifiable version (usually in Microsoft Word), that can be downloaded, then further adapted for your site. We do ask that acknowledgment be given to the H-CARDD program. We envision that all the materials included in the Toolkit could be uploaded into EMRs as easy-to-access materials for paper-based practice settings.

About the H-CARDD Program

This toolkit has been prepared by the Health Care Access Research and Developmental Disabilities (H-CARDD) program. H-CARDD is a research program based in Ontario, Canada, and has been studying health care outcomes of adults with developmental disabilities (DD). Through this research, we have learned about the various health disparities adults with developmental disabilities face. From 2013 - 2016, H-CARDD received a grant from the Health Systems Research Fund to conduct implementation research. Accordingly, we focused our efforts on implementing a quality initiative with several Emergency Departments in Ontario. The goal of this work was to better understand how to identify patients with DD in the ED setting, and then learn about the most effective strategies to optimize their care.

Look for these quick reference symbols!

PowerPoint slide decks
Promotional material for your site
Staff engagement surveys
Implementation tools
Clinical tools or handouts for staff
Resources for patients with DD, and/or their caregivers
Videos
Why is it important to know whether in fact your patient meets medical or legal criteria for a developmental disability?

It matters in terms of which services the person maybe eligible for. It could matter in terms of strategies that would be most successful.

Suspecting a disability, even without confirmation can be a flag or trigger for you to make some modifications to your standard practice. If these modifications improve the care you provide and ultimately improve the health of your patient, that is what is most important. It is often not possible to make this determination in an emergency situation.

Key modifications when you suspect a developmental disability include:

- Providing information in clear and simple ways; ensuring their understanding of these instructions.
- Seeking input from collateral sources and not just relying on that person’s ability to self-report.
- Screening for additional health issues that are common in patients with developmental disabilities.
- Linking the patient with supports to help them with follow-up.

Bottom Line:

- Know your patient. Use a tool like “About Me” to elicit important information.
- Don’t be afraid to ask if there is a developmental disability.
- If you suspect an individual has a developmental disability and may not be receiving services, you can share information about Developmental Services Ontario (DSO).
- Remember that there are many individuals who have impaired cognitive and adaptive abilities who may not meet criteria for developmental disability. This means they can’t access certain services, but they can still benefit from accommodations.
- Never forget your role as advocate. If the services are not there yet to meet their needs, work with your patient and those around him or her to help make that happen.
Building Awareness in your site

Adults with developmental disabilities (DD) are likely to make up a small percentage of patients who visit your emergency department. But did you know that within Ontario, adults with DD are disproportionately high users of the emergency department? In fact, they use the ED more often than people with serious mental illnesses and adults older than 65 without DD.

We think that before an improvement initiative is put in place, it might help to pause and take a pulse of the awareness and receptivity among your colleagues towards any efforts targeted at patients with DD. The following are some resources to help get started:

- **Evidence Base** - PowerPoint slide deck. Use all or a few to share the evidence on health disparities among people with DD.

- **Sample Process Map** - This one page visual is a sample overview of the intervention.

- **Key Ingredients for a Successful Initiative** - We share some strategies, and encourage you to think of your own, unique to your site.

- **Staff engagement survey** - This survey includes questions about perceived comfort, skills, and attitudes, as well as baseline knowledge re: health issues of adults with DD, and existing resources. This could act as a baseline measure, if there is interest in capturing any pre-post data.

**Promotional materials**

- **Sample role descriptions and interdisciplinary opportunities** - This handout provides examples of interdisciplinary opportunities. This is not a prescriptive list, rather could be used as an example for tailoring, depending on the capacities and interest at your site.

- **Promotional Materials (“I Am” awareness campaign)** - This campaign was created for the H-CARDD project and features individuals with DD from Ontario describing their health care experiences. You can use these posters as a series or pick the ones that feel most compelling. They can be hung in the clinic, in the staff bathroom(!), or used in presentations. You can also invite patients from your community to participate in this initiative and create new posters.

- **DD and health posters** - This series of posters contains knowledge and information on common health issues related to adults with DD. These can be posted sequentially, or as a whole series. They could also be sent around in the body of an email as part of an awareness raising campaign.

- **Email campaign** - To keep your improvement initiative visible, we suggest that you consider consistent communication to your team. Consider images or bullets of information.

Screen Savers! Consider using any of these promotional materials as a screen saver for computers within your department. This can offer ongoing visibility and reminders to staff.
What the research says

Over the years, there has been a significant amount of research conducted in Ontario on the emergency department use of adults with Developmental Disabilities (DD). We have summarized a few key points here, and also prepared a PowerPoint presentation that can be used to build awareness in your site.

**Key Findings:**

1) **People with DD have very high rates of ED use.**
   - 50% of all adults with DD visit an ED in a 2-year period.
   - 3-4 times more likely to be frequent visitors.

2) **In addition to clinical need, lack of access to prevention and management supports predict why people with DD visit the ED.**

3) **Treatment in the ED is inadequate for many people with DD, and users report dissatisfaction.**
   - Caregivers not often consulted; follow up often not requested or coordinated.

**What does the Research Tell Us?**

- **PowerPoint presentation**
- **Video:** Emergency Department use among people with DD.
Improving emergency care for people with developmental disabilities

What does the research tell us?

1 in 2 adults with a DD will go to the ED

- Lack of respect
- Rights
- Forced procedures
- Treated for a different complaint
- Consent
- Not given opportunity
- Chemical and physical restraint
- Prior to alternative approaches

Lumsy & Gracey, 2009

Download the PowerPoint presentation here or at www.hcardd.ca
Example of an ED intervention for patients with Developmental Disabilities

1) Front-line staff are trained to look for signs of DD, as well as simple, non-threatening questions that can be asked to help identify a suspected DD. See *Screening section* in toolkit.
2) Agree on a term to document and communicate it to colleagues. This could be “DD” or “DD CARES” of “query DD”.

