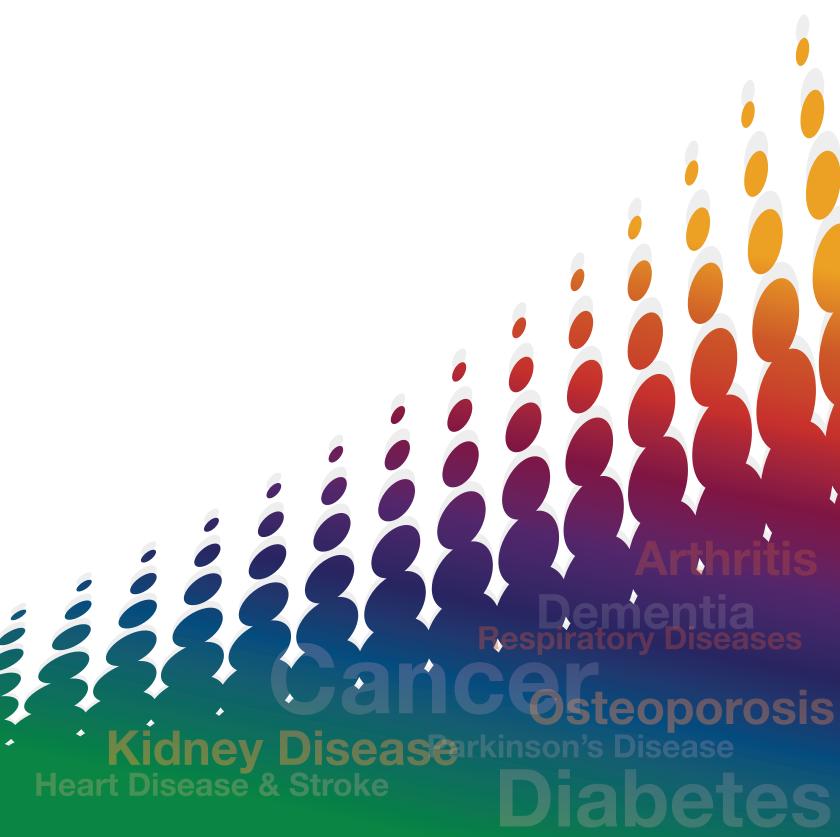


# Disaster **Preparedness**

for Persons with Chronic Disease



### **PREFACE**

This manual was prepared by University of Louisville Hospital with a grant from the Kentucky Department for Public Health.

It is intended for individuals with chronic disease, as well as family members and caretakers of those individuals, to prepare for disasters.

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### WHY PREPARE?

Disaster planning is essential for everyone. This is especially true for the more than 90 million Americans who currently live with chronic diseases. You may be able to easily manage your condition now, but during a disaster, many services you rely on may not be available. Your condition and a lack of these services make you very vulnerable in a disaster. It has been found that lack of access to routine health care is a leading cause of death after disasters. Proper disaster planning can help to limit your vulnerability.

There are many things to consider when planning for a disaster. Where will you, your family, your friends or personal care attendants be when an emergency or disaster strikes? You, and those you care about, could be anywhere – at home, work, school or in transit. How will you find each other? Will you know your loved ones will be safe? Emergencies and disasters can strike quickly and without warning. They can force you to leave your neighborhood or confine you to your home.

If utilities (water, gas, electricity or telephones) were not available, what would you do? Local officials and relief workers will be on the scene after a disaster, but they cannot reach everyone right away. You are in the best position to plan for your own safety. Why? Because you are best able to know your abilities and possible needs during and after an emergency or disaster situation. You can cope with disaster by preparing in advance with your family and care attendants. Knowing what to do is your best protection and your responsibility.

The information in this manual is to help you plan and prepare for disaster situations. A great deal of the information is general, in nature, and can be useful to anyone planning for disaster preparedness. There is also specific information to help you overcome the challenges that your chronic disease presents when preparing for disasters. Remember that stress can aggravate any chronic condition. Preparing now can help to reduce stress should a disaster occur.

### WHAT YOU NEED TO DO

### 1. Get Informed

In order for individuals to be properly informed about disaster preparedness they need to gather information from multiple sources. This is accomplished by completing an assessment in the following three areas:

- Personal
- Household
- Community

### **Personal Assessment**

Individuals should complete a personal assessment in order to identify their needs during and after a disaster. A personal assessment is especially important for those with chronic disease because of their increased vulnerability during a disaster.

Two main scenarios to consider are:

- Staying In
- Getting Out

**Staying In** – what individuals need to consider if they have to remain in their homes during or following a disaster.

<u>Daily Living</u>: Items for personal care such as bathing, grooming and dressing; adaptive feeding devices such as special utensils

<u>Loss of utilities</u> such as water or electricity (Note: Most utility companies require individuals who are dependent upon electrically run medical equipment to register with them before a disaster occurs)

<u>Mobility</u>: Dealing with debris in or around the home; using mobility aids such as motorized or manual wheelchairs, walkers, canes, etc.

Additional Supplies: Obtaining groceries, medications and medical supplies after the disaster kit has been exhausted

<u>Getting Help</u>: Notifying the personal support network (this concept will be discussed in greater detail later in this manual)

**Getting Out** – what individuals need to consider if they have to leave their homes during or following a disaster.

<u>Daily Living</u>: What personal care items to take along such as bathing, grooming and dressing; adaptive feeding devices such as special utensils

<u>Mobility</u>: Loss of the ability to use mobility aids such as damage to ramps; using alternative exits to get out; loss or damage to transportation such as cars or specially equipped vehicles; seeking alternate forms of transportation such as public transportation or ambulance services

Additional Supplies: Obtaining groceries, medications and medical supplies after the disaster kit has been exhausted

<u>Getting Help</u>: Notifying personal support network of location and possible needs; assistance with evacuation (friends, family, first and community responders)

Seeking Shelter: It is preferable to stay with family, friends or even in a hotel.

A public shelter should be a last resort. Individuals with chronic disease may not be able to receive care at a regular shelter. Some communities have special needs shelters available for those with chronic disease. These shelters often require advanced registration.

Even a special needs shelter may not have the correct medical supplies. Individuals are encouraged to bring the items their condition requires.

Most shelters do not allow pets other than licensed service animals. It is important to identify pet friendly shelters or boarding facilities ahead of time.

### **Household Assessment**

The Action Checklist is a tool that can be used to determine the general disaster preparedness of a household.

### Action Checklist: Items to Do Before a Disaster

### Considerations for People with Disabilities

Individuals with disabilities or other special needs often have unique needs that require more detailed planning in the event of a disaster. Consider the following actions as you prepare:

Learn what to do in case of power outages and personal injuries. Know how to connect and start a back-up power supply for essential medical items.
Consider getting a medical alert system. It will allow you to call for help if you cannot get to a phone in an emergency. Most alert systems require a working phone line, so have a back-up plan such as a cell phone or pager.
If you use an electric wheelchair or scooter, have a manual wheelchair for backup.
Teach those who may need to assist you in an emergency how to operate necessary items. Also, label items and attach laminated instructions for each item's use.
Store back-up items (mobility, medical, etc.) at your neighbor's home, school or your workplace.
Arrange for more than one person from your personal support network to check on you in an emergency, so there is at least one back-up if the primary person you rely on is unavailable.
If you use a personal care attendant from an agency, check to see if the agency has special provisions for emergencies. For example, do they provide services at another location should an evacuation be ordered?
If you live in an apartment, ask the management to identify and mark accessible exits and access to all areas designated for emergency shelter or safe rooms.
Have a cell phone with an extra fully-charged battery. If you are unable to get out of a building, you can let someone know where you are and guide them to you. Keep the numbers you may need to call with you if the 9-1-1 emergency number is overloaded.
Learn about devices and other technology available (PDAs, text radio, pagers, etc.) to assist you in receiving emergency instructions and warnings from local officials.
Be prepared to provide clear, specific and concise instructions to rescue personnel. Practice giving these instructions (verbally, pre-printed phrases, word board, etc.) clearly and quickly.
Prepare your personal support network to assist you with anticipated reactions and emotions associated with disaster and traumatic events, such as confusion, agitation, fear, panic and anxiety.

You do not have to be the only one prepared. Encourage others to be prepared and consider volunteering or working with local authorities on disability and other special needs preparedness efforts.
lities:  I Know how and when to turn off water, gas and electricity at the main switches or valves and share this information with your family and caregivers.
1 Keep any tools you will use near gas and water shut off valves.
Turn off the utilities only if you suspect damaged lines, a leak or if local officials instruct you to do so. (Note: Gas shut-off procedure – As part of the learning process, do not actually turn off the gas. Only a qualified professional can turn the gas back on. It might take several weeks for a professional to respond. In the meantime, you will require alternate sources to heat your home, make hot water and cook).
<b>Extinguisher:</b> Be sure everyone knows how to use your fire extinguishers (ABC type) and where they are located.
oke Alarms: I Install smoke alarms on each level of your home, especially near the bedrooms. I Follow local codes and manufacturer's instructions about installation requirements.
Install a carbon monoxide alarm in your home.
<ul> <li>Urance Coverage:</li> <li>Check if you have adequate insurance coverage. Homeowners insurance does not cover flood damage. It also may not provide full coverage for other hazards.</li> <li>Talk with your insurance agent and make sure you have adequate coverage to protect your family against financial loss.</li> </ul>
st Aid/CPR & AED (Automated External Defibrillation):  Take a first aid and a CPR/AED class. Red Cross courses can accommodate people with disabilities. Discuss your needs when registering for the classes.
rentory Home Possessions:  Make a record of your possessions to assist with claim reimbursement in case of loss or damage.
Store this information in a safe deposit box or other secure (flood/fire safe) location to ensure the records survive a disaster.
Include photographs or video of the interior and exterior of your home as well as cars, boats and recreational vehicles.
Have photos of durable medical items and be sure to make a record of the make and model numbers for each item.
Obtain professional appraisals of jewelry, collectibles, artwork or other items that may be difficult to evaluate.
Make copies of receipts and canceled checks showing the cost for valuable items.

	1 Records and Documents:				
	he following important documents should be kept in a safe deposit box or other safe locations				
	Birth and marriage certificates	□ Deeds			
	Social Security cards	☐ Financial records			
	Passports Wills	☐ Insurance records ☐ Immunization records			
_	WIIIS	a minumzation records			
In a	uce Home Hazards: disaster, ordinary items in the horduce your risk:	me can cause injury and damage. Take these steps			
	☐ Keep the shut-off switch for oxygen items near your bed or chair, so you can get to it quickly if there is a fire.				
	☐ Have a professional repair defective electrical wiring and leaky gas connections.				
	Place large, heavy objects on lowe away from beds.	er shelves, and hang pictures and mirrors			
	_	ecure tall cabinets, bookshelves, large appliances and refrigerator), mirrors, shelves, large picture studs.			
	Repair cracks in ceilings and four	ndations.			
	Store weed killers, pesticides and	flammable products away from heat sources.			
	Place oily rags or waste in covered to local regulations.	I metal cans and dispose of them according			
	Have a professional clean and rep	air chimneys, flue pipes, connectors and gas vents.			
Con	mmunity Assessment tact your local emergency manage rmation you will need to create a	ement office or American Red Cross Chapter to gather plan.			
•	Community Hazards:  o Ask about the specific hazards t tornados, earthquakes).	hat threaten your community (e.g., floods,			
	• Ask about your risk from those	hazards.			

- Community Disaster Plans:
  - Learn about community response plans, evacuation plans and designated emergency shelters.
  - Ask if your community has a shelter that can meet your special needs.
     If so, find out if you need to register with your community. Remember, most public shelters are not set up to care for those with special needs.
  - Ask about the emergency plans and procedures that exist in places you and your family spend time (e.g., places of employment, schools, childcare centers).
  - If you do not own a vehicle or don't drive, find out in advance what your community's plans are for evacuating those without private transportation.

- Community Warning Systems:
  - o Find out how local authorities will warn you of a disaster.
  - How will they provide information to you during and after a disaster?
  - Learn about National Oceanic and Atmospheric Administration (NOAA)
     Weather Radio and its alerting abilities.

#### • Assistance Programs:

- Ask about special assistance programs available in the event of an emergency.
   Many communities ask people with a disability to register, usually with the local fire, police or emergency management office. This is so needed help can be provided quickly in an emergency.
- Let your personal care attendant know you have registered, and with whom.
- o If you are electric-dependent, be sure to register with your local utility company.

