

Planning for a Caregiver in Crisis

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Presented by: Family Service Toronto

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For People For Change
FAMILY SERVICE TORONTO



United Way
Greater Toronto



Objectives

Have information prepared so that other people can step into the caregiving role

Have tools to create a plan for what happens should you not be able to be primary caregiver for a short period of time

Have the contact information for formal/ professional supports who you can contact

Agenda

Case example

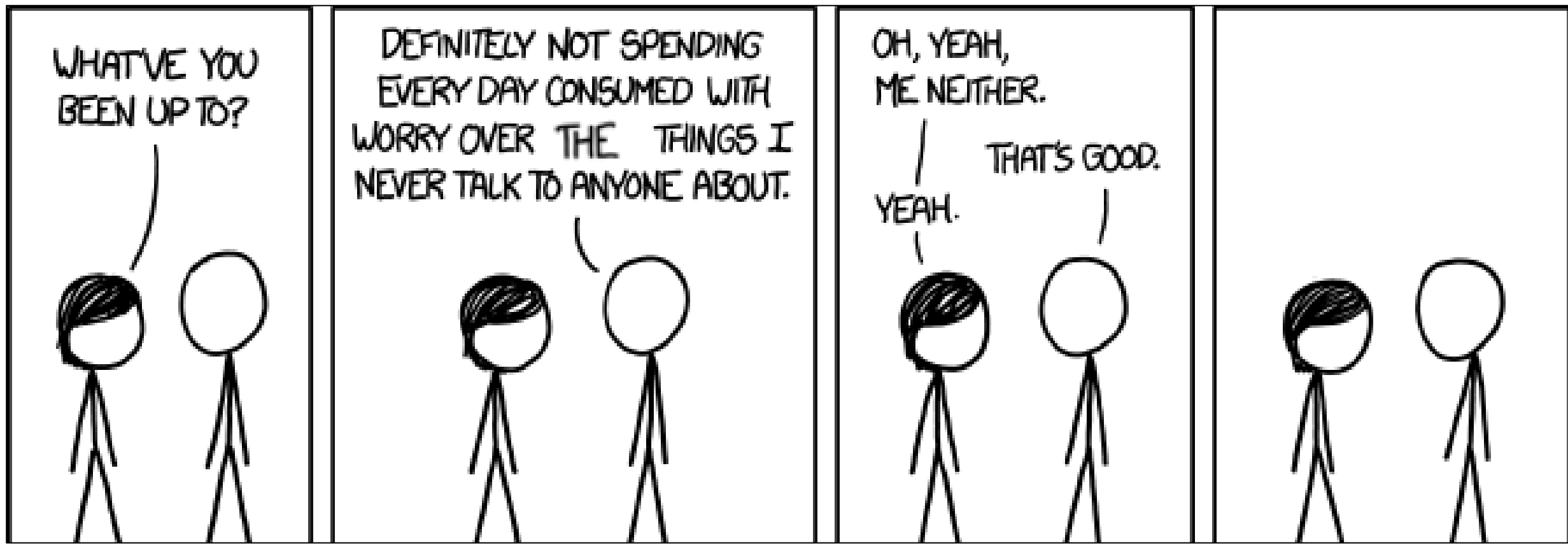
Preparing for an emergency

What to do during an emergency

Follow-up after an emergency

Additional tips

Case example: Resolution



It's okay to be worried.

Case Example

Amir is 35-years-old and is diagnosed with severe autism and a moderate-severe intellectual disability. Amir does not communicate verbally but can make some choices from a picture board. He requires support with almost all activities of daily living. He cannot be left unsupervised. Amir lives in a Toronto apartment with his mother, Sonia. Sonia and Amir do not have any close family living in Canada. Sonia has a couple friends, but none that could care for Amir.

One evening, Sonia begins feeling very unwell and she needs to be taken to the hospital. What should she do?

Preparing for an Emergency

At-a-glance emergency plan

Creating an information
binder

Who to involve

Help from the person with the
disability

Emergency Plan for Stand- in Caregiver

Step 1

Find and review information binder.



Step 2

Get in touch with the people listed in the information binder who have indicated that they will become involved in an emergency. Inform them about the circumstances.