**Consider if you can develop an electronic or automatic prompt that “pushes” this information out.**

**Tips for medical and nursing staff** are provided at the point of care. Includes assessment strategies & commonly missed diagnoses (see *MD and RN Tip Sheets*)

**Tips for Social Work** are provided at the point of care. Includes info on community services and resources for pt/caregiver. (See *SW Tip Sheet*)

Staff employ adapted approaches when interviewing, assessing and treating the patient.

Social worker liaises with caregivers; may call upon specialized DD services to see if additional supports are available.

1) **Dear Dr. letter** is created. Ideally, it is shared electronically with Family Physician/Case Manager.
2) **Dear Patient letters** are shared with patient, provided a clear language summary. Further, and **EXIT INTERVIEW** (see Tool) can be completed w patient/caregiver to enhance follow up.
3) **Crisis Planning** is discussed, as are **tips for preparing for future emergencies** (by SW, RN, etc.).

*See electronic infrastructure tip sheet for ideas.*
Key Ingredients for Successful Implementation

1) **Find champions and build a team** - Who is passionate about this topic?

2) **Invite all team members** - Think about IT, clerical, custodial, nursing, medicine, allied health, etc. All staff will have experiences with people with DD, and should be encouraged to share improvement ideas.

3) **Build the case to your colleagues (and management)** - Use a real life example from your department and share some of the statistics on their high rates of ED use.

4) **Come up with a term that staff are comfortable using** - (and documenting) in the chart to easily convey the suspicion of a DD, and the sense that additional accommodations are needed.

5) **Embed the tools and resources into your existing practices where possible.**

6) **Remember your ABC’s** - *All Behaviour is Communication.* Learn about the commonly missed diagnoses and rule these out.

7) **Draw parallels to other (more prevalent) patient groups** - such as people with dementia.

8) **Seek out and involve caregivers.**

9) **Learn about the relevant services** - such as Developmental Services Ontario (DSO), and your local “Healthcare Facilitator” from the Community Networks of Specialized Care (CNSC).

10) **Celebrate the small wins and achievements!** Improvements take a long time - to keep the momentum going, applaud the team for its efforts along the way. Share success stories or important learning as you go.

What makes your ED unique? What do you foresee as strengths of the department? What are some challenges? How will you introduce this to your team? Who do you need on board?
Staff Engagement Survey

Developmental Disabilities (DD) in the ED

1. What is your role in the ED (e.g., RN, MD, NP, Registration, Resident, SW, Physician Assistant, Crisis Worker, etc.)?

2. In the last year, have you been involved in caring for a patient with a suspected DD? YES or NO

3. Are you aware of any strategies to help identify if a patient may have a DD? YES or NO
   If yes, please share any of these strategies: ___________________________

4. When caring for a patient with a suspected DD, how often do you: (1= never, 2=sometimes, 3= often)
   A. Document DD in the chart: 1 2 3
   B. Communicate the DD verbally to your colleagues (even if not the presenting problem): 1 2 3
   C. Check to see if noises, lights, smells, or touch can trigger challenging behavior: 1 2 3
   D. Seek out appropriate accommodations: 1 2 3
   E. Adapt your approach: 1 2 3
   F. Adapt your process at discharge (e.g., clearly explain what happened during visit & next steps, ensure patient is connected with services in the community, connect with caregivers): 1 2 3

5. Which of the following are examples of adapting your approach? (check all that apply)
   □ Lower your voice
   □ Consider body language
   □ Carefully explain procedures
   □ Ask patient/caregiver for helpful strategies
   □ All of the above

6. When caring for a patient with DD, do you feel:
   (1=strongly disagree; 2=disagree, 3=neutral, 4=agree, 5=strongly agree)

   | a. Comfortable discussing the individual’s disability with the patient or caregiver? | 1 2 3 4 5 |
   | b. Knowledgeable about comorbidities and care issues in DD? | 1 2 3 4 5 |
   | c. Familiar with community resources for people with DD? (e.g. developmental services, Community Networks of Specialized Care, funding opportunities like the RDSP or Passport Funding, etc.) | 1 2 3 4 5 |
   | d. Skilled in adapting your communication and approach to a person with DD? | 1 2 3 4 5 |
   | e. Equipped with proper resources to make desired accommodations? (e.g., time, | 1 2 3 4 5 |

7. Place an x next to the statement that most closely reflects your position toward improving care for patients with DD:
   □ Improving care for people with DD is important, but I’m not sure I have the time or resources to commit to it.
   □ I plan to be involved in implementing tools in our department.
   □ Our department does not need the initiative. People with DD already receive excellent care.
   □ I am already well connected and enthusiastic about the initiative and tools.

