

Who Cares for the Caregiver?

Tools and information for caregivers.

Make Advance Care Planning a Priority

Much attention has been given in recent months to the importance of advance care planning. The Terry Schiavo case illustrated how critical one discussion can be and how putting that discussion in writing can ease a great burden from loved ones and caregivers.

Too few of us, at any age, have considered advance care planning that includes Advance Directives (Health Care Proxy, Living Will, Do Not Resuscitate order) that will assure our end-of-life care wishes are followed if we are unable to make necessary decisions for ourselves. Whether incapacitated due to illness, disease, or a tragic accident – who do you want to make decisions for you?

New York State's Health Care Proxy Law, enacted in 1990, enables individuals to appoint a health care agent, such as a family member, trusted friend or loved one, to make medical decisions on their behalf should they become unable to do so.

While New York does not have a statute governing Living Wills, the Court of Appeals, New York's highest court, has stated that Living Wills are valid as long as they provide "clear and convincing" evidence of your wishes. If you are 18 years of age or older, you may express your wishes in writing about your health care by signing a Living Will. There is no standard Living Will form. You may download a Living Will form at no charge at www.lastactspartnership.org or from the NYS Dept. of Health website.

The following are some common myths regarding Advance Directives:

MYTH 1: There is only one type of power of attorney. False - many patients (and their families) believe that if they have power of attorney for financial matters, they also have power of attorney for health care. These are typically separate legal documents, but sometimes are combined into one comprehensive document prepared by an attorney. In New York State, a Health Care Proxy is the legal document to appoint someone you trust to make health care decisions for you in the event you cannot speak for yourself.

MYTH 2: It is not appropriate to begin advance care planning on an outpatient basis. False--many studies have shown that patients want their doctors to discuss advance care planning with them before they become ill. Many others have shown a positive response from patients when Advance Directive discussions are held during outpatient visits.

MYTH 3: An Advance Directive means "don't treat". False - too often Advance Directives are triggers for disengagement by the medical staff. Advance Directives do not say "don't treat me." They say, "Treat me the way I want to be treated."

MYTH 4: Once a person names a health care proxy in an Advance Directive they lose control of their own care. False - as long as a person retains decision making capacity he/she retains control of their medical destiny.

MYTH 5: A lawyer is required to complete an Advance Directive. False - a lawyer may be helpful, but is not required. In New York State, two witnesses are required to sign the Health Care Proxy. The witnesses cannot be the person(s) named as proxy.

MYTH 6: Doctors and other health care providers are not legally obligated to follow Advance Directives. False - doctors and other health care providers are obligated to follow Advance Directives.

MYTH 7: Advance Directives are legal tools for old people. False - the stakes may actually be higher for younger people if tragedy strikes (think Terry Schiavo, Nancy Cruzan or Karen Ann Quinlan).

MYTH 8: The doctor can be the durable power of attorney for health care. False - no member of the health care team can be the durable power of attorney for health care.

The best way to be sure your wishes are followed is to appoint a Health Care Proxy. To download a Health Care Proxy form or for more information, visit www.ihaveone.org or www.oag.state.ny.us/health/EOLGUIDE012605.pdf to download the NYS Advance Directive guide.

References:

Aitkin PV, American Family Physician 1999;59(3):605-612 (SUPPORT) JAMA 1995;274:1591-1598
Sabatino CP, 10 Legal Myths About Advance Medical Directives

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Resources for caregivers, seniors, or low income candidates

HEAP: 438-4020 over 60 yrs old, 439-7744 under 60
278-8645 Niagara Falls under 60

Niagara County Dept of Social Services 439-7600
(Human Resources, N.F. 278-8400)

Niagara County Health Dept. – Niagara Falls 278-1900

Niagara County Legal Aid Society 284-8831

Niagara County Office for the Aging 438-4020
(Home Care Services for the Elderly)

Niagara Hospice 439-4417
(End-of-life care)

Emergency Response System

Peace of Mind 1-866-491-7246

Home Care Providers:

HANCI 433-2664; 285-8224

HART Interfaith, Inc. 754-8313

Palliative Home Care of Niagara 215-2085

Staff Builders Inc. 439-4251; 282-8000

Willcare 1-800-521-2322

Social Security Administration 283-1066

or 1-800-772-1213

Home Delivered Meals

Meals on Wheels 282-3468, 285-6875

Call for rates and more information.