Step 3

Pack up supplies for the person if they will be away from home.

A decorative blue dashed line consisting of several short, thick segments arranged in a curved path along the top-left edge of the white circle.A solid orange circle located at the bottom-right edge of the white circle, partially overlapping the green background.

Creating an Information Binder

Information Binder Contents



ONE-PAGE
PROFILE



IMPORTANT
CONTACTS



MEDICAL



PRESENTATION



COMMUNICATION



DAILY
ROUTINE/
SCHEDULE



PACKING LIST

Helen Sanderson's One-Page Profile

My One-Page Profile



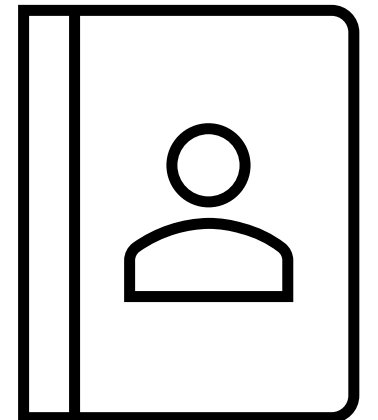
What people appreciate about me

What is important to me

How to support me

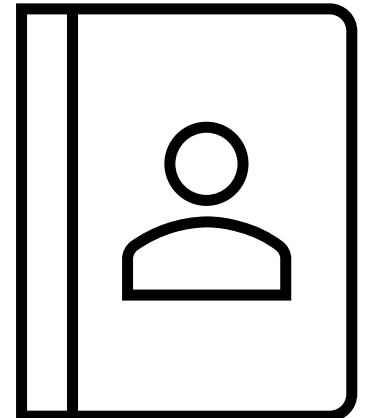
Important Contacts

- Family/ friends/ paid supports who can help in an emergency
 - Designate 1-2 people who could take the lead on implementing a plan
 - You can include those who live at a distance for logistical/ emotional support
- Family doctor
- Specialty doctors
- Day program/ employer/ school
- DSO
- Case manager
- Respite provider
- LHIN Care Coordinator
- Wheel Trans



Important Contact Information

- Name
- Phone number
- Role in person's life
- What they can help with
- Client codes/ passwords for services that require it



Medical

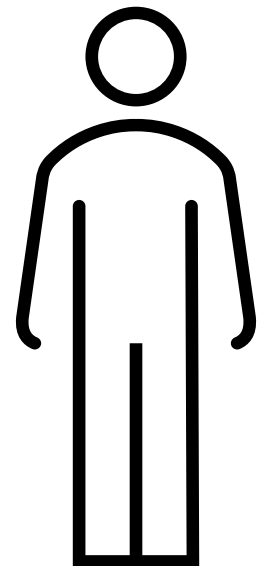
- Diagnoses
- Health card number
- Blood type
- Medications (time, dose, reason)
- Dietary restrictions/ allergies
- Recent illness/ injury
- Previous hospitalizations/ surgeries (date, reason, location)
- Pharmacy contact information
- Doctor requisitions (e.g. preferred hospital, do not resuscitate)
- Family doctor and specialist contact
- Religious/ cultural considerations
- Note: Health Care Access Research and Developmental Disabilities (HCARDD) has many resources available on their website



Presentation

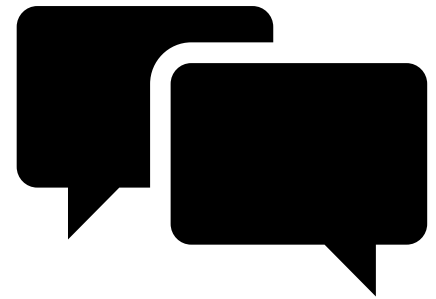


- Physical presentation
- Common behaviours
- Temperament
- Belongings that need to be kept on their person (e.g. tracking device, preferred toy)
- Religious/ cultural considerations



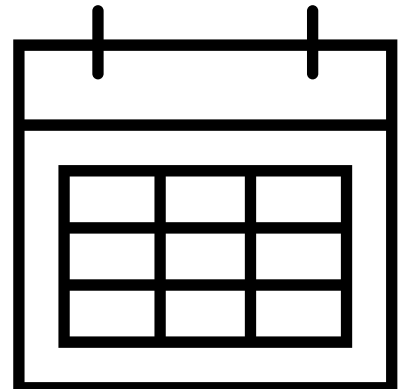
Communication

- How does the person communicate?
- Does the person require any alternative/ augmentative communication devices?
- Are there any communication systems that should be kept with the person?
- Who understands the person's communication best?