Thank you for your time.
## Sample Role Descriptions

<table>
<thead>
<tr>
<th>Role</th>
<th>Responsibilities</th>
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| **Triage**   | • Look for signs that a patient may have a developmental disability (DD); takes long to answer questions, trouble with paperwork, arrives with a caregiver/staff, not coping well in the community, presents with behavioural issues, repeat visitor for same issue.  
• If you suspect a DD, document this! You are not making a diagnosis, rather, communicating clinically relevant information and emphasizing the need for adapted approaches. Consider a patient alert for people with DD - a way to trigger this information for your colleagues. |
| **Clerical** | • Find out up-to-date caregiver/collateral information.  
• Many people with DD will be on social assistance. If so, look up their medication as you would for individuals over 65 (e.g. via Drug Profile Viewer).  
• If disruptive in the waiting room, alert a clinical team member. Suggest that the patient is relocated to a more quiet, less stimulating environment if at all possible. |
| **Nursing**  | • Screen for DD, in case it is missed at triage.  
• Adapt communication approaches; ensure patient is in as least-stimulating space as possible. Engage with their caregiver for strategies (signs of pain; underlying causes; behaviour change). Consider offering an About Me tool (found in this toolkit) to elicit helpful information.  
• Review list of commonly missed diagnoses |
| **Social Work** | • Contact Developmental Services Ontario (DSO) to see if the patient is connected to any developmental services. Ask for advice on crisis, transitional or respite services for this population. Ask for the Health Care Facilitator for the region. This person can help link with various sectors.  
• Offer short-term counseling to situational crisis, anxiety, etc.  
• Assess caregivers for burnout. Share resources on respite services.  
• Discuss crisis planning. Encourage that a plan is developed for next time. |
| **Medicine** | • Review list of commonly missed medical issues.  
• Adapt communication approaches; ensure patient is in as least-stimulating a space as possible. Engage with their caregiver for strategies (signs of pain; underlying causes; behaviour change)  
• Review list of commonly missed diagnoses.  
• Provide a clear language discharge summary to the patient. |
| **Pharmacy** | • Awareness of prescribing guidelines for patients with DD:  
  ◇ Psychotropic medication issues, Rapid Tranquilization  
  ◇ Compliance, appropriate use, medicine review, use of psychotropics. |
| **Information Technology** | • Is there a possibility of developing a patient alert? Can it trigger automatic referrals to SW? Can tip sheets be uploaded electronically and available to practitioners at the point of care? |
| **Mental Health** | • Share knowledge on specialized services for people with DD and mental health issues (dual diagnosis)  
• Provide resources on crisis planning, and encourage development of a plan. |
“I Am” Campaign: Voices of People with DD

I am Julian.
I am 25 years old. I belong to many clubs and enjoy having lots of friends. I love my life.

“At the doctor, I have a hard time explaining what’s wrong when I’m alone and that’s why I take my Mom or Dad with me.”

I am Francie.
I’m 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.”

I am Jenna-Joan.
Dancing and acting are my passions. I also love hanging out with my friends.

“I don’t get scared or nervous at the doctor’s because I have a great relationship with mine. They listen to me and that’s why I don’t want to switch.”

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.”
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

I am more than my disability.

Facebook.com/hcardd
@HCARDD
www.hcardd.ca

I am Terrence.

“I like to go to the library and read books.

“My doctor always does his best to help me. He cares.”

GET TO KNOW ME

I am more than my disability.

Facebook.com/hcardd
@HCARDD
www.hcardd.ca

I am Melanie.

“I love going to the movies and working with children.

“My family doctor takes the time to understand my concerns. She is a good and caring doctor.”

GET TO KNOW ME

I am more than my disability.

I am Mark.

“I do a lot of things, including photography.

“One I needed to get a brain scan. In the hospital, they did not tell me what to expect. They tied me to the bed so that I would not move during the procedure. I was only nine years old and scared. I will never forget it. Tell people what is going to happen and help them prepare for it. Please don’t let this happen to others.”

GET TO KNOW ME

I am more than my disability.
Developmental Disabilities in the ED

Complexities & Comorbidities

Ask & Adapt

Resources & Referrals

Exit Package

Safety & Support

Complexities & Comorbidities

Psychosocial
  - Stress caused by change of routine
  - Stress caused by social or situational anxiety
  - Change in behaviour caused by pain
  - Change in behaviour caused by anxiety

Medical
  - Epilepsy
  - Vision impairments/cataracts
  - Dental complications and disease
  - Hearing loss/ear infections
  - Cardiac disorders (e.g., MVP)
  - Respiratory disorders

Pain
  - Dental
  - Constipation
  - MSK Spasticity
  - Scoliosis

Ask & Adapt

Does anyone help you?

Do you have a job?

What changes can you make to your communication style and the environment?

Resources & Referrals

Check the ED portal for resources such as:
  - Health Watch Tables
  - Financial Resources
  - Pain Assessment

  - Medication use
  - Rapid Tranquilization
  - All about DD
Developmental Disabilities in the ED

**Exit Package**

The exit package includes a number of patient resources that may:

- better prepare patients for future visits
- improve communication and follow up at discharge

Exit package

About me

Crisis Plan

DDCARES Exit Package

Community Resources

Also includes:

- Financial Resources
- Griffith Centre
- Developmental Services Ontario

For more information check the ED portal or contact us at hcardd@camh.ca

Developmental Disabilities in the ED

**Safety & Support**

Working with patients with developmental DD can be challenging if staff do not feel equipped.

Work together with the family/caregivers to identify useful strategies to ensure safe and supportive interaction.

What techniques can you use to create a positive experience for both the patient and yourself?
Consider sending out these quick facts and figures as a way to foster awareness about the health disparities facing adults with developmental disabilities. Try one fact a week as part of a consistent communication and awareness raising campaign.

**Did you know?**

- Adults with developmental disabilities have higher rates of morbidity and are more likely to be diagnosed with a range of chronic diseases than other adults.

- Nearly one in two adults with developmental disabilities has a mental illness or addiction.

- Approximately one in five adults with developmental disabilities are prescribed 5 or more medications at once. Antipsychotics are the most commonly prescribed medication.

- Adults with developmental disabilities present with frailty issues 30 years younger than adults without developmental disabilities.

- Compared to the general population, adults with developmental disabilities are more likely to:
  - Present to the ED
  - Present repeatedly to the ED
  - Have preventable hospitalizations
  - Have repeat hospitalizations

- Compared to the general population, adults with developmental disabilities are less likely to:
  - Be screened for breast, colon, & cervical cancer
  - Receive guideline-recommended interprofessional care.

(from H-CARDD Snapshots, to learn more go to Knowledge Exchange —> H-CARDD Snapshots at www.hcardd.ca)
Video: Improving Emergency Care for People with DD

https://www.porticonetwork.ca/web/hcardd/special-topics/emergency-care

Use of emergency room services by patients with developmental disabilities. Every 1 in 2 adults with developmental disabilities is going to the emergency department at least once in a two year period. Yona Lunsy explains this research and talks about how to prevent these visits and plan for next time.

https://www.porticonetwork.ca/web/hcardd/resources/videos/research

These videos are available at www.hcardd.ca under the “Knowledge Exchange” —> “Videos” tab.
Identifying your patients + alerting the team

Before improved care can occur, patients with developmental disabilities (DD) 1) need to be identified. Then, 2) their disability (even if just suspected) needs to be documented and communicated to colleagues.