Home Delivered Meals

Office for Aging (RURAL) Call for rates & info. 438-4031

Transportation

See Niagara County Transportation Guide at end

Niagara County Crisis Hot Line 285-3515

Food providers

Catholic Worker 282-8683

Community Missions 285-3403

Heart, Love & Soul, Inc 282-5681
(leave message)

Independent Church of God 284-1501

NIACAP 285-9681

Niagara County Food Stamps 278-6822

Salvation Army 283-7697

Caregiver & Respite Services

Niagara County Office for the Aging 438-4020

Senior Companion Program 433-2664

285-8224

Police & Emergency

City Police 911 for emergencies

Niagara County Sheriff 438-3393

NYS Police 297-0755

434-5588

Public Safety: 286-4711 Niagara Falls; 433-7700 Lockport;
692-4111 North Tonawanda

If you need further assistance, call the County-Wide

Helpline: Niagara Falls 282-5432; Lockport 433-5432;
North Tonawanda 692-8800

Caregiver Survival Tips

- Know yourself. Know your limits. Admit when you are overwhelmed.
- Have realistic goals, and expectations: yourself, and the care-receiver.
- Don't expect perfection- you're not! You cannot, and won't do everything just right all the time. When you do some things very well you may not be recognized by the care-receiver.
- Know when to ask for help. Asking for help **does not** mean failure. It means that you know when it is best to have assistance to care for your loved one to the best possible level. It is not weakness, but strength to know when help is needed. Think about a team approach.
- Make time in the day for **YOU**. Take care of the caregiver. Maybe a cup of tea, or a coke. Find some pleasure, no matter how small it seems, for you. Find some moment to relax. Try the deep breathing, in and out. Time alone, away from the care-receiver if possible. Have some fun. Use your sense of humor often. Look for joy in the simple pleasures of life- in the priceless things.
- Learn all you can about your loved one's illness/disease, and what you might have to expect from the progress of it.
- Talk to others. Groups are great for some people. Try your circle of friends, or neighbors. Family can be very supportive if approached in the acceptable manner for the family. Sometimes, a stranger may be a good ear for you. But, be sure to vent as needed. This doesn't make you weak, or a bad person, nor does it mean that you will stop caregiving. It just simply means that you have a load on your plate and need to let off some steam, acknowledging it, without being judged.
- Accept yourself and know that you are doing a gallant, wonderful job. You are doing a hard thing because you choose to. Because you love that person. You have given up, perhaps sacrificed your life, for someone else's benefit. That is rare and noble these days. You unselfishly provide the very best care for your loved one that you can, because they cannot do it for themselves. Thank you.
- Understand that you will have good days and bad days (emotionally, and physically). You may feel sad at times, or angry, guilty, or even

resentful. You will have times of joy and happiness also. You will feel great satisfaction at times, knowing you have provided the very best of care for your loved one. You have done a good job- feel good about it. That is okay. This day, this moment, you have done well.

- Understand that this won't last forever, though it may seem like it at times. There is a light at the end, maybe dimly now, but a light none-the-less. You will feel good that day, knowing you did your very best to make a difference for your loved one. You cared, and gave of yourself for another.
- Learn what resources are available in the community (respites, senior groups, meals on wheels, support groups, etc). Make a list. Often, these can be a great relief for a short time, or in the long haul.
- Practice positive self-talk, not negative: "I can do this, I am doing a good job, I am making a difference," as opposed to, "What a lousy job, stupid, idiot, I messed this up didn't I?" Pat yourself on the back once in awhile.
- Learn to say "**NO**," when necessary, to yourself, and to your loved one when appropriate. Pick your battles. Know when to be firm, and when to be soft. Know when to stand your ground without feeling guilty. Know when it is okay to give in a little. Maintain your loved one's dignity and self respect.
- Watch movies together, listen to music, play cards, listen to tapes (religious, books, etc.), talk (reminisce) of good times. Think of things that re-focus attention away from the illness for a while. Routine and structure are good, but an occasional spontaneous activity or surprise is also helpful.
- Talk to others. If you belong to a faith community, speak to your minister or church family - they may provide great support and comfort.
- Remember that you have worth and value, as a person and a caregiver. No one can do it like you can. No one can care for your loved one as you do. You have chosen this because you love them. It is a precious time in your lives. Make every minute count. Enjoy what you can from it. Accept every minute as valuable because it may end when you least expect it. Embrace the pain as well as the joys.