### 2. Make a Plan

A disaster can disrupt your primary emergency plan. It is important for you to develop a back-up plan to ensure your safety.

### Create a Personal Support Network

- Meet with Your Family/Personal Care Attendants/Building Manager:
  - Review the information you gathered about community hazards and emergency plans.

#### • Choose an "Out-of-Town" Contact:

• Ask an out-of-town friend or relative to be your contact. Following a disaster, family members should call this person and tell them where they are. Everyone must know the contact's phone numbers. It is often easier to make a long distance call than a local call from a disaster area.

### • Decide Where to Meet:

- o If you separate from household members in an emergency, have a specific meeting spot.
- o Choose a place right outside your home in case of a sudden emergency, such as a fire.
- o Choose a location outside your neighborhood in case you cannot return home.

### • Complete a Communication Plan:

- Your plan should include contact information for family members, members of your support network, caregivers, work and school.
- Your plan should also include information for your out-of-town contact, meeting locations, emergency services and the National Poison Control Center (1-800-222-1222).
- Teach your children how to call the emergency phone numbers and when it is appropriate to do so.
- Be sure each family member has a copy of your communication plan and post it near your telephone for use in an emergency.
- Escape Routes and Safe Places. In a fire or other emergency, you may need to leave at a moment's notice.
  - ° Be ready to get out fast. Be sure everyone in your family knows the best escape routes out of your home.

- They also should know where the safe places are in your home for each type of disaster. For example, if a tornado approaches go to the basement or the lowest floor of your home or an interior room or closet with no windows.
- Use a blank sheet of paper to draw the floor plans of your home. Show the location of:
  - Doors

• First-aid kits

Windows

• Utility shut-off points

• Stairways

- Fire extinguisher
- Large furniture
- Important points outside such as garages, patios, stairways, elevators, driveways and porches
- Disaster supplies kit
- Collapsible ladders
- Smoke alarms
- Indicate at least two escape routes from each room.
- Mark a place outside of the home where household members and/or your personal care attendant should meet in case of fire.
- If you (or someone in your household) use a wheelchair, make exits from your home wheelchair-accessible.
- Practice emergency evacuation drills at least twice a year. Also practice when you update your escape plan.
- Be sure to include family and/or your personal care attendant in the drills.

#### • Plan for Your Pets:

- Take your pets with you if you leave. For health reasons, emergency public shelters do not allow pets (other than service animals).
- Prepare a list of family, friends, boarding facilities, veterinarians and "pet-friendly" hotels that could shelter your pets in an emergency.

### • Prepare for Different Hazards:

- Include in your plan how to prepare for each hazard that could affect your local community and how to protect yourself. For instance, most people shelter in a basement when there is a tornado warning, but most basements are not wheelchair-accessible.
- Determine in advance what your alternative shelter will be and how you will get there. Other hazards, such as a home fire, will require you to leave.
- Make sure both primary and secondary exits are accessible. Be able to locate them by touch or feel (since lights may be out and thick, black smoke may make it very hard to see).

### 3. Assemble a Disaster Supplies Kit

Some emergencies may require you to leave at a moment's notice. Others may require you to remain at home. Either way you probably will not have the opportunity to shop or search for the supplies you and your family will need. Every household should assemble a disaster supplies kit and keep it up-to-date.

A disaster supplies kit is a collection of basic items a family would probably need to stay safe and be more comfortable during and after a disaster. Disaster supplies kit items should be stored in a portable container(s) as close as possible to the exit door. Review the contents of your kit at least once per year or as your family's needs change. Also, consider having emergency supplies in each vehicle and at your place of employment. Individuals should prepare to be on their own for 72-96 hours.

### Basic disaster supplies

The following items should be included in your basic disaster supplies kit:

- Three-day supply of nonperishable food and manual can opener See the disease specific Dietary Needs sections for more information based on your chronic condition.
- Three-day supply of water (one gallon of water per person per day) Your condition may require more water. Ask your physician about your needs.
- · Portable, battery-powered radio or television and extra batteries
- Flashlight and extra batteries
- · First aid kit and manual
- Sanitation and hygiene items (hand sanitizer, moist towelettes and toilet paper)
- · Matches in waterproof container
- Whistle
- Extra clothing and blankets
- · Kitchen accessories and cooking utensils
- Photocopies of identification, credit cards and other important papers (e.g., Social Security card, insurance policies, financial information)
- · Cash and coins
- Special needs items (eye glasses, contact lens solution, hearing aid batteries, etc.)
- Items for infants, tools, pet supplies, a map of the local area and other items to meet your unique family needs

Think about your clothing and bedding needs. Be sure to include one set of the following for each person:

- Change of clothing
- · Sturdy shoes
- · Sleeping bag or warm blanket
- Extra items for cold weather (jackets, gloves, scarves, boots, etc.)
- Extra items for warm weather (sunscreen, wide brimmed hat, bug spray, etc.)

Supplies for your vehicle include:

- Flashlight, extra batteries and maps
- First aid kit and manual
- · White distress flag
- Tire repair kit, booster/jumper cables, pump and flares
- · Bottled water and non-perishable foods such as granola bars

### Medical items/needs

The items listed here may apply to many different chronic diseases. Additional information can be found in the medical items/needs sections and will help you with your specific needs.

- Wear a medical ID bracelet to quickly alert responders to your condition and allergies.
- Two-week supply of all medications and medical supplies and copies of all prescriptions in case medications are lost or damaged
- Necessary medical equipment (e.g. oxygen, wheelchair, walker, monitors)
- A list of important health-related information, to include:
  - Copy of health insurance card(s)
  - Model/serial number of any medical devices and company contact information in case they are lost or damaged
  - Summary of your medical history (See Additional Resources: Personal Medical Information Form for a sample form)
    - List of past and current conditions or diagnoses
    - List current medications, amounts taken, purpose taken, times taken and any other special information (e.g., take with meals)
    - List allergies to medicine, food and materials
    - Immunization record
    - Names and phone numbers of your healthcare providers
    - List of physician contact information outside of area in case of evacuation
    - Place copies of medical history with your other important documents.

### Dietary needs

- When gathering food items for your disaster supplies kit, keep in mind any dietary restrictions you may have (e.g., low sodium) foods that may be difficult to eat and foods that you do not tolerate well.
- Try to pack foods that you enjoy and will eat. This can make a disaster situation more tolerable. As the food supply nears its expiration date, you can eat the food without wasting it then restock with new items.
- Keep general health guidelines in mind when gathering non-perishable foods
  for your kit. It may be tempting or convenient to load up your kit with chips,
  cookies and other kinds of "junk" food since they are usually nonperishable.
  Maintaining a healthy diet can help you feel better and provide additional
  strength to cope with the situation and fight off illness.

Disease specific dietary information can be found in the dietary section.

### 4. Maintain Your Plan

**Quiz:** Review your plan every six months and quiz your family about what to do in an emergency.

**Drill:** Conduct fire and emergency evacuation drills on a regular basis with your family.

**Restock:** Check food supplies for expiration dates and discard or replace stored water and food every six months. If you have stored extra medical supplies, make sure they have not expired or are unusable.

**Test:** Read the indicator on your fire extinguisher(s) and follow the manufacturer's instructions to recharge. Test your smoke alarms monthly and change the batteries at least twice a year. Replace alarms every 10 years.

### IF DISASTER STRIKES

### If you are instructed to take shelter immediately, do so at once!

### If you are instructed to evacuate:

Should you need to evacuate, your first option and plan should always be to stay with family or friends. They can have room for you, your pets and help you be most comfortable in a stressful situation. Emergency public shelters will be available and can provide meals and a safe place to stay while you are there. However, they do not provide personal health care. If you require the care of a personal attendant and choose to go to a shelter, bring the attendant with you.

- Listen to the radio or television for the location of emergency shelters. Note those that accommodate people with special needs.
- Shut off water, gas and electricity if instructed to do so.
- Wear appropriate clothing and sturdy shoes.
- Take your disaster supplies kit.
- Lock your home.
- Use travel routes specified by local authorities and do not use shortcuts because certain areas may be impassable or dangerous.
- Confirm upon arrival at an emergency shelter that it can meet your special care needs.
- Inform members of your support network and out-of-town contact of your location and status.

### ADDITIONAL RESOURCES

### 1. Sources For Emergency Preparedness Information

### State

### **Kentucky Office of Homeland Security**

http://homelandsecurity.ky.gov/

### **Kentucky Division of Emergency Management**

http://kyem.ky.gov/

### **Kentucky Emergency Management Association**

http://www.kyema.org/

### Kentucky Cabinet for Health and Family Services Public Health Preparedness

http://chfs.ky.gov/dph/epi/preparedness/KentuckyDisasterResponsePlans.htm

### Kentucky Outreach and Information Network (KOIN)

http://www.chfs.ky.gov/dph/epi/preparedness/KOIN.htm

### **Kentucky Community Crisis Response Board**

http://kccrb.ky.gov/

### **Federal**

### **CDC Emergency Preparedness**

http://emergency.cdc.gov/

### **Disaster Research**

http://www.disaster-research.us/special\_needs1.htm

### FEMA Disaster Preparedness Guide

http://www.fema.gov/areyouready/

### **Red Cross Disaster Preparedness**

http://www.redcross.org/services/disaster/0,1082,0\_9\_,00.html

### **Sources for Medical Emblems**

### **MedicAlert Foundation**

http://www.medicalert.org 1-800-ID-ALERT (1-800-646-4777)

Your local pharmacy

### 2. Community Emergency/Disaster Resource Form

Complete this form as you are preparing your emergency plan. It can be a quick reference if you have a question or are updating your plan.

Hospitals / Urgent Care Centers / Outpatient Medical Facilities				
Contact person or office	Location	Phone/Email/Web site		
Emergency Preparedness Planner/Office				
Contact person or office	Location	Phone/Email/Web site		
Red Cross				
Contact person or office	Location	Phone/Email/Web site		
Public Health Department				
Contact person or office	Location	Phone/Email/Web site		
Emergency Shelters (Include special needs shelters and note accordingly)				
Contact person or office	Location	Phone/Email/Web site		
Other Resources (e.g. Fire and Police Departments, Senior Center, Food Bank, Utility Companies, etc.)				
Contact person or office	Location	Phone/Email/Web site		

### 3. Personal Medical Information Form

Complete this form and update it regularly so you always have your medical information ready to take with you in a disaster.

DOB:	
State: Zip:	
Mobile Phone:	
Physician Information	
Primary Care Provider	
Name:	
Address:	
Phone:	
Specialty Care Provider	
Name:	
Specialty:	
Address:	
Phone:	
Specialty Care Provider	
Name:	
Specialty:	
Address:	
Phone:	
Specialty Care Provider	
Name:	
Specialty:	
Address:	
Phone:	
Allergies (List food, environmental	
and medication allergies):	

Medication Information: It is important to not only know the name and dosage of the medication, but also why you take it and what can happen it you stop.		
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19.		
20.		
Please copy this sheet if more medications need to be listed.		

### 4. Emergency Contact Information Cards

Make sure your family has a plan in case of an emergency. Fill out these cards and give one to each member of your family to make sure they know who to call and where to meet in case of an emergency.

<b>Emergency Contact Information</b>	Emergency Contact Information
Contact Name:	Contact Name:
Phone:	Phone:
Out-of-Town Contact Name:	Out-of-Town Contact Name:
Phone:	Phone:
Neighborhood Meeting Place:	Neighborhood Meeting Place:
Phone:	Phone:
Additional Important Contacts & Info	Additional Important Contacts & Info
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	<u> </u>
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Emergency Contact Information	Emergency Contact Information
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Contact Name: Phone:	Contact Name: Phone:
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### 5. Pets and Disasters

If you are evacuating, remember that if it is not safe for you, it is not safe for your pets. While preparing your family's disaster supplies kit, include items your pets may need. Listed below are recommendations from the American Society for the Prevention of Cruelty to Animals (ASPCA):

- Food: Keep at least a three-day supply of food in an airtight, waterproof container.
- **Water:** Store at least a three-day supply of water specifically for your pets in addition to water you need for yourself and your family.
- **Medicines and medical records:** Keep an extra supply of medicines your pet takes on a regular basis in a waterproof container.
- **First aid kit:** Talk to your veterinarian about what is most appropriate for your pet's emergency medical needs. Most kits should include:

Cotton bandage rolls

Latex gloves

o Bandage tape

Isopropyl alcohol

o Scissors

- Saline solution
- Antibiotic ointment
- Pet first aid reference book
- Flea and tick prevention

### • Collar with ID tag, harness or leash:

- Your pet should wear a collar with its rabies tag and identification at all times.
- o Include a backup leash, collar and ID tag in your pet's emergency supply kit.
- Place copies of your pet's registration information, adoption papers, vaccination documents and medical records in a clean plastic bag or waterproof container and add them to your kit.
- Consider talking with your veterinarian about permanent identification such as microchipping and enrolling your pet in a recovery database.