It is likely that team members may be able to readily identify many of the patients with DD who come to your ED. This is excellent! There remains a good chance, however, that there could still be patients that are easily missed, lesser known or newer to us, whose DD is not easily identifiable. We may not know “for sure” so, we don’t say anything. These patients, not surprisingly, may be more likely to fall through the cracks. This leads into the need for documentation.

Depending on the comfort of the staff members, there could be variation in how the disability is recorded, which could pose some challenges for a streamlined identification process. We have found that a common concern among ED stuff is the worry of ‘labeling’ or stigmatizing a patient by documenting that they suspect a DD, when it is not visible or offered up by the patient/caregiver themselves.

We understand this concern, but we encourage you to think of this as clinically relevant information. You are not making a diagnosis, you are not patronizing the individual; you are communicating to your team that you suspect there are some intellectual or functional limitations and that an adapted approach may be helpful.

The following resources offer some assistance on signs to look for, and questions to ask if you aren’t sure if a person has a DD or not.

**Screening for DD** - This is a screening tool that grew out of our implementation work, as we learned that there were many patients whose functional presentation suggested the possibility of a developmental disability. This quick-to-use guide includes clinical signs and symptoms, as well as interview questions you could ask a patient. This is not a diagnostic tool.

**About Me** - This is a patient tool (modified from other patient ‘passports’) and could be offered in the waiting room with signage encouraging people with DD to complete. If a patient/caregiver fills this out, it is likely to be a sign that they are seeking out additional assistance. Plus, this prompts them to provide tips and strategies to enhance their care. Attach it to the chart and you’re already ahead of the game!

**Electronic Solutions for tracking your patients visit-to-visit** - This is a handout that offers suggestions on how to incorporate a flagging system into the chart to then ‘push’ out clinical tip sheets to your colleagues.
Screening for Developmental Disability

Observations to look out for:

- Slow response time
- Difficulty filling out forms/paperwork
- Repeat visits for same issue(s)
- Difficulty following instructions
- Difficulty with basic math, telling time
- Chronic social or legal troubles
- Concrete/literal thinking
- Difficulty rephrasing information
- Frequently misses follow-up
- Gaps in daytime activity

Questions to ask:

- **Education level:** Can you tell me about school? How old were you when you left? (People with DD can stay until 21) Were you ever in a separate class? Did you ever find school hard?

- **Day time activity:** How do you spend your days? (look for volunteering, social programming/day programming, lack of work, boredom). If working, “Do you receive any help in your job?”

- **Functional abilities:** Ask the patient to tell the time. Check their literacy - for example, point to a sign and ask them to read; Are they able to complete requisite paperwork? Ask about navigating community (how did they get here; how will they get home, etc.)

- **Support level:** Can you tell me about where you live? Do you live with anyone else (look for roommates, workers, boarding/group home) Do you have a case manager? Would you like one? Have you ever been involved with any developmental agencies? Could we call the DSO (Developmental Services Ontario) to see if they can help? (Can ask if registered, 1-855-372-3858, or go to the DSO website, [www.dsontario.ca](http://www.dsontario.ca)).
About Me: Patient Communication Tool

*To Download, please click the images

About Me:
My Health Information

My Information:

- My name:
- My birthday: Month Day Year
- My address:
- My phone number:

Other Information:

- I receive ODSPI: yes no
- I live (choose one): in my own house/apt with family group home
- Who to call for help:
  - Name:
  - Phone number:
  - Relationship to me:
  - My family doctor:

For staff: *medication and allergy information on back page

Other Information About Me

Things that I liked to do to feel good:

Information about my medications:

Allergies:
- What I am allergic to:
- What happens to me:

Patients/Caregivers: If you would like to provide feedback on how you used this tool, please contact the 02 CARES team at: ddcare@cmh.ca

How can you help me today?

My biggest fear about going to see Doctors and Nurses is:

- If I’m in pain, I show it by:
- If I get upset, I show it by:

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

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

- 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:

I have a crisis plan: yes no

A crisis plan may include de-escalation techniques and interventions. Ask caregivers for this information

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:

What happened?

When did this start?

Where does it hurt, or not feel well?

What do you think will help me feel better?

For Staff

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?
Because adults with DD may not be a prevalent population that you serve, a range of 1 pager clinical tools are available to assist in the provision of care when they come in. We encourage sites to embed these into existing care processes as much as possible to optimize their use.

**Head-to-Toe assessment (commonly missed diagnoses in DD)** - We know that adults with DD have particular health needs. We also know that there are underlying medical issues that may be missed – particularly when an individual presents in a state of crisis. This resource, developed by Dr. Liz Grier, provides a 1 page guide of what to look for when doing a head-to-toe and you wish to look beyond your usual assessment.

**MD Tip Sheet** - This is a 1 page highlight of tips, made by an MD, for other MDs.

**RN Tip Sheet** - This is a 1 page summary of highlights relevant to nursing staff.

**Social Work Tip Sheet** - This is a 1 page summary on the ways in which Social Workers can support people with DD, in the emergency department.

**Developmental Services Ontario** - Provides an overview of what the DSO is and gives contact information for the 9 DSO sites.

**Environmental Adaptations** - This provides considerations and strategies on how small changes to the setting and environment can have a major impact on someone with DD.

**Rapid Tranquilization** - Prepared by the Developmental Disabilities Primary Care Initiative, this 5-page resource provides invaluable recommendations on the use of psychotropics for the purpose of rapid tranquilization and sedation.

**Educational Videos** - These brief instructional videos review 3 commonly encountered scenarios in the ED involving patients with DD. Do’s and Don’ts are provided.