Niagara County Transportation Guide

Provided by C.A.S.E.
Coalition of Agencies in Service to the Elderly

** Last update: January 2006*

* Contact the agency listed for the most current information regarding services and fees.

All resources are phone area code 716 unless listed differently

Ambulances

Rural Metro Medical Services **284-4228**
2621 Lockport Rd. **882-8400**
Niagara Falls, NY 14305

Tri Community Ambulance Service **731-2604**
Business Office
6276 Ward Road
Sanborn, NY 14132

Tri-Town Ambulance Service, Inc. **772-7711**
8405 State Rd.
Gasport, NY 14067

Twin City Ambulance **692-2100**
365 Filmore Ave.
Tonawanda, NY 14150

Metro Bus

NFTA – Metro **855-7286**
1124 Portage Rd. **285-9319**
Niagara Falls, NY 14301

Metro Bus services Niagara County with various schedules and rates available. Elderly/handicapped receive ½ off adult fare with proper I.D. card.

Applications can be made on the second Monday of every other month at the Trott Access Center, 1001 Eleventh Street in Niagara Falls from 10 a.m. to noon.

Applicants must obtain pre-approval from the NFTA's ADA Coordinator before a reduced fare photo will be taken. Walk-ins without pre-approval will not be accepted.

For Hearing Impaired only call: **855-7337**

Paratransit Service **855-7286**

The Paratransit service provides low cost curb to curb service to individuals with disabilities in limited areas. Call for more information and for an application.

Non-profit Agency Transportation

American Cancer Society
101 John James Audubon
Amherst, NY 14228

1-800-ACS-2345
1-800-743-6724
689-6981

Available to cancer patients able to walk on their own. Call 2 -3 weeks in advance. Service provided by volunteers.

Carrier Coach
2393 Niagara Falls Blvd.
Niagara Falls, NY 14304

731-3540

M-F, 6AM to 5PM. Call 2 -3 days ahead and must pre-pay. Call for rates.

The Dale Association
33 Ontario Street
Lockport, NY 14094

433-1939

The Dale Association provides adults and Medicaid recipients a ride to-and-from doctor, medical testing and treatment appointments for a reasonable fee. Appointments can be made for weekdays Monday-Friday with 72 hours notice.

Home Helpers
7480 E. Britton Dr.
Niagara Falls, NY 14304

297-8585

Home Helpers provides transportation to medical appointments, therapy sessions, barbershops, beauty salons, shopping or recreational activities. Call one week in advance. Transportation plus waiting time as needed is \$12 per hour. A minimum charge of \$6 applies to shorter trips. The mileage fee is \$.15 per mile and is charged starting from the client's home to the appointment and back to the client's home. Does not have wheelchair van. (Rates are as of January, 2006)

Independent Living

836-0822

3108 Main St.
Buffalo, NY 12124

Mainly serves Erie County but can do some in Niagara County. Must have disability and one week notice. Hours 7:30am to 10:00pm. Service is curb to curb, no age requirement. Call for rates.

Lewiston Senior Center

754-2071

4361 Lower River Road
Youngstown, NY 14174

For Lewiston residents only. Schedule 24 hours in advance. Must be able to get on and off van, unassisted. Friday morning trips to Tops and the bank. Wednesday and Thursday trips to hairdressers and barbers. Cost is \$1 locally and \$4 to Niagara Falls. (Rates are as of January, 2006).

Lockport Senior Centre

433-1939

Bewley Building, Suite 315
Lockport, NY 14094

Available to Niagara County residents for medical appointments. Wheelchair accessible. Hours available are 7:30am - 4:30pm. Can provide door to door service. Medicaid reimbursable. Call for rates.

Medicaid Transportation

439-7701

20 East Avenue
Lockport, NY 14094

Transportation is provided for active Medicaid cases when other transportation is unavailable and travel is over 5 miles. Prior approval needed at least 24 hours in advance, up to 7 days ahead.