### • Crate or other pet carrier:

o The carrier should be large enough for your pet to stand, turn around and lie down in.

#### • Sanitation:

- Pet litter and litter box (if appropriate), newspapers, paper towels and plastic trash bags
- Household chlorine bleach (can be used as a disinfectant, dilute nine parts water to one part bleach)

### • A picture of you and your pet together:

- A picture of you and your pet together will help you document ownership and allow others to assist you in identifying your pet, if you become separated
- Include detailed information about species, breed, age, sex, color and distinguishing characteristics

### • Familiar items:

 Put favorite toys, treats or bedding in your kit. Familiar items can help reduce stress for your pet.

### • Sheltering pets:

Other than service animals, animals are not allowed in public shelters. Prepare
a list of family, friends, boarding facilities, veterinarians and "pet-friendly"
hotels that could shelter your pets in an emergency.

### • Emergency contact information:

- o Gather contact information for emergency animal treatment.
- Make a list of contact information and addresses of area animal control agencies including the Humane Society or ASPCA and emergency veterinary hospitals.
- Keep one copy of these phone numbers with you and one in your pet's emergency supply kit.

### 6. Transfer Trauma

#### **Definition:**

Transfer trauma is defined as the negative impact of sudden relocation usually following abrupt, unplanned moves of the frail elderly. This condition may occur whether in a shelter, hotel or staying with friends or relatives.

### Signs and Symptoms:

- Confusion
- Aggression
- Obsessive Behaviors
- Depression
- Serious illness that could lead to death

### **Behavioral Symptoms:**

- Asks frequently, 'What time is it?"
- Distrustful-afraid someone will steal their belongings
- Crying
- Refusal to eat, bathe or change clothes
- Jumbling facts
- May become combative
- Increased incontinence

### How to Minimize the Effects of Transfer Trauma:

- Learn all you can about the nature of the disaster.
- Develop and update your disaster plan.
- Designate who will be responsible for transportation of all family members.
- Have a family meeting and share the plan with everyone.
- Include physical, personal and emotional security issues in the plan.
- Bring a calendar to provide a visual picture of day and length of stay.
- Establish a chain of command and a common meeting place.
- Make arrangements for pets.
- Gather medical supplies.
- Take small valuables and familiar objects.
- Assign a constant companion to the elderly.
- Write down where and with whom each person is going and have one person to contact.

### 7. Stress Reactions

It is normal to feel anxious and upset when you are involved in a disaster or crisis situation. Individuals with a chronic disease may feel the symptoms more intensely than other individuals who do not have to plan for medical care. The following signs and symptoms are very common in crisis situations. You may experience just one or several at a time. Do not be too alarmed; these symptoms are normal. If, however, they last longer than two to four weeks and are affecting your health, please talk to a member of your health care team (doctor, nurse, social worker, etc.).

### **Common Symptoms of Stress**

- Anxiety
- Crying Spells
- Irritability
- Memory Problems
- Nightmares
- Anger

- Sleeplessness
- Panic Attacks
- Appetite Loss
- Difficulty Making Decisions
- Inability to Concentrate
- Feeling Overwhelmed

Remember, in most cases, you are reacting normally to an abnormal situation. Some things you can do for yourself and your family, during this time, include:

- Recognize your own feelings
- Talk to others; it will help relieve your stress
- Accept help from others
- Get enough rest
- Get as much physical activity as possible

### 8. Medical Items/Needs

### Medical items/needs

It is important that you take all medications as prescribed and do not interrupt or stop any treatments without your doctor's approval. Doing so may result in a return of your symptoms and progression of your disease. A disaster or emergency situation may make it difficult to continue with your treatment regime. That is why it is so important to plan ahead. In addition to those items previously listed in this manual, the following may be helpful to have available in a disaster situation:

- If you use supplemental oxygen:
  - Have an extra portable cylinder of oxygen available.
  - Try to estimate the time it takes to use an oxygen cylinder. This will help in determining how long your supply will last. Remember, stressful situations may cause you to breathe more quickly, causing your oxygen supply to run down faster.
  - Contact your oxygen provider and ask how much oxygen is required in your home so that oxygen flow is uninterrupted, even during a power outage or snow emergency. This length of time is dependent on a number of factors, including how easy it is to get to your home with snow or ice on the ground.
  - If you live in a rural or remote area where frequent or long-lasting power outages occur, you should consider purchasing and installing a generator.
  - Have a plan to obtain additional oxygen should your supply run out.
  - Pack extra nasal cannulas so they can be changed particularly if the prongs become soiled or uncomfortable. In many places they are free from your suppliers.
- Store all of your supplies and parts for your nebulizer or other medical equipment in a plastic container or storage bag next to your equipment. It can be gathered up quickly in case you have to evacuate your home.

- Pack any items needed to properly clean and sanitize your equipment.
- Include a mask or other equipment to minimize your contact with irritants. Disasters can stir up a variety of irritants (smoke, pollen, mold, fumes, etc.).
- You may be extra sensitive to temperature extremes (cold or hot weather). Pack the following items in your kit to help with this:
  - Cold weather a coat, sweaters, shawls or blankets, socks, gloves and a scarf or cold-weather mask (Make sure the coat is warm, but light-weight enough that it won't make you overheat.)
    - Cold weather can make arthritis and certain circulation problems worse. Pack disposable heat packs to warm up stiff hands.
  - o Hot/humid weather: A small battery-operated or manual fan may help to keep you cool.
- Put on shoes and take comfortable slippers with you.
- If you are on special treatments such as chemotherapy or radiation you should have copies of your chemotherapy or radiation treatment plans in addition to any medications you are taking.
- If you have to leave your area and are undergoing chemotherapy or radiation treatment, consult your physician or ask your treatment facility how to plan for an alternative treatment location if needed. Contact the alternative treatment facility to find out where they are located and how it would work if you needed to see them during a disaster.
- Your condition and/or treatment may make you more susceptible to an infection. Pack plenty of hand sanitizer, disinfectant wipes, etc. Also, make sure you only drink water and eat food that you know is safe.
- Some cancer treatments, certain blood pressure medications and fluid pills can make you very sensitive to the sun. Be sure to pack sunscreen, a wide-brimmed hat, an umbrella or other items that can shield you from the sun if needed.
- Your condition and treatment can cause you to become easily fatigued. Take several naps or rest breaks during the day, rather than one long rest. Plan your day to include rest breaks. Take short walks or get regular exercise, if possible. Some people find this helps to lessen their fatigue and raise their spirits.
- Side effects from certain treatments (e.g., vomiting, diarrhea) may require additional medication including over-the-counter medications. Remember to consult your physician about what you can take and include these in your kit.
- Your condition may also require more water than the gallon a day per person recommendation. If you have been advised to drink more fluids, have more available.
- Communication Devices
  - If you do require a communication device, it may be helpful to have preprogrammed statements or preprinted cards alerting rescue personnel of your condition and possible needs.
  - If you do not require a communication device, preprinted cards listing your condition and possible needs may still be helpful. You may be unable to speak quickly and emergency situations may make it difficult for you to clearly communicate with responders.
- Store needed mobility aids (canes, crutches, leg braces, walkers, wheelchairs) close to you in a convenient location. If possible, keep extras in several locations throughout your house.
- If you fall easily, consider getting hip protectors. In a disaster situation, you may be forced to get around debris or walk around in an unfamiliar place. Hip protectors can help prevent a fracture if you should fall.

- Avoid heavy lifting or carrying. Place disaster supplies in a cart with wheels that can be pushed or pulled.
- A portable scale may be necessary if you have been told to monitor daily weights for heart failure.
- If you use a wheelchair:
  - o Keep a patch kit or extra inner tubes in your kit.
  - Manual wheelchair: Keep a pair of heavy gloves in case you have to wheel over glass or other sharp debris.
  - Motorized wheelchair: In case of a power outage, keep an extra battery and have a plan to recharge your chair. For example, purchase a converter that plugs into your vehicle's cigarette lighter.
  - o Consider having a lightweight manual wheelchair as a back-up
  - There will be times when you may have to leave your wheelchair in order to
    evacuate safely. If you cannot use stairs, familiarize yourself and your personal
    care network with lifting and carrying techniques that work for you. Also, be
    prepared to give these instructions to rescue workers.
  - When preparing your exit plan, make sure more than one exit is wheelchair accessible.
- Have your medication and dosing schedule printed out clearly.
- If possible, inform any responders or new caregivers about any pattern of ups and downs that are part of your usual functioning due to "on-off" fluctuations.

### 9. Dietary

### Dietary needs

- When gathering food items for your disaster supplies kit, keep in mind the nonperishable foods in your disaster supplies kit should be as well-balanced as possible with foods providing protein, carbohydrates, and fats; remembering to pack foods that are found in an overall healthy diet.
- Keep in mind any dietary restrictions you may have. For example, foods high in sodium can cause fluid retention which may make your feet swell and affect your breathing. Most canned foods contain a lot of sodium. Cured or smoked meats (jerky or beef sticks) also contain very high levels of salt. If you are on a sodium restricted diet, look for nonperishable foods that are low in sodium.
- Pack nonperishable foods that you are able to prepare and eat. For example, your condition may make it difficult to use a manual can opener, so choose food items such as granola bars or cans with pop-tops.
- Make sure the foods you choose do not interact or interfere with the effectiveness of your medications
- If you use any special devices to help you prepare or eat food, remember to include them in your emergency supplies kit. These can include easy to grip forks, spoons, and knives, non-skid plates and bowls, as well as cups and mugs with lids and straws.
- Some of these suggestions may be difficult to follow during a disaster situation. Perishable foods such as milk, cheese and eggs may be hard to come by and are unlikely to be stored in a disaster supplies kit. High protein foods can be found in nonperishable forms. For example, powdered milk, canned meats and protein bars can all be used. Other examples are granola, protein or other meal replacement bars that have tear open packages.

- Check to make sure food items do not contain any allergens that can affect your breathing.
- Eating several small meals throughout the day makes digestion easier on the body and uses less energy!
- Avoid or limit foods that cause heartburn or gas, because bloating makes breathing more difficult.
- Maintain good fluid intake. Drink plenty of fluids (at least one gallon of water each day) unless you have been told by your physician to limit your fluids. This will prevent dehydration, especially if you have diabetes or are on certain medications. It also helps thin secretions, making it easier to cough up mucus if you have lung disease.
- If you have cancer, your doctor or dietician may make recommendations that are different from your regular diet. You may be told to eat more calories. You may also be told to increase your protein by eating more eggs, cheese and milk. You may even be told to eat less of certain high-fiber foods because they can aggravate problems such as diarrhea or a sore mouth.
- Side effects from cancer treatment often affect eating. It is important to know what the effects are so that you can stock the appropriate foods in your disaster supplies kit. Also, side effects such as vomiting and diarrhea may cause dehydration. Pack extra water and any over-the-counter medications your doctor has suggested to treat these symptoms in your kit. Work with your physician or your dietitian to learn about the foods items you should include in your disaster supplies kit. Your nutrition needs and the foods you tolerate well may change as you go through treatment.
- Your physician or dietitian may also recommend that you take nutritional supplements (vitamins and/or liquid supplements) based on your individual needs. Remember to include these in your disaster supplies kit.
- If taking in enough calories and swallowing has become difficult, you may need to pack liquid nutrition drinks, a thickener for fluids or even feeding tube supplements.
- If you are a diabetic, be sure to pick fruit canned in juice, not syrup.
- Please consult your physician for more information or any questions about planning for a disaster and dietary restrictions.

### DISEASE SPECIFIC INFORMATION

## 1. Asthma, Chronic Obstructive Pulmonary Disease (COPD) and Other Lung Diseases

### **Asthma**

Asthma is a lung disease that causes you to have difficulty breathing. More than 20 million Americans suffer from asthma. People with asthma may have airways that are inflamed. This means that they swell and produce large amounts of thick mucus. They are also overly sensitive to certain things like dust, cigarette smoke or even exercise, which are called triggers. This sensitivity causes the muscles that surround the airways to tighten up. The combination of airway inflammation and muscle tightening narrows the airways and makes it difficult for air to move through. This is what happens to a person's lungs during an asthma attack.