- The Aggressive Patient
- The Frequent Visitor
- The Difficult Blood Draw

**Tip Cards** - These cards can be screensavers, laminated as full size, or printed as cue cards.
Commonly Missed Diagnoses: Head-to-Toe Assessment

**H** Headache and other pain, or Hydrocephalus related issue (ex. Shunt blockage)

**E** Epilepsy

**A** Aspiration pneumonia or dysphagia

**D** Drugs! Patients are at high risk for adverse effects or polypharmacy.

*Have a follow up plan if prescribing psychotropics!*

**T** Teeth! Dental abscesses or impacted teeth can cause pain, aggressive behavior, food refusal

**O** Ocular or Otolaryngology issue – Vision problem, Hearing issue, Obstructive Sleep Apnea (up to 80%)

**T** Tummy – GERD, Constipation, Bowel obstruction and volvulus

**O** Osteoporosis and atypical fractures, pressure sores

**E** Etiology or cause of IDD - is it known? – some genetic syndromes have important acute presentations
(ex. Calcium disturbance in William’s Syndrome)

**S** Serious illness can present atypically – ask caregivers how this patient expresses pain.

Is there a subtle sign that they are very ill?

**S** Screen for abuse

All Behaviour is Communication!

- Listen to Caregivers
- Ensure access (reduce noise, fluorescent light)
- Link – ask about community supports
- Look for a Care Plan
- Wallet sized Health Passport

Do you suspect a patient you are seeing has developmental disability but has not been identified? Refer to Developmental Services Ontario!

(Do you think your patient might benefit from a Coordinated Care Plan because of their complex health needs and repeated visits to hospital? Refer to “Health Links”.)
For some patients with DD, their MEDS LIST is available from ODSP even if they are under 65.

Ask “how is their current behavior compared to baseline”?

PAIN often presents as CHANGE IN BEHAVIOUR.
   ○ Think “ABC”:

All Behaviour is Communication

- Commonly missed diagnosis/physical findings:
  - Bowel obstruction
  - Constipation
  - Abdominal Sepsis
  - Cerumen impaction
  - Dental sores, caries, abscesses

- Sensory hypersensitivity is common:
  ○ Lights, noises, smell, touch, may lead to behavioural change.

- Hearing and vision are often impaired. Ask GEM RN for a “Communikit” (communication aids).

- Body language is critical! Slow down, lower your voice, and adjust your approach - it will improve the visit.

- Most people with DD will have experienced trauma/abuse in their past.
If the patient is on ODSP (income supports), their medication information is accessible through the ODB Drug Viewer

*(even if they are under 65)*

Pain often manifests in aggressive or altered behavior. Think “ABC”:

**All Behaviour is Communication**

Life changes may lead to an ED visit

- New roommate, change in worker, death of friend, etc.

Sensory hypersensitivity is common:

- Lights, noises, smell, touch, may lead to behavioural change.

The patient may have experienced abuse or trauma in their past (prevalence rates in DD are upwards of 90%). This person may be afraid of the hospital, or have fears of undergoing procedures.

- E.g. bloodwork, IV lines, x-rays, internal exams etc.
  - How can these be adapted?

Supportive body language, voice and rapport will help.

Hearing and vision can often be impaired. Ask about accommodations, or how you can help.
Some tips for SW include:

• Statistically speaking, most people with DD function in the “mild” range – some people equate this to an age equivalent that is similar to a 9-12 year old. However, people will have various areas of strength. Always try to involve the patient as much as possible.

• People with DD may have lower rates of comprehension. Asking the person to repeat/explain in their own words can often highlight these gaps. Sometimes this is referred to as “the cloak of competence”. A person may be more conversant, and appear as though they are following along, when in reality they are struggling. When left undetected, this can result in poor history provided, and missed follow up.

• Whenever possible, it is important to take the time to get collateral information. Individuals with developmental disabilities may not be the best historians and having a second perspective can be very helpful in understanding the presenting issue and making treatment decisions.

• If you are not able to connect with or locate a caregiver, the DSO (Developmental Services Ontario), may be able to share with you which agencies (if any) the person is connected to. The DSO is the gatekeeper to developmental services (See Developmental Services Ontario: What you and your patients need to know).

• People with DD have extremely high rates of trauma/abuse - they may be afraid of hospital, or escalate when feeling unsafe. A trauma-informed approach is always recommended for people with DD. Try to find out what calms the person (likes/dislikes) and any triggers that they may have.

• People will DD are commonly very sensitive to change (no matter how big or small). Difficulty coping is a precipitant of many ED visits.

• Ask if the patient (or caregivers) has a Crisis Plan. If not, this may be something to introduce prior to discharge. A template is available here.

• Prior to discharge, offer to complete an Exit Interview with the patient. This may improve continuity and prevent a repeat visit by reviewing in clear language today’s visit and any follow-up.
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 Accessed 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.dsontario.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 16-18 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).
How does my patient apply for DSO?

Contact the local DSO to confirm if they are eligible for DSO services or encourage them to contact DSO as part of follow-up.