Niagara Falls Memorial Medical Center **278-4444**
CARExpress
621 10th St.
Niagara Falls, NY 14302

No age limit. In Niagara Falls, the hours are 8:45am - 3:30pm to Summit Medical Center. Memorial Medical Center hours are 9:15 a.m. to 2:00 p.m. Call 24 hours in advance. Must be able to get on and off van, unassisted. Not wheelchair accessible. \$1 for one-way transportation (companions ride free).

Mt. St. Mary's VanGo **298-2370**
5300 Military Rd.
Lewiston, NY 14092

Hours available M-F from 8:30am - 3:30pm. Call 24 hours in advance. Only goes to hospital and sites affiliated with the hospital. Must be able to get on and off van, unassisted. Not wheelchair accessible. \$1 for one-way transportation (companions ride free).

Niagara County Office for the Aging **438-4038**
Medical Van **438-4033**
111 Main St. Suite 101
Lockport, NY 14094

M-F appointments from 9am-1:30 p.m. Call 2 weeks in advance during working hours of 8am-3:30pm. Medical appointments only. Suggested contribution: \$2 each way inside cities, \$3 each way outside cities, and \$7 each way to Erie County. Not wheelchair accessible.

Rural Niagara Transportation **285-9357**
120 13th Street
Niagara Falls, NY 14303

Route starts and ends at Niagara County Community College. Hours 6:20am - 6:35pm.

Youngstown Senior Citizen Dept. **745-7721**
P.O. Box 168
Youngstown, NY 14174

Van available for senior citizens to doctor appointments and shopping. Must be over 55 years of age. Advance notice of 48 hours required. Contributions accepted.

Taxi Cabs

Lockport

All American Discount Taxi
6597 S. Transit Rd.
Lockport, NY 14094

625-8400

24 hours a day

Custom Tax
270 State Rd.
Lockport, NY 14094

433-7100

Discount Cab
38 S. Niagara
Lockport, NY 14094

433-8900

434-7100

Rainbow County Dispatch Taxi
907 Niagara Ave.
Niagara Falls, NY 14305

438-5555

Union Cab
38 S. Niagara
Lockport, NY 14094

433-2222

434-4444

Niagara Falls

All American Discount Cab

609-3254

Blue United Taxi
1898 Buffalo Ave.
Niagara Falls, NY 14303

285-3333

LaSalle Cab
2821 Pine Ave.
Niagara Falls, NY 14301

284-8833

284-8834

284-8835

Niagara Airport Taxi
717 Portage Rd.
Niagara Falls, NY 14301

282-7622

Rainbow County Dispatch Taxi
907 Niagara Ave.
Niagara Falls, NY 14305

438-5555

North Tonawanda

All American Discount Taxi **609-3254**

Liberty Communications **877-7111**
1524 Kenmore Ave.
Buffalo, NY 14217

Kenmore Cab **876-3030**
440 Ontario St. **876-2300**
Kenmore, NY 14207

Yellow Cab **877-5400**
1524 Kenmore Blvd.
Buffalo 14216

Wheelchair Transportation

All American Discount **625-8400**
Wheelchair Transportation

Call for rates

Carrier Coach **731-3540**
2393 Niagara Falls Blvd.
Niagara Falls, NY 14304

M-F 6am - 5pm, prior notice required. Pre-pay ahead.

Lockport Senior Centre **433-1939**
Bewley Building Suite 315
Lockport, NY 14094

Available to Niagara County residents for medical appointments.
Wheelchair accessible. Hours available are 7:30am - 4:30pm. Can provide door to door service. Medicaid reimbursable. Call for rates.

Rural Metro Medical Services **284-4228**
2621 Lockport Rd. **882-8400**
Niagara Falls, NY 14305

Covers all of Niagara County. Prior notice required.

Rural Niagara Transportation

285-9357

2393 Niagara Falls Blvd.
Niagara Falls, NY 14304

Route starts and ends at Niagara County Community College. Can accommodate wheelchairs.

Twin City Ambulance

692-2342

365 Fillmore Ave.
Tonawanda, NY 14150

Union Taxi Cab

433-2222

38 S. Niagara St.
Lockport, NY 14094

We Care Wheelchair Van

433-1119

54 S. Niagara St.
Lockport, NY 14094

278-3333