### What are the Symptoms of Asthma?

Most people with asthma only have difficulty breathing every so often. When it does happen, it is known as an asthma flare-up or an asthma attack. A person having an asthma attack may cough, wheeze (make a whistling sound while breathing), be short of breath and feel an intense tightness in the chest. Many people say it feels extremely hard to get air in and out of their lungs, like they are breathing through a small straw. An asthma attack can last for several hours or longer if a person doesn't use asthma medication. Afterwards, the person usually feels better.

#### What Causes Asthma?

The exact cause of asthma is not known, but it is believed to be a combination of environmental and genetic factors. It isn't contagious. Asthma symptoms can be triggered by many things. What causes symptoms in one person might not bother another at all. The following are some of the common triggers:

- Allergens
- Airborne irritants and pollutants
- Exercise
- Weather
- Respiratory tract infections

There are other things that can trigger symptoms, even laughing, crying, and yelling can sometimes cause the airways to tighten in sensitive lungs, triggering an asthma attack.

### How do Doctors Diagnose Asthma?

In diagnosing asthma, the doctor will study your medical history and also perform a physical exam. Your doctor may perform some tests including spirometry and peak flow meter tests. These tests measure how well your lungs are performing. Your doctor may also recommend allergy tests to see if allergies are causing your symptoms or special exercise tests to see whether your asthma symptoms may be brought on by physical activity.

### How is Asthma Treated?

There's no cure for asthma, but the condition can usually be managed and flare-ups can be prevented. Asthma is treated in two ways, by avoiding potential triggers and with medication. Avoiding triggers that make asthma symptoms worse is important. They can't always be avoided (like catching a cold), but you can control your exposure to some triggers such as pet dander, for example.

Each person with asthma is treated differently because each person has a different severity level and a different set of triggers. There are a variety of treatment medications doctors can choose from. Most asthma medications are inhaled (which means that a person takes the medication by breathing it into the lungs), but asthma medications can also take the form of pills or liquids. They fall into two categories:

- **Rescue medications** are taken as needed and act quickly to halt asthma symptoms once they start.
- Controller medications prevent symptoms from occurring in the first place.

Many people with asthma need to take medication every day to control the condition overall. Controller medications (also called "preventive" or "maintenance" medications) work differently from rescue medications. They treat the problem of airway inflammation instead of the symptoms (coughing, wheezing, etc.) that it causes. Controller medications are slow acting and can take days or even weeks to begin working. Although you may not notice them working in the same way as rescue medications, regular use of controller medications should lessen your need for the rescue medications. Doctors also prescribe controller medications as a way to minimize any permanent lung changes that may be associated with having asthma.

The best way to control asthma is prevention. Although medications can play an essential role in preventing flare-ups, environmental control is also very important. Here are some things you can do to help prevent coming into contact with the allergens or irritants that cause your asthma flare-ups:

- Keep your environment clear of potential allergens.
- Pay attention to the weather and take precautions when you know weather or air pollution conditions may affect you. You may need to stay indoors or limit your exercise to indoor activities.
- Don't smoke (or if you're a smoker, quit). Smoking is a bad habit, especially for someone who has asthma.
- Exercise, but be careful. If you're prone to exercise-induced asthma attacks, talk to your doctor about how to manage your symptoms.

Preventing asthma symptoms may be difficult to do during an emergency situation. A disaster can stir up a variety of irritants into the air. Take precautions by attempting to avoid areas (outdoors or indoors) where there are high levels of irritants. Wearing a dust mask may also help to cut down on exposure. It is also important that prescribed medications be continued. Interrupting or stopping medications can cause an increase in airway inflammation, leading to coughing, wheezing, shortness of breath, chest tightness and more frequent asthma attacks. Overuse of fast acting or relief medications can also cause them to lose their effectiveness.

### Chronic Obstructive Pulmonary Disease (COPD)

Chronic obstructive pulmonary disease (COPD) is an umbrella term for chronic bronchitis, emphysema and a range of other lung disorders. These disorders are characterized by obstruction of airflow that interferes with normal breathing. In COPD, the airways that carry air in and out of your lungs become partially blocked, making it difficult to get air in and out. COPD is a major cause of death and illness throughout the world and is the fourth leading cause of death in the U.S.

### What are the Symptoms of COPD?

The symptoms of COPD include a cough that does not go away, coughing up sputum (mucus), shortness of breath (especially with exercise), wheezing or a whistling sound when you breathe, tightness in the chest and fatigue (tiredness). These symptoms often start years before the flow of air in and out of the lungs is reduced. Not everyone who has a cough and sputum will develop COPD later in life.

#### What Causes COPD?

COPD usually develops slowly over time. Symptoms may develop when an individual is breathing in fumes, dusts and other irritants that damage the lungs and airways over a long period of time. Smoking tobacco (cigarettes, cigars and pipes) is the most common cause of COPD. Most people with COPD are smokers or have been smokers in the past.

Individuals who have worked many years around certain kinds of chemicals and breathed in the fumes, worked in a dusty area or have had heavy exposure to air pollution may also develop COPD. In rare cases, COPD is caused by a gene-related disorder called alpha 1 antitrypsin deficiency. People with the alpha 1 antitrypsin protein in their blood may experience lung damage and COPD. If people with this condition smoke, the disease progresses more rapidly. If you smoke, the most important thing you can do to prevent more lung damage is to stop smoking. It is also important to stay away from people who smoke and places where you know there will be smokers.

### How do Doctors Diagnose COPD?

Your doctor will diagnose COPD by examining you, listening to your lungs, asking you questions about your medical history and what lung irritants you may have been around for long periods of time. Your doctor may also use a spirometer measure how much air your lungs can hold and how fast you can blow air out of your lungs. Based on this test, your doctor can determine if you have COPD and how severe it is. Your doctor may also order a chest X-ray and an arterial blood gas test. The blood test shows the oxygen level in the blood to see if oxygen treatment is needed.

### How is COPD Treated?

There is no cure for COPD. Damage to your airways and lungs cannot be reversed, but there are things you can do to feel better. COPD symptoms can be managed and damage to the lungs can be slowed. The most important thing you can do to slow the progress of the disease is to quit smoking. Your doctor may recommend treatments to relieve your symptoms and there are things you can do to live better with the disease. The goals of COPD treatment are to:

- Relieve symptoms with no or minimal side effects of treatment
- Slow the progress of the disease
- Improve the ability to stay active and exercise
- Prevent any complications from the disease
- Improve health overall

Treatment for each person is different and is based on whether symptoms are mild, moderate or severe. There are a variety of treatments that can help reduce symptoms and manage complications, including:

• **Bronchodilators** - medications that work by relaxing the muscles around your airways, opening them and making it easier to breathe. They can last either 4-6 hours or 12 hours, depending on the type. Most are inhaled directly into the lungs with the use of an inhaler.

- **Inhaled steroids** used for some people with moderate or severe COPD to reduce the inflammation or swelling in the airways.
- **Vaccines** it is recommended that you get a pneumococcal vaccine to prevent pneumonia and an annual flu shot to avoid any breathing complications.
- Pulmonary or lung rehabilitation (rehab) helps you stay active despite your COPD. It includes exercise training, nutrition advice and education about managing the disease. A custom pulmonary rehab program is managed by a multidisciplinary team (doctors, nurses, respiratory therapists, exercise specialists, dietitians).
- Oxygen therapy for severe COPD and low levels of oxygen in the blood. Using extra oxygen can help you perform tasks or activities with less shortness of breath, protect the heart and other organs from damage, improve the quality and duration of your sleep, improve your alertness during the day and help you live longer.
- **Surgery** is usually done for patients who have severe symptoms, have not improved with medications and have a hard time breathing most of the time. There are two types of surgery for COPD: a bullectomy, which removes a large air sac that may compress a good lung, or a lung transplant.

The goal of COPD treatment is to prevent or minimize the progression of the disease. During a disaster or emergency situation it may be difficult to follow all treatment recommendations. Stopping treatments may increase the frequency or severity of breathing difficulties. You may also become overly tired and eventually require hospitalization. You should also call your doctor if you have sudden chest tightness, more coughing, a change in your sputum or fever. This could signal a lung infection. It is important that all treatment recommendations be followed to the best of your ability in order to maintain lung function, prevent further lung damage and maintain your quality of life.

#### **Chronic Bronchitis**

Chronic bronchitis is an inflammation of the main airways in the lungs that continues for a long period of time or keeps coming back. Cigarette smoking is the main cause of chronic bronchitis. The more a person smokes, the more likely the person will develop severe bronchitis. Secondhand smoke may also cause chronic bronchitis. Air pollution, infection and allergies make chronic bronchitis worse.

Symptoms include a cough that produces mucus (sputum), which may be blood streaked; shortness of breath aggravated by exertion or mild activity; frequent respiratory infections that worsen symptoms; wheezing; fatigue; ankle, foot and leg swelling that affects both sides; and headaches.

Chronic bronchitis is one form of chronic obstructive pulmonary (lung) disease. Chronic bronchitis, emphysema, and asthma as a group are a leading cause of death in the U.S.

### **Emphysema**

Emphysema is a lung disease that involves damage to the air sacs (alveoli) in the lungs. The air sacs are unable to completely deflate, and are therefore unable to fill with fresh air to ensure adequate oxygen supply to the body.

Cigarette smoking is the most common cause of emphysema. Tobacco smoke and other pollutants are thought to cause the release of chemicals from within the lungs that damage the walls of the air sacs. This damage becomes worse over time, affecting the exchange of oxygen and carbon dioxide in the lungs.

Symptoms of emphysema include shortness of breath; chronic cough with or without sputum production; wheezing and decreased ability ability to exercise. Additional symptoms that may be associated with this disease include: anxiety; unintentional weight loss; ankle, feet, and leg swelling; and fatigue.

Smoking cessation is the most important and effective treatment. Quitting smoking can stop the progression of lung damage once it has started. Medications used to improve breathing include bronchodilators (hand-held inhaler or nebulizer), diuretics and corticosteroids. Antibiotics may be prescribed when respiratory infections occur. Influenza (flu) vaccines and Pneumovax (pneumonia vaccine) are recommended for people with emphysema.

### Sources for Additional Asthma, COPD and Other Lung Diseases Information

### **American Lung Association**

www.lungusa.org 1-800-LUNG-USA (1-800-586-4872)

### Asthma and Allergy Foundation of America

www.aafa.org 1-800-7-ASTHMA (1-800-727-8462)

### National Heart Lung and Blood Institute

COPD - http://www.nhlbi.nih.gov/health/dci/Diseases/Copd/Copd\_WhatIs.html Asthma - http://www.nhlbi.nih.gov/health/dci/Diseases/Asthma/Asthma\_WhatIs.html

### Kentucky Cabinet for Health and Family Services

COPD - http://chfs.ky.gov/dms/hi/COPD.htm Asthma - http://chfs.ky.gov/dms/hi/Asthma.htm

### Free Tobacco Cessation Assistance

1-800-QUIT-NOW (1-800-784-8669) http://1800quitnow.cancer.gov

### 2. Cancer

Cancer is an umbrella term for more than 100 life-threatening diseases characterized by the uncontrolled, abnormal growth of malignant (cancerous) cells. Normally, cells grow and divide until they eventually die. Cancer cells continue to grow and divide. The resulting mass or tumor can invade and destroy surrounding normal tissues.

### What are the Symptoms of Cancer?

There are many different types of cancer. As a result, there are many different symptoms. There are a few common symptoms including:

- Unintentional weight loss (10 or more pounds)
- Extreme exhaustion
- Headaches
- Blurred vision
- Nausea

- Swelling or lumps in certain parts of the body (e.g., abdomen or neck)
- Problems with walking or balance
- More infections
- Unusual bleeding

#### What Causes Cancer?

Scientists and researchers do not really know what causes cancer, but there is some understanding of why people get cancer. People get cancer based on their genetics and certain environmental or behavioral triggers. For example, if a close relative had lung or skin cancer, you may be more likely to inherit the tendency to get lung or skin cancer. If you are exposed to environmental or behavioral triggers such as smoking cigarettes or excessive sun exposure, you may be more likely to get lung or skin cancer. The combination of genetics and environmental and behavioral triggers determine the likelihood that you will get cancer.

### How do Doctors Diagnose Cancer?

If cancer is suspected, your doctor will order several tests. These may include blood tests, x-rays or an MRI. A biopsy, which involves the removal of a small tissue sample to examine it for cancer cells, may also be performed.