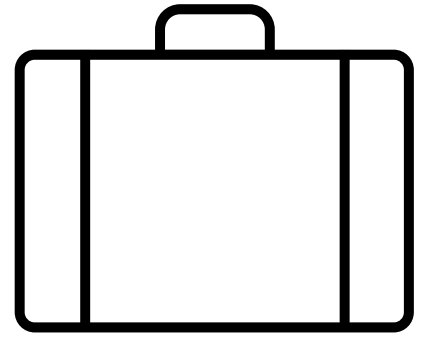


Daily Schedule/ Routine

- Waking/ sleeping times
- Meal/ snack times
- Medication times
- Attendance at programs
- Morning/ bedtime routine



Packing List



- Clothing needs
- Medications
- Quantities of medical supplies per day
- Quantities of incontinence supplies per day
- Security/ comfort items



Who to Involve

Creating a Support Circle

Who can provide physical support?

- Staying with the person
- Physically helping with activities of daily living
- Transporting to/ from appointments/ programs etc.
- Caring for the household
- Cooking/ cleaning
- Administering medication
- Caring for animals
- Entering/ exiting the home (who has a key?)

Who can provide logistical support?

- Making calls (e.g. contacting relatives, programs)
- Accessing/ managing emergency funds
- Coordinating a care schedule

Who can provide emotional support?

- Comforting the person
- Explaining the situation



Who to Inform

- Informing the public that someone with disability lives there (e.g. superintendent, neighbour)
- Provide copy of emergency plan to anyone who has a role in it (e.g. day program provider, neighbour)
- Information sheet to share with first responders

Information for First Responders

- Person with a disability CANNOT be left unattended
 - Location of information binder
 - One line about diagnoses
 - One line about communication (e.g. non-verbal)
 - One line about presentation (e.g. if person can get aggressive)
 - Tips for communicating with the person
 - Who lives in the household (i.e. other people, animals)
-

Getting Help from the Person with the Disability

Use Alexa/ Siri to call
for help

Identify if there's
someone the person
with a disability can call
who can coach them
through responding to
an emergency (e.g.
grandparent, sibling)

Create a visual safety
plan for a person with a
disability to recognize
when caregiver needs
help and access help

Visual Safety Plan

PERSONAL SAFETY PLAN FOR AMIR

Something's not right with: MOM
HOME

How do I know when I need to get help?

Something is not right with mom if she has had a fall



Something's not right with mom if she has a problem talking or can't talk



When this happens Amir should...



- FIRST call 9-1-1
- THEN call cousin Subrina at (647) 123-4567
- If Subrina doesn't answer, Amir should try to call again

During an Emergency

At-a-glance emergency
plan

Who to call

'When the dust settles'

At-a-Glance Emergency Plan for Caregiver

1

1. Call 911 (if needed)

2

2. Call the contact person you have identified to implement the emergency plan, or a backup person

3

3. Ensure the emergency plan and information binder are accessible

Who to Call Immediately- Children

- Your case manager
- Children's Aid Society of Toronto
 - Age 0-18
 - Phone: (416)924-4646
 - Hours: 24/7
- Griffin Community Support Networks
 - Age 16+
 - Phone: (416) 222-3563. Ask to speak to a Network Intake Worker.
 - Hours: Mon-Fri, 9am-9pm
 - Website: http://www.griffin-centre.org/downloads_programs/TSS_GCSN.pdf

Who to Call Immediately- Adults

- Your case manager
- DSO-Toronto Region
 - Phone: 1 (855) 372- 3858
 - Hours: 8:30am-5pm
- Griffin Community Support Networks
 - Age 16+
 - Phone: (416) 222-3563. Ask to speak to a Network Intake Worker.
 - Hours: Mon-Fri, 9am-9pm
 - Website: http://www.griffin-centre.org/downloads_programs/TSS_GCSN.pdf
- Gerstein Crisis Centre
 - Age 16+
 - Phone: (416) 929-5200
 - Hours: 24/7
 - Website: <https://gersteincentre.org/>