<table>
<thead>
<tr>
<th>Region</th>
<th>Email</th>
<th>Phone</th>
<th>Fax</th>
</tr>
</thead>
<tbody>
<tr>
<td>Central East</td>
<td><a href="mailto:dsocentraleast@yssn.ca">dsocentraleast@yssn.ca</a></td>
<td>905-953-0796</td>
<td>905-952-2077</td>
</tr>
<tr>
<td></td>
<td></td>
<td>1-855-277-2121</td>
<td></td>
</tr>
<tr>
<td>Central West</td>
<td><a href="mailto:dso@dsocwr.com">dso@dsocwr.com</a></td>
<td>1-888-941-1121</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Dufferin: 519-821-5716</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Halton: 905-876-1373</td>
<td></td>
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<tr>
<td></td>
<td></td>
<td>Peel: 905-453-2747</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Waterloo: 519-741-1121</td>
<td></td>
</tr>
<tr>
<td>East</td>
<td><a href="mailto:admin@dsoer.ca">admin@dsoer.ca</a></td>
<td>1-855-376-3737</td>
<td>1-855-858-3737</td>
</tr>
<tr>
<td>Hamilton-Niagara</td>
<td><a href="mailto:info@dsohr.ca">info@dsohr.ca</a></td>
<td>1-877-376-4674</td>
<td></td>
</tr>
<tr>
<td>North East</td>
<td><a href="mailto:dso@handstfhn.ca">dso@handstfhn.ca</a></td>
<td>1-855-376-6376</td>
<td>705-495-1373</td>
</tr>
<tr>
<td>Northern</td>
<td><a href="mailto:info@lcctbay.org">info@lcctbay.org</a></td>
<td>1-855-376-6673</td>
<td>1-807-346-8713</td>
</tr>
<tr>
<td>South East</td>
<td><a href="mailto:esteele@dsoser.com">esteele@dsoser.com</a></td>
<td>1-855-237-6737</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>1-613-354-7977</td>
<td></td>
</tr>
<tr>
<td>South West</td>
<td><a href="mailto:maryregan@dsoswr.ca">maryregan@dsoswr.ca</a></td>
<td>1-855-437-6797</td>
<td>519-673-1509</td>
</tr>
<tr>
<td>Toronto</td>
<td><a href="mailto:DSOTR@surreyplace.on.ca">DSOTR@surreyplace.on.ca</a></td>
<td>1-855-372-3858</td>
<td></td>
</tr>
<tr>
<td></td>
<td><a href="http://www.dsotoronto.com">www.dsotoronto.com</a></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

We would like to acknowledge the DSO website (http://www.dsontario.ca/), DSO Central West Region, and DSO Central East Region for providing information on this handout.
Communication Tips for patients with Developmental Disabilities

**General Strategies:**
- Familiarity helps: seek out someone who the patient knows, and is comfortable with. Do inquire about caregiver stress/burnout.
- Ask for strategies and tips - what do they find helpful? Should I write things down? Use technology?
- Encourage the use of ‘comforters’ - items or activities they find soothing (favourite item, music, phone, doll, food/snack, etc.)
- Try to find a quiet spot without too many distractions (isolation room?) (vision and hearing deficits)
- Use simple words, and speak slowly. Give pauses and allow extra time for processing. Do not shout.
- Use a Tell, then Show, then Do approach - pausing in between each step to help build readiness.
- Be extra mindful of your non-verbals and body language. Many people with DD have experiences of trauma - they could be very afraid of the hospital, so extra sensitivity can help.
- Use visuals - gestures, or drawings, when possible.
- Give ongoing positive praise and encouragement, after even the smallest of steps.

**Behavioural Concerns?**
- What is the behavior trying to tell us? (Pain? Unmet need? Attention? Sensory loss? Avoidance?)
- How is today’s presentation (*behavior) different from baseline? How long has this been going on for? What has helped in the past? What are you currently trying?
  - Pain: How do we know when the person is in pain?
  - Commonly missed medical causes:
    - Dental Pain;
    - Constipation/obstruction;
    - Infection;
    - Cerumen impaction;
    - Abdominal sepsis
  - Environment: Have there been any changes to supports? Occupational issues?
  - Emotional needs: Recent life changes/losses? Bullying? Vulnerabilities? Triggering anniversary?
  - Is there a known psychiatric disorder?

**Maximizing Comprehension, Optimizing Discharge**
- Ask the patient to rephrase in their own words to assess their understanding
- Give simple written information, with concrete next steps to help summarize and improve follow-up
Environmental Adaptations

The emergency department is a fast-paced, loud, and overstimulating environment. This will be overwhelming for most of us—especially so for people with DD. How can your environment be adapted to better support people with disabilities?

- Quiet space: Can the patient (and caregivers) be offered a quiet/adapted space? In some settings, there may be a space already dedicated for such a purpose, but if not, the following are considerations:
  - An isolation or infection control room (remembering you will be using this just temporarily)
  - A mental health interviewing room
  - A corner room
  - If no rooms are available, a bed that is further from hallways or nursing station may provide a slight reduction in stimuli.

- Turn off any non-essential monitoring equipment

- Fluorescent lighting can be distracting or irritating. Is it possible to dim the lights in the patient’s area? Or turn off? If not, a pair of sunglasses may be beneficial.

- Limit the number of different team members going in and out of the patient’s space. Consistency is always best if this this possible.

- Encourage caregivers to remain present for testing and imaging. Ask them about what has helped (or not helped) in the past.

- Sit at eye level.

- Use a show-tell-do approach. Show the patient the instrument or procedure you will use, allowing the to touch/explore it; describe the steps involved, and what can be expected; then proceed.

- Consider a Sensory Box that is offered to patients. This can include very simple items that may go a long way in soothing, calming or distracting a patient while they are waiting, and during care/assessment:
  - Squishy balls
  - Fidgets
  - Noise reducing headphones
  - Sunglasses
  - Brush
  - Weighted lap pad/blanket

- Have coloring books, playing cards on hand.
# Rapid Tranquillization of Adults with Crisis Behaviours

This tool was developed to help primary care providers in community and Emergency Department settings whose patients with DD are exhibiting crisis behaviours and require rapid tranquilization.