#### **How do Doctors Treat Cancer?**

There are three common methods for treating cancer: surgery, chemotherapy and radiation. Cancer treatment plans are tailored to each patient because cancer is different in each patient. A person with cancer may undergo any one of these treatments or a combination of them:

- **Surgery** removes cancerous tissue. A surgeon removes the cancerous tissue along with a small amount of the healthy tissue surrounding it to make sure that all the cancer is removed and has not spread.
- **Chemotherapy** is the treatment of cancer using medication to destroy malignant (cancerous) cells. Side effects include nausea, fatigue, hair loss or other side effects. Chemotherapy may destroy some healthy cells in the process of removing of the malignant cells. These healthy cells will eventually start to grow again and the side effects should disappear.
- **Radiation or radiotherapy** is when high levels of radiation are used to kill cancer cells or to shrink tumors. It is usually painless, but there are side effects including fatigue,

nausea, vomiting or diarrhea. Sometimes, the area of skin that has been irradiated becomes inflamed. Most of these side effects are temporary.

An interruption in chemotherapy or radiation treatment can result in a spread of the cancer or a more rapid progression of the disease. It can also increase any pain that the individual was suffering due to the cancer. It is important that your treatments continue as scheduled even in a disaster.

**Side Effects to Certain Cancer Treatments** 

Cancer Treatment	How it Can Affect Eating	What Sometimes Happens: Side Effects
Surgery	Increases the need for good nutrition. May slow digestion. May lessen the ability of the mouth, throat and stomach to work properly. Adequate nutrition helps wound-healing and recovery.	Before surgery, a high-protein, high-calorie diet may be prescribed if a patient is underweight or weak. After surgery, some patients may not be able to eat normally at first. They may receive nutrients through a needle in their arm or through a tube in their nose or stomach.
Radiation Therapy	As it damages cancer cells, it also may affect healthy cells and healthy parts of the body.	Treatment of head, neck, chest or breast may cause:  • Dry mouth  • Sore mouth  • Sore throat  • Difficulty swallowing (dysphagia)  • Change in taste of food  • Dental problems  • Increased phlegm  • Nausea and vomiting  • Diarrhea  • Cramps, bloating
Chemotherapy	As it destroys cancer cells, it also may affect the digestive system and the desire or ability to eat.	<ul> <li>Nausea and vomiting</li> <li>Loss of appetite</li> <li>Diarrhea</li> <li>Constipation</li> <li>Sore mouth or throat</li> <li>Weight gain or loss</li> <li>Change in taste of food</li> </ul>
Biological Therapy Immunotherapy	As it stimulates your immune system to fight cancer cells, it can affect the desire or ability to eat.	<ul> <li>Nausea and vomiting</li> <li>Diarrhea</li> <li>Sore mouth</li> <li>Severe weight loss</li> <li>Dry mouth</li> <li>Change in taste of food</li> <li>Muscle aches, fatigue, fever</li> </ul>
Hormonal Therapy	Some types can increase appetite and change how the body handles fluids.	Changes in appetite     Fluid retention

Chart source: National Cancer Institute www.cancer.gov

### Sources for Additional Cancer Information

### **American Cancer Society**

http://www.cancer.org 1-800-ACS-2345

TTY: 1-866-228-4327

TTY: 1-800-332-8615

### **National Cancer Institute**

http://www.cancer.gov 1-800-4-CANCER (1-800-422-6237)

### **Kentucky Cancer Program**

http://louisville.edu/org/kycancerprogram

### **Cancer Care**

http://www.cancercare.org 1-800-813-HOPE (1-800-813-4673)

### National Coalition for Cancer Survivorship

http://www.canceradvocacy.org 1-888-650-9127

### Free Tobacco Cessation Assistance

1-800-QUIT-NOW (1-800-784-8669) http://1800quitnow.cancer.gov

### 3. Dementia and Memory Loss

Dementia is a condition of declining mental abilities, especially memory. An individual with dementia will have problems doing things he or she used to be able to do, like keep the check book, drive a car safely or plan a meal. The individual will often have problems finding the right words and may become confused when given too many things to do at once. Dementia may also cause change in personality, making one become aggressive, paranoid or depressed.

It may take longer to remember things or to find the right word to say as people get older, but this is **not** dementia. Dementia causes mental changes that keep people from doing the things they used to do. Aging alone does not interfere with the ability to function.

### What are the Symptoms of Dementia?

Dementia causes many problems for the person who has it and for the person's family. Many of the problems are caused by memory loss. Some common signs of dementia are listed below. Not everyone who has dementia will have all of these signs.

- **Recent memory loss** People with dementia often forget things, but they never remember them. They might ask you the same question over and over, each time forgetting that you've already given them the answer. They won't even remember that they already asked the question.
- **Difficulty performing familiar tasks** People who have dementia might cook a meal but forget to serve it. They might even forget that they cooked it.
- **Problems with language** People who have dementia may forget simple words or use the wrong words. This makes it hard to understand what they want.
- **Time and place disorientation** People who have dementia may get lost on their own street. They may forget how they got to a certain place and how to get back home.
- **Poor judgment** People who have dementia can forget simple things, like forgetting to put on a coat before going out in cold weather.
- **Problems with abstract thinking** People who have dementia may forget what numbers are and what has to be done with them.
- **Misplacing things** People who have dementia may put things in the wrong places and can't find them later.
- **Changes in mood** People with dementia may have fast mood swings, going from calm to tears to anger in a few minutes.
- **Personality changes** People who have dementia may have drastic changes in personality. They might become irritable, suspicious or fearful.
- Loss of initiative People who have dementia may become passive. They might not want to go places or see other people.

#### What Causes Dementia?

There are many causes of dementia, including strokes, low vitamin B12 levels, thyroid conditions, depression, AIDS and other infections. Medications and some illnesses can cause confusion (delirium) in older people that may look like dementia. Dementia is also caused by the destruction of brain cells. A head injury, a stroke, a brain tumor or Alzheimer's disease can damage brain cells.

### How do Doctors Diagnose Dementia?

If dementia is suspected, the doctor will perform a medical exam, order blood work and run some memory tests. Other tests, including a CT scan or MRI scan of the brain, may also be done.

#### How is Dementia Treated?

Some cases of dementia are caused by medical conditions that can be treated, fully or partly restoring mental function. When dementia cannot be reversed, the goal of treatment is to make life as easy as possible for the person and the caregivers.

If the cause of dementia can be reversed, the doctor will prescribe treatment. For example, the person might take vitamins for a deficiency of folic acid, vitamin B12, or thiamine; take medicines to treat an infection, such as encephalitis, that is causing changes in mental state; or stop or change medications that are causing memory loss or confusion.

If the cause of dementia cannot be treated, the doctor will work with the person and caregivers to develop a plan to make life easier and more comfortable. Care plans may include tips to help the person be independent and manage daily life as long as possible. Education of the family and other caregivers is critical to successfully caring for a person with dementia.

### Tips for Managing a Person with Dementia in a Disaster

People with dementia are especially vulnerable to chaos and emotional trauma. They have a limited ability to understand what is happening, and they may forget what they have been told about the disaster. Planning ahead now can help to reduce trauma and ease agitation should an emergency or disaster situation occur. In addition to those listed previously in this manual, other items that may be helpful to have in a disaster situation, include:

### Additional Items to Include in Your Kit

- Change of clothing make sure these items are comfortable to wear and are easy to get on or off.
- Sleeping bag or warm blanket older individuals can not tolerate the cold as well as younger people. Consider packing extra blankets. Also, a familiar blanket may be a comfort item to an individual with dementia.
- Extra identification items such as clothing tags, wallet cards or ID jewelry (bracelets, necklace, dog tags, etc.)
- A recent photo of your loved one in case he/she wanders away in the commotion
- Activities to keep the individual occupied (e.g., books, crossword puzzles, newspapers, playing cards)
- Additional health care information:
  - o Copies of any legal documents such as your power of attorney
  - Make sure other care attendants that help you also have copies of your loved one's dementia medical history, physician information and family contacts.

### **During an Evacuation**

Be alert to potential reactions that may result from changes in routine, traveling or new environments.

• When appropriate, inform others (hotel or shelter staff, family members, airline attendants) that your loved one has dementia and may not understand what is happening.

- Do not leave the person alone. It only takes a few minutes to wander away and get lost.
- Don't ask a stranger to watch the person. A person who doesn't understand dementia and its effects, and who doesn't know you or the person, won't understand how to react in a difficult situation.
- Changes in routine, traveling and new environments can cause:
  - o Agitation
  - Wandering
  - o Increase in behavioral symptoms, including hallucinations, delusions and sleep disturbance
  - $\circ$  Do your best to remain calm. The person with dementia will respond to the emotional tone you set.

### **Tips for Preventing Agitation**

- Try to spend extra time with the person to help him or her adjust to the new environment.
- Try to maintain daily routines as much as possible.
- Reassure the person. Hold hands or put your arm on his or her shoulder and assure them things will be fine.
- Find outlets for anxious energy. Take a walk together or engage the person in simple tasks.
- Redirect the person's attention if he or she becomes upset.
- Limit news media exposure to the disaster.
- Move the person to a safer or quieter place, if possible. Limit stimulation.
- Make sure the person takes medications as scheduled.
- Try to schedule regular meals and maintain a regular sleep schedule.
- Avoid elaborate or detailed explanations. Provide information using concrete terms. Follow brief explanations with reassurance.
- Be prepared to provide additional assistance with all activities of daily living.
- Pay attention to cues that the person may be overwhelmed (fidgeting, pacing).
- Remind the person that he or she is in the right place.
- Provide comfort items, such as:
  - o A pillow or familiar stuffed animal that can be hugged
  - o Lotion or other items that can help soothe the individual

### Helpful Hints During an Episode of Agitation

- Approach the person from the front and use his or her name.
- Use calm, positive statements and a patient, low-pitched voice. Reassure.
- Respond to the emotions being expressed rather than the content of the words. For example, say, "You're frightened and want to go home. It's okay. I'm right here with you."
- Don't argue with the person or try to correct him. Instead, affirm his or her experience, reassure and try to divert attention. For example, say, "The noise in this shelter is frightening. Let's see if we can find a quieter spot. Let's look at your photo book together."

### **Wandering Behavior**

- Identify the most likely times of day that wandering may occur, and plan activities at that time.
- Provide opportunities for activities and exercise, such as folding towels, listening to music and dancing.
- When night wandering is a problem, make sure the person has restricted fluids two hours before bedtime and has gone to the bathroom just before bed. Limit daytime naps, if possible.
- Monitor reaction to medications. Consult a physician, if necessary.
- Utilize communication focused on exploration and validation (not correcting) when the individual says that he or she want to leave to go home or to work.
- If wandering is in progress, use distraction to re-direct the individual's focus.
- Consider enrolling your loved one in the Alzheimer's Association's Safe Return® program Imore information in next section. An individual with dementia may not have this particular disease, but wandering behavior may be a symptom of his or her dementia. This program can help in locating an individual.

#### Take Care of Yourself

- Take care of yourself by finding a good listener to hear your thoughts and feelings about the event.
- Find moments to breathe, meditate and reflect.
- Ensure proper nutrition and hydration.

### Alzheimer's Association Safe Return®

The Alzheimer's Association Safe Return® program assists in the safe return of individuals with Alzheimer's disease or a related dementia who wander and become lost. Safe Return is a nationwide identification and support program working at the community level. Assistance is available 24 hours a day whenever a person is lost or found. One call immediately activates the community support network to help reunite a lost person with Alzheimer's disease with his or her caregivers. When an individual is missing, Safe Return faxes the enrolled person's information and photo to local law enforcement. When a person is found, a citizen or law official calls the 800-number and Safe Return notifies listed contacts. The local Alzheimer's Association chapter provides support to the family during the incident.

#### Safe Return® Benefits

- The Alzheimer's Association 24-hour toll-free emergency incident line
- A registration line available Monday through Friday between 7 a.m. and 11:30 p.m. (CST)
- Personalized identification products
- Five steps for a Safe Return® magnet card, which provides useful tips when someone is missing
- Enrollment in a national information and photo database that includes emergency contact information to help reunite a lost person with his or her caregivers
- The Alzheimer's Association 24/7 Helpline, which is available day and night, every day, for information and care consultation

- Your Alzheimer's Association local chapter, which provides information, referral and other services
- Education and training on wandering behavior for families, caregivers and emergency responders

For safety and peace of mind, enroll in Safe Return today. Contact us today by calling toll-free at 1.888.572.8566 or online at http://www.alz.org/safereturn.