Who to Call Immediately

- If you absolutely cannot find anyone to step in and the person cannot be left unattended, insist that the person with the disability stays with you (e.g. If you must go to the hospital, insist that they come along and figure things out from there).
- If the person with the disability somehow ends up home alone and you're worried about their wellbeing but they are not at imminent risk, call Toronto Police Service's general number at (416) 808-2222 and request a welfare check.
 - Police will bring the person to the hospital if it's unsafe for them to be home or if they're found to be unwell.

What to Tell Service Providers

Indicate that it is an emergency/ crisis.

Inform them that you are the primary/ sole caregiver and you are not sure how the person's care needs will be met.

Provide the contact for the best person for service providers to coordinate with.

When the Dust Settles

Update the DSO about the circumstances. DSO needs to be kept up-to-date about issues happening in the family context that relate to the person with a disability.

Check-in with stand-in caregiver. Ensure emergency plan has been activated.

After the emergency has resolved, meet with anyone who was involved to review what worked, what didn't and any changes that need to be made to the plan.

Additional Tips



Include something in your wallet about the person you care for in case you're found unconscious (or medical ID on Apple phone)



Include a laminated important contact sheet that the person can carry with them in a backpack/ coat pocket



Review the safety plan annually with anyone who's involved, or more often as needed (depending on the health status of the caregiver)



Consider how technology can be used to add to everyone's safety



Be creative

Case Example Resolution- Part 1

Sonia identified that she was having a medical emergency and immediately called 911. She unlocked the front door and left her phone connected to 911. Sonia knew that Amir's information binder was where it was supposed to be and that there was a note on the fridge that indicated where the binder could be found. Sonia grabbed the information sheet to provide to first responders that she kept near the phone so that she would have it on-hand and then she could quickly give them information about Amir. Sonia texted Subrina, the person identified to implement the emergency plan, that the plan had to be implemented. Subrina said that she'd be on her way immediately. Sonia had already given Subrina a key to the apartment. EMS arrived and kept Sonia stable while they awaited Subrina's arrival, as they knew Amir couldn't be left alone. Once Subrina arrived, Sonia was taken to the hospital.

Case Example Resolution- Part 2

Subrina easily found the binder about Amir's care. Since Amir was upset, Subrina put on an episode of his favourite tv show, as indicated in the binder. Since it was before 9pm, she contacted GCSN and informed them of the circumstances. Subrina agreed to stay with Amir until he went to his day program the next morning, which would also give GCSN some time to plan staffing supports. With GCSN's support, a plan was created. Subrina would stay overnight with Amir for the first couple nights until he went to his day program in the morning. GCSN hired staffing to cover the period when Amir was home but Subrina was still at work. Amir's overnight respite provider also agreed that Amir could come stay there for a couple nights. While Subrina was busy providing physical care for Amir, she asked Sonia's friend, who was listed in the care plan, if the friend could update Amir's day program provider, Wheel Trans and the overnight respite provider with the plan. Sonia was hospitalized for 4 nights. Once she came home and recovered from her health scare, she called DSO and updated them about what happened and her health condition. Sonia then took the time to call each person who was involved in providing care for Amir to review how things went.

Participant Tips/ Ideas

- Engrave a pet identification tag with important contact information and attaching it to a keychain/ backpack
- Present common behaviours and what they might communicate visually, in table form:

	Angry	Anxious	Bored	Uncomfor table	Happy	Tired
Clenching fist	x	x	x	x		
Covering ears	x	x		x		x
Crying	x	x	x	x		x
Echolalia	x	x			x	x
Flapping		x			x	
Jumping		x			x	
Rocking		x	x		x	
Yelling	x	x	x	x	x	x

- Include links to YouTube videos to provide instruction on providing care with medical devices (E.g. Search, “How to clean a g-tube area”)

Participant Tips/ Ideas

- Prey Project (<https://preyproject.com/>) to help track people
- Note that most TTC subway “Designated Waiting Areas” have cellular service and line up with where the train conductor will be when the train stops.