

Caregivers

A caregiver can be a family member or friend that has a supportive relationship with the patient and is willing to help in a variety of ways.

They can help with:

- Daily activities -laundry, groceries, homemaking and transportation
- Escorting patients to appointments
- Providing the patient with physical and emotional support

Sometimes caregivers experience burnout, and neglect to care of themselves in order to meet the needs of their loved one.

It is important to realize that you can only be helpful to your loved one if you also take care of yourself.

Caregiver Rights

- Acknowledge your feelings
- Recognize your limits of endurance and strength
- Take time out to learn caregiving skills and seek out accurate information
- Ask for help

- Receive appreciation and emotional support
- Take time away from caregiving for your own health, spirit, and relationships
- Provide care at home as long as you are able but remember, no one can be a caregiver forever
- Access available services that aid in caring

- Take pride in your accomplishments and applaud your courage
- Take care of yourself; this is not a selfish act
- Protect your individuality/identity

- LAUGH!
- Protect yourself against caregiver burnout

Caregiver Stress Test

Answer “never”, “sometimes”, “usually”, or “always” for each of the following:

1. I find I can't get enough rest
2. I don't have time for myself
3. I don't have enough time to be with other family members beside the person I care for
4. I feel guilty about my situation
5. I don't get out much anymore
6. I have conflicts with the person I care for
7. I have conflicts with other family members
8. I cry everyday

9. I worry about having enough money to make ends meet
10. I don't feel I have enough knowledge or experience to give care as well as I'd like
11. My own health is not good

If you answered “usually” or “always” to any of the above, you may be experiencing caregiver stress.

Common Types of Caregiver Stress

- **Physical**
 - Roles and responsibilities cause an increase in strain on the body
 - You may experience fatigue, sleep disturbances, tremors and tension
- **Financial**
 - You may have to deal with costs involved in providing care
- **Environmental**
 - You may be required to cope with major changes in their previous living arrangements and daily routines
- **Social**
 - You may be committed to providing care. Sometimes the patient may neglect family and friends
- **Emotional/Psychological**
 - All of the above factors can lead to intense emotional and psychological distress
 - You may feel: angry, depressed, lonely, afraid, guilty, embarrassed, frustrated, helpless and neglected
 - You may have difficulty concentrating, making decisions and become forgetful

Burnout

- Can occur if you feel emotionally and physically drained from your caregiver role
- Can occur if you don't get needed help, or if you try to do more than you are able
- If unnoticed, it can affect the lives of your loved one and yourself
- Symptoms are similar to stress and depression:
 - Withdrawal from friends and family
 - Loss of interest in activities you previously enjoyed
 - Feeling down, hopeless, and helpless
 - Change in appetite, weight, or both
 - Changes in sleep patterns
 - Getting sick more often
 - Feelings of wanting to give up on yourself or providing care
 - Emotional and physical exhaustion
 - Irritability

Avoiding Burnout

- Eat 3 balanced meals a day
- Get out and exercise at least once a week
- Get a good night's sleep
- Build a support system or join a support group
- Maintain open, honest communication with friends and family
- Be gentle to yourself and accept your feelings
- Make sure you keep your medical and dental appointments
- Be realistic about what you can and cannot do
- Look at your priorities; don't try to do everything
- Delegate tasks

- Ask for and accept help when you need it
- Make time for relaxation and self-care for yourself
- Create a communication system to update people
- Keep track of medical information
- Keep your own personal diary or journal

- Take time for yourself
- Take it one step at a time
- Plan for a journey
- Be careful not to use/abuse alcohol or recreational drugs to cope with stress
- Ask the Transplant Program Social Worker about support groups and the mentor program

- Participate in the Mindfulness-Based Stress Reduction (MBSR) program offered by Transplant Psychiatry. To self-refer, please call: 416-340-4452.
For more info about the MBSR program:
http://www.uhnmodules.ca/about_uhn/programs/pain_management/patientinfo/mindfulness.asp

Information Management

- Remember to update information regularly and keep it with you:
 1. Names and phone numbers
 2. Hospital admissions
 3. Medication lists

- Keep information located in one place (get a notebook)
- Use a patient passport (www.sickkids.on.ca/myhealthpassport/)
- Get a calendar to organize appointment dates and routines
- Bring medication lists to every hospital appointment

Communication and Updates

- **Have a plan** – provide family and friends with a way to receive information
- **Designate a contact person** – they can keep everyone informed and reduce disruptive calls to you and the hospital
- **Use e-mail** – a cost-effective and quick way to inform others of patient progress and changes
- **Use voicemail** – messages can be left so people can phone in and listen to the update
- **Create an internet blog** where you can post messages and pictures
- **CarePages** – private, personalized Web pages
 - Share information automatically every time you post a message
 - Keep in touch before, during, and after the transplant
 - Post messages about the patient's progress
 - Friends and family may post messages at anytime, from anywhere and provide support and encouragement
 - Post photographs
 - For more information: <https://www.carepages.com>