The Alzheimer's Association, the world leader in Alzheimer research, care and support, is dedicated to finding prevention methods, treatments and an eventual cure for Alzheimer's.

# 24/7 Helpline 800-272-3900 TDD Access 312-335-8882 Web site http://www.alz.org e-mail info@alz.org

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## Sources for Additional Dementia and Memory Loss Information

### National Institute for Neurological Disorders and Stroke

http://www.ninds.nih.gov/disorders/dementias/dementia.htm

#### Alzheimer's Association

http://www.alz.org Tel: 1.800.272.3900

#### Alzheimer's Association Safe Return

http://www.alz.org/safereturn

Tel: 888.572.8566

#### **National Institute on Aging**

#### Alzheimer's Disease Education and Referral (ADEAR)

http://www.alzheimers.nia.nih.gov

Tel: 1.800.438.4380

#### **Family Caregiver Alliance**

http://www.caregiver.org

Tel: 1.800.445.8106

#### **Children of Aging Parents**

http://www.caps4caregivers.org

Tel: 800.227.7294

#### **Eldercare Locator**

http://www.eldercare.gov

Tel: 800.677.1116

#### Well Spouse Association

http://www.wellspouse.org

Tel: 800.838.0879

#### 4. Diabetes

If you have diabetes, your body cannot make or properly use insulin. Insulin is a hormone that helps control the sugar, or glucose, in your blood. Glucose is the main source of fuel for your body. When you have diabetes, the levels of blood glucose are too high. There are 20.8 million children and adults in the U.S., or 7 percent of the population, who have diabetes. While an estimated 14.6 million have been diagnosed, 6.2 million people (or nearly one-third) are unaware that they have the disease.

#### What are the Symptoms of Diabetes?

Diabetes is often called a "silent" disease because many people have no signs or symptoms before they are diagnosed. Symptoms can also be so mild that you might not notice them. More than 5 million people in the U.S. have type 2 diabetes and do not know it. The signs of diabetes are:

- Being very thirsty
- Urinating often
- Feeling very hungry or tired
- Losing weight without trying
- Having sores that heal slowly
- Having dry, itchy skin
- Having blurry eyesight
- Losing the feeling in your feet or having tingling in your feet

#### What Causes Diabetes?

Diabetes prevents the body from properly converting foods into the energy needed for daily activity. When you eat, your body changes most of the food into a form of sugar called glucose. Glucose travels through the blood stream to "fuel," your cells. For glucose to get into cells, the hormone insulin must be present. If your body does not make enough insulin or if the insulin doesn't work the way it should, glucose can't get into your cells. It remains in your blood, while the cells are starved of energy. The level of glucose in your blood then gets too high, causing diabetes. Over time, high levels of glucose in the blood damage nerves and blood vessels. This can lead to complications such as heart disease and stroke, kidney disease, blindness, nerve damage, gum infections and lower limb amputation.

- **Type 1** diabetes is an autoimmune disease. The immune system attacks the insulin-producing cells in the pancreas and destroys them. The pancreas then produces little or no insulin.
- **Type 2** diabetes, the most common form, usually begins when the cells do not use insulin properly (called insulin resistance). As the need for insulin goes up, the pancreas gradually loses its ability to produce as much as needed. Insulin production tends to decrease in people with Type 2 diabetes after several years.

Diabetes risk factors include:

- Being overweight or obese
- Having a first-degree relative (a parent, brother or sister) with diabetes
- Being African American, American Indian or Alaskan Native, Asian American or Pacific Islander or Hispanic American/Latino
- Having gestational diabetes, or giving birth to at least one baby weighing more than 9 pounds
- $\bullet$  Having blood pressure of 140/90 or higher, or having been told that you have high blood pressure or on therapy for high blood pressure

- Having abnormal cholesterol levels (HDL level of 35 or lower, or a triglyceride level of 250 or higher)
- Being inactive or exercising fewer than three times a week
- Women with Polycystic Ovarian Syndrome (PCOS)
- Conditions associated with insulin resistance (severe obesity and acanthosis nigricans)
- History of cardiovascular disease

### How do Doctors Diagnose Diabetes?

Doctors use the following tests to diagnose diabetes:

- Fasting plasma glucose (FPG test) measures your blood glucose after you have gone at least 8 hours without eating.
- **Oral glucose tolerance test (OGTT)** measures your blood glucose after you have gone at least 8 hours without eating and 2 hours after you drink a sweet beverage.
- Random plasma glucose test measures blood glucose without regard to when you ate your last meal.

#### How is Diabetes Treated?

Diabetes cannot be cured, but it can be controlled. Strict control of blood glucose, or blood sugar, as well as blood pressure and cholesterol is the best defense against the serious complications of diabetes. People with type 1 diabetes control their blood sugar with insulin injections and frequent self-monitoring of blood glucose. People with type 2 diabetes generally control their blood sugar with oral medications and, in some cases, insulin. Sometimes a person with type 2 diabetes can control blood glucose levels with diet and exercise alone. Good control of blood glucose requires:

- **Following a Meal Plan:** Healthy eating is very important, helping you reach and stay at a healthy weight, keeping your blood glucose in a desirable range and preventing heart and blood vessel disease.
- **Getting Regular Physical Activity:** Exercise helps keep weight down, helps insulin work better to lower blood glucose, is good for your heart and lungs and gives you more energy. Before you begin exercising, talk with your doctor.
- Taking Your Diabetes Medicine Every Day
- Checking Your Blood Glucose as Recommended
- Monitoring Your Diabetes ABCs: Heart disease and stroke are the leading causes of death for people with diabetes. If you have diabetes, heart disease is more likely to strike you and at an earlier age than someone without diabetes. Therefore, people with diabetes need to control their A1C or blood glucose average, their Blood pressure, and their Cholesterol the ABCs of diabetes.

Proper monitoring of your diabetes is vital, especially in a disaster situation. While it may be difficult to monitor glucose levels and take medications, failing to do this can lead to diabetic complications including:

- Vision problems diabetes is the leading cause of blindness in the U.S.
- Numbness or pain in arms, legs, hands and feet

- Kidney disease
- · Increased risk for heart disease
- Poor wound healing
- Decreased immune system function
- Diabetic ketoacidosis this is a severe and life threatening complication

#### **Foot Care**

Foot care is very important for people with diabetes. High blood glucose levels and a reduced blood supply to the limbs cause nerve damage that reduces feeling in the feet. Someone with nerve damage may not feel a pebble inside his sock that is causing a sore. One may not feel a blister caused by poorly fitting shoes. Foot injuries such as these can cause ulcers, which may lead to amputation. People with diabetes should check their feet every day and watch for any cuts, sores, red spots, swelling and infected toenails. This is especially true in a disasters situation when you are more likely to be walking on or over debris. Sores, blisters, breaks in the skin, infections or buildup of calluses should be reported right away to a podiatrist or a family doctor.

#### Skin Care

Skin care is very important too. Because people with diabetes may have more injuries and infections, they should protect their skin by keeping it clean, using skin softeners to treat dryness and taking care of minor cuts and bruises. Preventing cuts or scrapes may be difficult in a disaster situation. Be sure to pack a first aid items into your disaster supplies kit. If a wound appears to be infected or not healing properly, seek medical attention immediately.

- If you are a diabetic, make sure you include your glucose testing supplies including your glucose meter, extra insulin, glucagon, syringes, lancets, blood test strips, ketone test strips and alcohol wipes.
- Insulin pump users should have basal rates, insulin-to-carb ratios and correction factors and any supplies associated with the pump.
- Extra batteries for your glucose monitor and/insulin pump
- If any of your medications (e.g., insulin and certain osteoporosis and arthritis injections) requires refrigeration, make sure your kit contains a small insulated cooler. Have ice ready or purchase FRIO cooling packs.
- In a disaster, it may be difficult to monitor your blood sugar as often as you should. Try to do your best. Pay attention to any unusual symptoms you may experience and seek help immediately.
- Try to prevent the following:
  - Dehydration Remember it can be caused by hyperglycemia (high blood sugar).
     Make sure to get enough fluids to meet your body's needs.
  - Hypoglycemia (low blood sugar) Try to keep something with sugar or emergency glucose tabs with you at all times.
  - Infections (especially foot infections) Try your best to avoid wading through
    contaminated water or injuring your feet. Inspect them regularly for cuts, sores
    or blisters. Seek medical care immediately if you notice any signs of infection
    (swelling, redness, and/or discharge from a wound).
  - Hyperglycemia (high blood sugar) Make sure you take your medications as prescribed by the doctor and avoid food choices that can increase your blood sugar.

## Sources for Additional Diabetes Information

## **American Diabetes Association**

http://www.diabetes.org 1-800-DIABETES (1-800-342-2383)

## Kentucky Cabinet for Health and Family Services

http://chfs.ky.gov/dph/ach/cd/diabetes.htm 1-502-564-7996

## Defeat Diabetes Foundation, Inc.

http://www.defeatdiabetes.org

## **National Diabetes Information Clearing House**

http://diabetes.niddk.nih.gov 1-800-860-8747

## 5. Heart Disease, High Blood Pressure and Stroke

#### **Heart Disease**

Heart disease can be defined as any of a number of diseases related to the heart and blood vessels. When grouped together, these diseases are the leading cause of death in the U.S. Today, more than 80 million Americans have some form of it. This disease includes a variety of problems, including heart failure, high blood pressure and stroke. Some other problems that go along with heart disease are:

- Hardening of the arteries, also called **arteriosclerosis**, means the arteries become thickened and are no longer as flexible.
- A buildup of cholesterol and fat that makes their arteries narrower so less blood can flow through is called **atherosclerosis**. Those deposits are called plaque.
- A pain in the chest that means the heart isn't getting enough blood is called **angina**.
- When a blood clot or other blockage cuts blood flow to a part of the heart it is called a **heart attack**.

#### **Heart Failure**

In heart failure, the heart cannot pump enough blood through the body or it cannot fill with enough blood or pump with enough force or both. Heart failure develops over time as the pumping action of the heart gets weaker. It can affect the right, the left, or both sides of the heart. In most cases, heart failure affects the left side of the heart when it cannot pump enough oxygen-rich blood to the rest of the body. When heart failure affects the right side, the heart cannot pump enough blood to the lungs, where it picks up oxygen.

#### What are the Symptoms of Heart Failure?

Common symptoms of heart failure are fatigue, shortness of breath and swelling. This is because the heart can't pump blood in and out of the heart well enough to prevent blood and fluid from backing up. The fluid back up causes swelling in the ankles, feet, legs and sometimes in the abdomen. This fluid buildup can lead to weight gain, frequent urination and a chronic cough. The cough can be worse at night and when lying down.

## What Causes Heart Failure?

Heart failure is caused by other conditions that damage the heart muscle including coronary artery disease, heart attacks and heart defects. Diabetes and high blood pressure can also contribute to heart failure risk.

#### How is Heart Failure Diagnosed?

Many of the symptoms of heart disease are similar to those of other diseases. Because of this, there is no single test that can detect heart disease. A physician will make a heart failure diagnosis after taking a medical history, performing a physical exam and running some tests. Tests that are given to determine heart failure include:

- EKG or ECG (electrocardiogram) measures the rate and regularity of your heartbeat.
- **Chest X-ray** will show whether your heart is enlarged or your lungs have fluid in them, both signs of heart disease.
- **BNP blood test** measures the level of a hormone called BNP (B-type natriuretic peptide) that is increased in people with heart failure.

Your primary care physician may send you to a cardiologist (a doctor who specializes in the diagnosis and treatment of heart disease). He/she will also perform a physical exam and may order more tests. There are several tests that can identify the cause of heart failure. These tests include:

- **Echocardiogram** uses sound waves to create a picture of the heart and shows how well the heart is filling with blood.
- **Holter monitor** is worn for 24 hours, provides a continuous recording of heart rhythm during normal activity.
- Exercise stress test reads your EKG and blood pressure before, during or after exercise to see how your heart responds to exercise.

#### How is Heart Failure Treated?

Heart failure cannot be cured, but treating the conditions that caused it can help to manage symptoms. Treatment includes lifestyle changes and medications. Treatment for heart failure will help improve symptoms and stop them from getting worse. It is very important that you follow your treatment plan by keeping appointments with your doctor, taking medications and making lifestyle changes.