## TABLE 1: GOALS AND CONSIDERATIONS IN RAPID TRANQUILLIZATION OF ADULTS WITH DD

<table>
<thead>
<tr>
<th>Specific Considerations regarding Psychotropic Medications for Adults with DD</th>
<th>Initial treatment</th>
</tr>
</thead>
</table>
| • Should guide management decisions, including in crisis situations.  
• Often on multiple medications and at increased risk of adverse medication interactions.  
• Some may have atypical responses or side-effects at lower doses, and some cannot describe harmful or distressing effects of the medications that they are taking.  
• Adults with DD associated with Autism Spectrum Disorders (ASD), about 30% of adults with DD, may react paradoxically to new psychotropic medications (e.g., when given a benzodiazepine, they may become agitated rather than sedated).  
• When considering psychotropic medications for adults with DD it is important to elicit their history with such medications and the patient’s or caregivers preferences. | • Use a single medication initially, preferably a benzodiazepine at a sufficient dose (e.g., lorazepam 4 mg), and wait the indicated time prior to repeating the dose. Experienced Emergency Department psychiatrists who work with adults with DD report that most crisis behaviours can be managed with 10 mg or less of lorazepam. This is preferable when effective, as it avoids the distressing side effects that often accompany antipsychotics.  
• Given that antipsychotic medications are often inappropriately prescribed for adults with DD, reducing the exposure of adults with DD exhibiting crisis behaviours to these medications would help to mitigate this problem. |

“The Aggressive Patient”
An agitated young man was brought to the Emergency department by police. In the first scenario the situation quickly escalates. In the improved practice, the young man is calmed and the underlying "cause" of the agitation is better understood.

“The Frequent Visitor”
A man with Down Syndrome in the emergency department has returned after having several previous visits because of stress at home. The improved practice segment of this video illustrates how hospital and community can work together to prevent unnecessary repeat visits. Tools are provided to connect with caregivers about crisis planning.

“The Difficult Blood draw”
An anxious young woman with Down syndrome is getting her blood drawn in hospital. In the first scenario, the nurse cannot get the blood drawn at all. In the improved practice, strategies to improve her care experience include explaining before doing, encouraging her to seek support from her sister, and sharing the "About Me" patient communication tool.

The HCARDD program encourages you to visit the excellent teaching resources available at http://machealth.ca/programs/curriculum_of_caring/. The Curriculum of Caring is focused on helping health care professionals and trainees to effectively care for people affected by developmental disabilities and includes teaching scenario in the emergency department.
Adapting clinical approaches

Resources for Patients and Caregivers:

These are materials prepared specifically for patients with developmental disabilities, and their caregivers. We encourage EDs to integrate these into the care that is provided. Some materials can be given out as information, whereas others can be used during the visit to foster communication and understanding.

About Me: My Emergency Department Visit - If not completed during this visit, hand it out and encourage the patient complete and bring with them next time. It will help staff to know about the person!

My Exit Interview - This is to be completed by an SW/RN/MD with the patient. It contains prompts for you to summarize the visit and follow up in a clear and simple way to optimize patient involvement and understanding.

Going to the Emergency Department: A Social Story - A social story is a person-centred telling of ‘what to expect’. These can help prepare an anxious or curious patient. This is a general version that you can download and modify to your setting.

Getting a Blood Test: A Social Story - Bloodwork can be an anxiety-provoking experience for people with DD. This social story is meant to help patients understand the purpose of a blood test, and what they can expect. Review this with patients, and encourage any questions. This is a general version that you can download and modify to your setting.

Getting More Money - Most people with DD experience poverty which will impact their health. This handout is written in clear language for people with DD/caregivers and explains some of the financial programs that they may be eligible for.

Videos for patients and their caregivers

Helpful Websites - Print this out as a handout that provides a simple listing of website designed for people with DD, focused on healthy living.
# About Me: Get to know me!

*To Download, please click the images*

## About Me: My Health Information

### My Information:
- **My name:**
- **My birthday:** Month ____ Day ____ Year ____
- **My address:**
- **My phone number:**

### Other Information:
- **I receive ODSP:** yes ____ no ____
- **I live:** (choose one) in my own house/apt _____ with family ____ group home __________
- **Who to call for help:**
  - Name:
  - Phone number:
  - Relationship to me:
  - My family doctor:

*For Stuff: Medication and allergy information on back page*

## 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?**

## How can you help me today?

- **My biggest fear about seeing doctors and nurses is:**
- If I’m in pain, I show it by:
- If I get upset, I show it by:
- The best way to help me if I get upset is to:
- If you have to do a medical procedure (e.g., needle, x-ray), these things might help:

### 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:

### Things I don't like:

- I have a crisis plan: yes ____ no ____

A crisis plan may include de-escalation techniques and interventions. Ask caregivers for this information.

---

For the Large Print Version, click here.
Today’s ER Visit:

My Exit Interview

A summary of today’s visit, to improve continuity of care.

Name: __________________________
Date: __________________________
Hospital: _______________________

For ED Staff:
- Note and discuss the visit and next steps in clear language with the patient.
- Ask them to repeat or rephrase in case they misunderstood.
- Has this led to increased understanding of community services if at all possible.

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 ______ time 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 I, 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.

Notes: (Include strategies that were helpful for today, recommendations for follow up, considerations for future planning, etc.)

CAMH, 2013
I have to go the emergency room at the hospital.

Going to the hospital will help me feel better.

You can download, modify and print the rest of the Social story at www.hcardd.ca.
Getting a Blood Test

I have to get a blood test!

A blood test helps the doctor know that I am healthy.

A blood test can also help the doctor to know if something is wrong.

You can also watch a video!

Hcardd.ca —> Knowledge Exchange —> Videos —> For People with Developmental Disabilities
Getting More Money

*To Download, please click the images

Getting extra money
Learn about how you can get more money.

ODSP
Ontario Disability Support Program
This is money from the government for people with disabilities. A doctor will need to complete papers that explain to the government that you have a disability and that you need some help.

To get your ODSP forms, you have to go to an ODSP office. If you call 2-1-1, they can help you find the closest ODSP office. Then, bring the forms to your doctor.

Everyone on ODSP has:
- Extra forms can help some people pay for other things, like:
  - Medications.
  - Eye exam every 2 years.
  - Eyeglasses every 3 years.
  - Dentist care.
  - Use the drug and dental card you get each month.