Lifestyle changes that you may need to make include losing weight, quitting smoking and limiting the amount of alcohol you drink. You will probably have to follow a low-salt diet as well. Salt can cause extra fluid to build up in your body, making heart failure worse. Your doctor may also ask you to limit the fluids you drink and to weigh yourself every day. If you have sudden weight gain, let your doctor know right away. This could mean extra fluid is building up. Your doctor may prescribe medications to improve your heart function and symptoms including:

- Diuretics reduce fluid in your lungs and swelling in your feet and ankles.
- ACE inhibitors lower blood pressure and reduce strain on your heart.
- Angiotensin II Receptor Blockers (ARBS) are newer blood pressure drugs that protect your blood vessels from angiotensin II. They make the blood vessels relax and become wider and your blood pressure goes down.
- **Beta blockers** slow your heart rate and lower blood pressure to relieve some of the workload on your heart.
- **Digoxin** helps the heart beat stronger and pump more blood.

Those with heart failure should try to avoid respiratory infections like pneumonia and the flu. It is recommended that you get a pneumococcal vaccine to prevent pneumonia and an annual flu shot to avoid any breathing complications from the flu. Your doctor may also order extra oxygen if you have trouble breathing. The oxygen can be used in your home or in the hospital.

Following all of your doctor's recommendations during a disaster may be difficult. It is important that they be followed to the best of your abilities. This includes continuing to weigh yourself daily, take all medications on a consistent schedule and eat a balanced diet. Failing to continue your treatments can cause all of your symptoms to return or get worse. Fluids can build up and cause extra strain on your heart, lungs and even your kidneys.

#### **High Blood Pressure**

Blood pressure is the force of the blood pushing against the walls of the arteries. Blood pressure is always given as two numbers, the systolic and diastolic pressures. Both are important. Usually they are written one above or before the other – for example, 120/80 mmHg. The top number is the systolic and the bottom number is the diastolic.

If your blood pressure is 120/80, you say that it is "120 over 80." Your blood pressure changes throughout the day. It is lowest when you're asleep and it rises when you awaken. It also can rise when you are excited, nervous or active. So it varies throughout the day.

A systolic blood pressure of 140 mmHg or higher, or a diastolic blood pressure of 90 mmHg or higher, is considered high blood pressure or hypertension. Hypertension is the medical term for high blood pressure. High blood pressure currently affects more than 65 million Americans.

#### What are the Symptoms of High Blood Pressure?

High blood pressure usually has no symptoms and is often referred to as the "silent killer". Many times, people only find out they have high blood pressure when they have trouble with their heart, brain or kidneys. When high blood pressure is not diagnosed and treated, it can lead to other life-threatening conditions, including heart attack, stroke and kidney failure. High blood pressure can cause:

- Your heart to work too hard and become larger, which can lead to heart failure.
- Small bulges (aneurysms) to form in your blood vessels. Common locations for aneurysms are the aorta, which is the main artery from the heart; the arteries in your brain, legs, and intestines; and the artery leading to your spleen.
- Blood vessels in your kidneys to narrow, which can cause kidney failure, and blood vessels in your eyes to burst or bleed, which may cause vision changes and can result in blindness.
- Arteries throughout your body to "harden" faster, especially those in your heart, brain, kidneys and legs. This can cause a heart attack, stroke or kidney failure, or lead to amputation of part of the leg.

## What Causes High Blood Pressure?

There is no specific cause of high blood pressure, but there are several risk factors that can make you more likely to develop it including:

- Overweight or obese
- A man over the age of 45 or a woman over the age of 55
- A family history of high blood pressure
- Pre-hypertension, (120-139/80-89 mmHg)
- Eating too much salt
- Drinking too much alcohol
- Physical inactivity
- Certain medicines
- Long-lasting stress

#### How is High Blood Pressure Diagnosed?

High blood pressure is diagnosed when your doctor checks your blood pressure several times on different days. If several of the readings are 140/90 mmHg or higher (130/80 mmHg or higher if you have diabetes or chronic kidney disease) you have high blood pressure.

#### How is High Blood Pressure Treated?

Normal blood pressure is less than 120/80. Your doctor will tell you what you normal range should be. Several lifestyle changes can help lower blood pressure including:

- Eating healthy foods that include fruits, vegetables and low-fat milk products
- Cutting down on salt and sodium in the diet
- Losing excess weight and staying at a healthy weight
- Being physically active for 30 minutes each day
- Limiting alcohol intake

Lifestyle changes don't always lower blood pressure enough and your doctor may prescribe medications. There are a variety of medications that your doctor may prescribe for your high blood pressure. Some drugs lower blood pressure by removing extra fluid and salt from your body. Others affect blood pressure by slowing down the heartbeat or by relaxing and widening blood vessels. Often, your doctor will prescribe more than one medication. The types of medicines used to treat high blood pressure include:

- **Diuretics** "water pills." They work by helping your kidneys flush excess water and salt from your body. This reduces the amount of fluid in your blood and your blood pressure goes down.
- **Beta blockers** cause your heart to beat more slowly and with less force. Your heart pumps less blood through the blood vessels and your blood pressure goes down.
- Angiotensin converting enzyme (ACE) inhibitors keep your body from making a hormone called angiotensin II, which normally causes blood vessels to narrow. ACE inhibitors prevent this narrowing so your blood pressure goes down.
- Angiotensin II Receptor Blockers (ARBS) are newer blood pressure drugs that protect your blood vessels from angiotensin II. They make the blood vessels relax and become wider and your blood pressure goes down.
- Calcium channel blockers (CCBs) keep calcium from entering the muscle cells of your heart and blood vessels. This causes blood vessels to relax and your blood pressure goes down.
- **Alpha blockers** reduce nerve impulses that tighten blood vessels, allowing blood to pass more easily and causing blood pressure to go down.
- **Alpha-beta blockers** reduce nerve impulses to blood vessels the same way alpha blockers do, but they also slow the heartbeat, as beta blockers do. As a result, blood pressure goes down.
- **Nervous system inhibitors** relax blood vessels by controlling nerve impulses from the brain. This causes blood vessels to become wider and blood pressure to go down.
- **Vasodilators** open blood vessels by directly relaxing the muscle in the vessel walls, causing blood pressure to go down.

Stopping treatment can lead to headaches, an increase in blood pressure and all of the possible complications due to high blood pressure (stroke, heart attack, heart failure, kidney failure). It is important that you take your blood pressure medication the same time each day. This may be difficult to do in a disaster situation, but try your best to keep to your medication schedule.

#### Stroke

Each year in the U.S., there are more than 700,000 new strokes. Stroke is the third leading cause of death in the country, after heart disease and cancer. Stroke causes more serious long-term disabilities than any other disease. Nearly three-quarters of all strokes occur in people over the age of 65.

There are two kinds of stroke. The most common kind of stroke is called ischemic stroke. It accounts for approximately 80 percent of all strokes. An ischemic stroke is caused by a blood clot that blocks or plugs a blood vessel in the brain. The other kind of stroke is called hemorrhagic stroke. A hemorrhagic stroke is caused by a blood vessel that breaks and bleeds into the brain.

#### What are the Symptoms of Stroke?

It is very important to know the signs and symptoms of a stroke. Seeking treatment immediately can help to lessen complications. If you observe one or more of the following signs of a stroke, don't wait. Call a doctor or 911 right away!

- Sudden numbness or weakness of the face, arm, or leg, especially on one side of the body
- Sudden confusion, trouble speaking or understanding
- Sudden trouble seeing in one or both eyes
- Sudden trouble walking, dizziness, loss of balance or coordination
- Sudden severe headache with no known cause
- Other danger signs that may occur include double vision, drowsiness, and nausea or vomiting.

#### What Causes Stroke?

There are different causes for the two types of strokes; ischemic and hemorrhagic. Ischemic strokes are caused by:

- The formation of a clot within a blood vessel of the brain or neck, called **thrombosis**
- The movement of a clot from another part of the body, such as from the heart to the neck or brain, called an **embolism**
- A severe narrowing of an artery in or leading to the brain, called **stenosis**

The common cause of a hemorrhagic stroke is a bleeding aneurysm. An aneurysm is a weak or thin spot on an artery wall. Over time, these weak spots stretch or balloon out due to high blood pressure. The thin walls of these ballooning aneurysms can rupture and spill blood into the space surrounding brain cells. Artery walls can also break open because they become encrusted, or covered with fatty deposits called plaque, eventually lose their elasticity and become brittle, thin and prone to cracking. High blood pressure increases the risk that an artery wall will give way and release blood into the surrounding brain tissue.

While family history of stroke plays a role in your risk, there are many risk factors you can control:

- Get your high blood pressure under control.
- If you smoke, quit.
- If you have diabetes, learn how to properly manage it.
- If you are overweight, start maintaining a healthy diet and exercising regularly.
- If you have high cholesterol, work with your doctor to lower it.

#### How is Stroke Diagnosed?

A stroke is diagnosed with a variety of things including questions about when the symptoms began and a neurological exam. Your doctor may also order blood tests, an electrocardiogram and a brain scan (either CT or MRI). These scans can help your doctor determine what kind of stroke it is so that treatment can be decided.

#### How is Stroke Treated?

With stroke, treatment depends on the stage of the disease. There are three treatment stages for stroke: prevention, therapy immediately after stroke and rehabilitation after stroke. Stroke therapies include medications, surgery and rehabilitation.

Medication or drug therapy is the most common treatment for stroke. Thrombolytic drugs stop the stroke by dissolving the blood clot that is blocking blood flow to the brain and are

used for ischemic strokes. Another type of drug, antithrombotics are used to prevent stroke. They may be given to someone who is at high risk of stroke, which includes someone who has already had a stroke. Antithrombotics prevent the formation of blood clots that can become stuck in an artery of the brain and cause strokes.

Surgery can be used to prevent stroke, to treat stroke or to repair damage to the blood vessels or malformations in and around the brain.

- **Carotid endarterectomy** is a surgical procedure in which a doctor removes fatty deposits, or plaque, from the inside of one of the carotid arteries. The procedure is performed to prevent stroke. The carotid arteries are located in the neck and are the main suppliers of blood to the brain.
- EC/IC bypass surgery is a procedure that restores blood flow to a blood-deprived area of brain tissue. The surgeon reroutes a healthy artery in the scalp to the area of brain tissue affected by a blocked artery.
- A surgical procedure for treatment of brain aneurysms that can cause hemorrhage, or bleeding, is a technique called **clipping**. Clipping involves clamping off the aneurysm from the blood vessel, which reduces the chance that it will burst and bleed.

Stroke is the number one cause of serious adult disability in the U.S. There are a variety of therapies that can often help an individual regain functioning:

- Physical therapy helps the stroke patient relearn simple motor activities such as walking sitting.
- Occupational therapy helps patients relearn daily activities including eating and dressing.
- **Speech therapy** helps stroke patients relearn language and speaking skills or learn other forms of communication.
- **Talk Therapy**, along with the right medication, helps patients with the psychological problems such as depression, anxiety, frustration and anger that are common disabilities in people who have suffered a stroke.

For many people, 3-6 months after a stroke is a key time for recovery. If you are in this time, it is important that therapy does not get interrupted or stopped. This may be difficult to do in an emergency or disaster situation. If you go to a specific place for your rehab, arrange with your therapists an alternate location you can go to in case of a disaster situation. If you receive therapy at home, make arrangements with the agency to have them come to your new location (family or friend's home). If you have to stay far from your home, your agency may not be able to come to your new location. Ask your agency how far they will travel. If they are unable to go to your out of town location, ask them to assist you in arranging rehab services in that area.

### Early intervention in Stroke and Heart Disease

If you begin to suffer from any symptoms of stroke or heart disease **SEEK MEDICAL ATTENTION IMMEDIATELY!!** Often people wait to see if symptoms will go away on their own. They often want to rest for a while or get a good night sleep first. **DO NOT WAIT**. A variety of treatment options are available, but physicians can only use them if you seek care. Prompt medical treatment not only helps to prevent complications from stroke and heart disease, but may also allow physicians to use medications and other interventions instead of surgery. It may be difficult to seek medical assistance in a disaster situation, but prompt care is necessary. If you begin to experience any stroke or heart related symptoms tell your family, friends, shelter workers, or anyone that can help you get the medical assistance you need.