If you decide you would like to start working, contact your ODSP worker. They can help you!

Services
Services are money that your caregivers can use to pay for someone to go stay with someone else if the break is needed.

Disability Tax Credit
You can apply for this when you do your taxes. This form ("T2201") may help you get more money back from the government in your taxes. There are 2 parts: one that you fill out (Part A) and one that your doctor fills out (Part B). Bring the form to your doctor's office.

www.rdsp.com

Henson Trust
Another way that family can save money for you. It's best they speak to a bank about this!

For the Large Print Version, click here.

Download and print at www.hcardd.ca
When printing, item needs to be printed double sided with "flip on short edge" to maintain booklet style.
A talk about health. This brief video clip with Yona Lusky walks through what happens when you visit the emergency department with some tips on how to make the most of the visit. This video is designed for use for people with developmental disability and their families.

What to expect when you go to the ER? This brief video clip with Yona Lusky walks through what happens when you visit the emergency department with some tips on how to make the most of the visit. This video is designed for use for people with developmental disability and their families.

Getting a blood test?

www.hcardd.ca —> Knowledge Exchange —> Videos —> For People with Developmental Disabilities
## Helpful Websites about Health and DD

<table>
<thead>
<tr>
<th>Website</th>
<th>URL</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Easy Health</strong></td>
<td><a href="http://www.easyhealth.org.uk">www.easyhealth.org.uk</a></td>
<td>This website is from England. It has a lot of videos and handouts about health! It covers so many topics, and is made for people with disabilities. It is a very helpful website!</td>
</tr>
<tr>
<td><strong>ConnectAbility</strong></td>
<td><a href="http://www.connectability.ca">www.connectability.ca</a></td>
<td>This website has lots of information for people with disabilities and our friends and family. It has ideas on how to get services, and has a space where you can type in questions to ask other people.</td>
</tr>
<tr>
<td><strong>Developmental Services Ontario (DSO)</strong></td>
<td><a href="http://www.dsontario.ca">www.dsontario.ca</a></td>
<td>The DSO is the place to call to see so that your name can be added to waiting lists for things like day programs, a support worker, or extra money (called “Passport”). The DSO website has lots of information. You can also call them. Their phone number is 1-855-372-3858.</td>
</tr>
<tr>
<td><strong>Magnusmode!</strong></td>
<td><a href="http://www.magnusmode.com">www.magnusmode.com</a></td>
<td>Magnusmode is an “app” (like a game!) that teaches people about different things—like, going to the doctor, going to the dentist, going to the emergency room (and fun things too!). Magnus is the boy’s name in the game, and your job is to learn new things with Magnus and earn coins along the way.</td>
</tr>
<tr>
<td><strong>H-CARDD</strong></td>
<td><a href="http://www.hcardd.ca">www.hcardd.ca</a></td>
<td>H-CARDD is a website about research. There is lots of information on this website. There is a section that is made just for people with disabilities, and includes handouts and videos about health!</td>
</tr>
</tbody>
</table>
Enhancing discharge information & preventing future emergencies

Exit Interview - This is an example of a patient friendly discharge summary. This is completed by hand, with the patient present. This will take additional time, but the hope is that the upfront investment will support the patient in planning their follow up from today’s visit. This closely mirrors a ‘patient friendly discharge summary’ which you may already have. The difference is that this would be actively completed with the patient.

Preparing for future emergencies

- Checklist for patients and caregivers
- Crisis Planning - preventing a future emergency
My Exit Interview: A *patient-centred discharge plan*

*To Download, please click the images*

**Today’s ER Visit:**

**My Exit Interview**

A summary of today’s visit, to improve continuity of care.

Name: __________________________

Date: __________________________

Hospital: __________________________

**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 I, 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.

**Notes:** (Include strategies that were helpful for today, recommendations for follow-up, considerations for future planning, etc.)

**Patients/Caregivers:**

If you would like to provide feedback on this tool, please contact us at dkaress@camh.ca. We would love to hear from you!

CAMH, 2013

For the Large Print Version, click here.
Preparing for Future Emergencies
- Checklist for Patients & Caregivers

☐ **Identification or Health Card:** The hospital will need to know your name, address, how old you are and where you live.

☐ **Crisis Plan:** If you already have a crisis plan, bring this with you to the hospital. This will have information that you can give to the hospital staff that will tell them how they can help you in an emergency.

☐ If you don’t have a crisis plan, you can still tell the hospital about ways that they can help you. You can also tell them things you do NOT like, or what you are afraid of. The hospital might not remember to ask you this, so it is important that you remember to tell them.

☐ **List of Medications:** What medications are you taking and how much of it? You can print this off from your pharmacist. Or, if you get ODSP money, let the hospital know. They can then look up your list of medications in the computer.

☐ **Name of your family doctor:** Write down the name of your family doctor – and anyone else that helps you.

☐ **List of all your health problems:** This information will help the doctors understand what is wrong and how to make you feel better.

☐ **Food and Drink:** You may have to wait for a very long time. Take your favourite food and a drink so you can eat it if you get hungry.

☐ **Activities to do while you wait** You may have to wait for a very long time, take activities to keep you comfortable while you wait (your favourite music, pictures, books).

☐ **Comforters:** Bring something that makes you feel safe and comfortable. Things like a favourite blanket, shoes, stuffed animal, etc.
A crisis plan is a recommended tool for individuals with DD and their caregivers to complete. The lack of an effective crisis plan is a known precipitant of ED visits. For this reason, it may be beneficial to ask patients if they have a crisis plan, and if not, offer them a crisis planning package.

A crisis plan consists of 4 stages:
1) Prevention strategies
2) Signs of escalation & how to help
3) Crisis—how to respond
4) Post-crisis follow-up

The Developmental Disabilities Primary Care Initiative has prepared information on crisis planning, included a template, with examples. It is available for free download on their website. Screenshots are below.
Clinical Guidelines

Research Papers