## Sources for Additional Heart Disease, High Blood Pressure and Stroke Information

#### **American Heart Association**

http://www.americanheart.org 1-800-AHA-USA-1 (1-800-242-8721)

#### **American Stroke Association**

http://www.strokeassociation.org 1-888-4-STROKE (1-888-478-7653)

## **National Stroke Association**

http://www.stroke.org 1-800-STROKES (1-800-787-6537)

#### The National Women's Health Information Center

http://www.4women.gov/FAQ/heartdis.htm 1-800-994-9662

#### Kentucky Cabinet for Health and Family Services

http://chfs.ky.gov/dph/ach/cd/cardiovascular.htm 1-502-564-7996

#### Free Tobacco Cessation Assistance

1-800-QUIT-NOW (1-800-784-8669) http://1800quitnow.cancer.gov

## 6. Kidney Disease/Dialysis

Your kidneys filter waste from your blood. The wastes from your blood that comes from the normal breakdown of active tissues and from food you eat. If your kidneys do not remove these wastes, they build up in the blood and damage your body. In addition, your kidneys also:

- Regulate your body water and other chemicals in your blood such as sodium, potassium, phosphorus and calcium.
- Remove drugs and toxins introduced into your body.
- Release hormones into your blood to help your body.
- Regulate blood pressure.
- · Make red blood cells.
- Promote strong bones.

Kidney disease results from damage to the nephrons, the tiny structures inside your kidneys that filter blood. Usually the damage occurs very gradually over years.

#### What are the Symptoms of Kidney Disease?

Most people may not have any severe symptoms until their kidney disease is advanced. However, you may notice that you:

- Feel more tired and have less energy
- Have trouble concentrating
- Have a poor appetite
- Have trouble sleeping
- Have muscle cramping at night
- Have swollen feet and ankles
- Have puffiness around your eyes, especially in the morning
- Have dry, itchy skin
- Need to urinate more often, especially at night

#### What Causes Kidney Disease?

The two main causes of chronic kidney disease are diabetes and high blood pressure, which are responsible for up to two-thirds of the cases.

- Diabetes: In diabetes, the body doesn't use glucose (sugar) very well. The glucose stays in your blood and acts like a poison. If you have diabetes, you can prevent kidney disease by controlling your blood sugar levels.
- High Blood Pressure: High blood pressure can damage the small blood vessels in
  your kidneys. When this happens your kidneys cannot filter wastes from your blood
  very well. If you have high blood pressure (hypertension) be sure to take any medicines
  your doctor prescribes.

Some kidney diseases result from hereditary factors and can run in families. If your family has a history of any kind of kidney problems, you may be at risk for kidney disease and should talk to your doctor.

#### How do Doctors Diagnose Kidney Disease?

Early kidney disease is a silent problem, like high blood pressure, and does not have any symptoms. You may have it, but not know it, because you don't feel sick. To detect the disease doctors can do very simple tests that include:

- Measure the level of serum creatinine in your blood to estimate your glomerular filtration rate (GFR).
- Measure the level of protein in your urine (increased levels of protein show your kidneys are not working right).
- Checking your blood pressure.

#### How is Kidney Disease Treated?

Kidney disease often cannot be cured. If you are in the early stages of a kidney disease, you can take certain steps that may help to make your kidneys last longer. It is also important to reduce you risk factors for stroke and heart attack since kidney patients are susceptible to these problems.

If you are diabetic, it is important to monitor your blood sugars to keep your diabetes under control. People with reduced kidney function should have their blood pressure controlled, and an ACE inhibitor or an ARB should be one of their medications. Many people will require two or more types of medication to keep the blood pressure below 130/80 mm Hg. A diuretic is an important addition to the ACE inhibitor or ARB.

Complete and irreversible kidney failure is sometimes called end-stage renal disease, or ESRD. If your kidneys stop working completely, your body fills with extra water and waste products. This condition is called uremia. Your hands or feet may swell and you will feel tired and weak because your body needs clean blood to function properly. Untreated uremia may lead to seizures or coma and will ultimately result in death. If your kidneys stop working completely, you will need to undergo dialysis or kidney transplantation.

#### **Dialysis**

You need dialysis if your kidneys no longer remove enough wastes and fluid from your blood to keep you healthy. This usually happens when you have only 10 to 15 percent of your kidney function left. You may have symptoms such as nausea, vomiting, swelling and fatigue. However, even if you don't have these symptoms yet, you can still have a high level of wastes in your blood that may be toxic to your body. Your doctor is the best person to tell you when you should start dialysis.

There are two major forms of dialysis:

- In **hemodialysis**, your blood is sent through a machine that filters away waste products. The clean blood is returned to your body. Hemodialysis is usually performed at a dialysis center three times per week for 3 to 4 hours.
- In **peritoneal** dialysis, a fluid is put into your abdomen. This fluid, called dialysate, captures the waste products from your blood. After a few hours, the dialysate containing your body's wastes is drained away. Then, a fresh bag of dialysate is dripped into the abdomen. Patients can perform peritoneal dialysis themselves. Patients using continuous ambulatory peritoneal dialysis (CAPD), the most common form of peritoneal dialysis, change dialysate four times a day.

No matter what stage of kidney disease you have, it is important that treatment recommendations are followed, even during a disaster. Not following treatment can increase the risk for

complications including increased blood pressure and associated cardiovascular problems. It can also decrease kidney function leading to a need for dialysis or a kidney transplant.

## Medical & Dietary Information for Kidney Disease/Dialysis

### Medical items/needs

It is important that you take all medications as prescribed and do not interrupt or stop any treatments without your doctor's approval. Doing so may result in a return of your symptoms and progression of your disease. A disaster or emergency situation may make it difficult to continue with your treatment regime. That is why it is so important to plan ahead. In addition to those listed previously in this manual, here are additional items that may be helpful to have in a disaster situation:

- Wear a medical ID bracelet to quickly alert responders to your condition and allergies. Do not wear the bracelet on the same side as your dialysis access. It could block blood flow if it is pulled up the arm.
- Have instructions for Kayexalate administration.
- Know how to care for your access.
- Have a copy of your dialysis treatment plan (see Additional Resources: Treatment Information Form).
- Know the emergency preparedness plan of your dialysis unit. Know how to take yourself off the machine in an emergency if the dialysis unit staff are unable to. (The dialysis unit staff can instruct you on how to do this.)
- Make sure your dialysis unit can easily contact you in case of emergency.
- Hospitals may not be able to give you maintenance dialysis treatments.
- Have alternate dialysis units planned in case of disasters. Note: Contact the alternate dialysis unit ahead of time. Some units require advanced registration for disaster situations because they may be at capacity or they may have different hours available.
- Have a summary of your medical history that includes all of your dialysis information (See Additional Resources: Dialysis Patient Information Form)

#### If you are a home hemodialysis patient:

- Keep a list of dialysis units in your area at home and at your workplace.
- Keep a two-week stock of dialysis supplies at all times. Check expiration dates regularly and replace supplies when needed.
- Register with your local water and power companies for priority restoration of service.
- Learn to be comfortable taking yourself off the machine in an emergency.
- If you lose power while dialyzing during the emergency, follow the directions for discontinuing dialysis given to you by your home training staff.
- If you are not able to continue your treatments at home during the emergency, contact the home training staff so alternate arrangements can be made.

# If you are on CAPD (continuous ambulatory peritoneal dialysis) or CCPD (continuous cycling peritoneal dialysis):

- Keep a two-week stock of peritoneal dialysis supplies.
- Check expiration dates regularly and replace supplies when needed. If you use an ultraviolet device, keep the battery charged.
- Include in your emergency medication pack a five-day supply of the antibiotic that your doctor orders for peritonitis. If a disaster occurs, it may be difficult to maintain a clean environment and your risk of peritonitis may be higher.
- Register with your local water and power companies for priority restoration of service.
- If you do CCPD, you should also know how to do CAPD exchanges in case you are unable to use the cycler.
- If you are a CCPD patient and you lose power while dialyzing, follow the instructions given to you by the CCPD training staff for discontinuing dialysis in an emergency situation.

## Dietary needs

If you are unable to receive your scheduled dialysis treatment due to extreme weather or any other disaster, remember to follow the suggested Emergency Diet in this guidebook and/or changes which you have discussed with your dietitian. Be sure to choose the correct diet version and grocery list. Included are diets and grocery lists for adults (diabetic and non-diabetic) and one for pediatric patients. This diet is intended to limit the sodium, potassium, protein and fluid load on your body in the event that your time between treatments is extended beyond your control. Following this diet will lessen the risk of high blood pressure, shortness of breath or increased potassium levels that could cause your heart to stop. You should follow this diet only for the period of time that is necessary until your dialysis services can be resumed.

#### Fluids: It is necessary to restrict fluids even more than before!

Take your phosphate binder with the fluid specified in your meal plan. Your 2 cup daily limit allows for 4 ounces or 1/2 cup of fluid in addition to the 1 1/2 cups in your meal plan. Canned or bottled carbonated beverages will provide more calories than bottled water and often is a better choice for non-diabetics. Chew gum to quench thirst.

#### Sodium:

Avoid table salt and salt substitutes – flavor foods with herbed seasoning, garlic powder and lemon juice.

One egg or one ounce of meat (cooked) that has been stored at a safe temperature can be substituted for 1/4 cup of low sodium canned meat.

#### **Supplement Option:**

If purchasing emergency food supplies keeps falling to the bottom of your "to do" list, you may consider purchasing a convenient specialized liquid nutrition product to drink instead of following the suggested meal plan. Your dietitian can advise you of the commercially prepared product that will provide lower amounts of protein, sodium, potassium and fluid. This option reduces concerns for storage, space and preparation. Your dietitian can help you to determine the correct amount to consume and how to adjust your other fluid intake.

# Adult Renal Non-Diabetic Diet 3-day Meal Plan for Emergencies

The sample meal plan given contains approximately 42 grams of protein, 1200 mgs sodium, 1200 mgs potassium, 630 mgs phosphorus, and 1925 calories per day.

## Day 1

Breakfast	Lunch	Dinner
½ cup non-dairy creamer	2 slices white bread	2 slices white bread
<sup>3</sup> / <sub>4</sub> cup dry cereal	2 oz unsalted tuna fish*	2 oz unsalted chicken*
1tblsp sugar	1tblsp margarine, oil or mayonnaise*	2 tblsp margarine, oil or mayonnaise*
½ cup drained pineapple	½ cup green beans	½ cup drained pears
	½ cup cranberry juice or drink from powdered mix	½ cup cranberry juice or drink from powdered mix
Morning Snack	Afternoon Snack	<b>Evening Snack</b>
10 candies (see grocery list)	10 marshmallows	5 vanilla wafers or 5 sugar wafers or 3 graham cracker squares or 6 unsalted crackers
	½ cup applesauce	2 tblsp honey or jelly
	10 candies	10 candies

## Day 2

Breakfast	Lunch	Dinner
½ cup non-dairy creamer	2 slices white bread	2 slices white bread
³⁄4 cup dry cereal	2 oz unsalted turkey*	2 oz unsalted chicken*
1tblsp sugar	1tblsp margarine, oil or mayonnaise*	2 tblsp margarine, oil or mayonnaise*
½ cup drained peaches	4 spears low sodium asparagus	½ cup drained pineapple
	½ cup cranberry juice or drink from powdered mix	½ cup cranberry juice or drink from powdered mix
Morning Snack	Afternoon Snack	Evening Snack
½ cup applesauce	10 marshmallows	5 vanilla wafers or 5 sugar wafers or 3 graham cracker squares or 6 unsalted crackers
10 candies	10 candies	2 tblsp honey or jelly
		10 candies

<sup>\*</sup>If unable to keep food chilled in refrigerator, after opening, keep packed in cooler with ice or snow and discard at the end of the day.

## Day 3

Breakfast	Lunch	Dinner	
½ cup non-dairy creamer	2 slices white bread	2 slices white bread	
<sup>3</sup> / <sub>4</sub> cup dry cereal	2 oz unsalted tuna fish*	2 oz unsalted turkey*	
1tblsp sugar	1tblsp margarine, oil or mayonnaise*	2 tblsp margarine, oil or mayonnaise*	
½ cup drained pears	4 spears low sodium carrots	½ cup drained cherries	
	½ cup cranberry juice or drink from powdered mix	½ cup cranberry juice or drink from powdered mix	
Morning Snack	Afternoon Snack	Evening Snack	
10 marshmallows	10 candies	5 vanilla wafers or 5 sugar wafers or 3 graham cracker squares or 6 unsalted crackers	
½ cup applesauce		2 tblsp honey or jelly	
10 candies (see grocery list)		10 candies	

<sup>\*</sup>If unable to keep food chilled in refrigerator, after opening, keep packed in cooler with ice or snow and discard at the end of the day.

## Suggested Grocery List for Emergency Adult Renal Non-diabetic Diet

Bread/cereal (Choose 5-6 servings per day)

White Bread Dry Cereal (sweetened preferred)

Vanilla Wafers Puffed Wheat Graham Crackers Puffed Rice Unsalted Crackers (plain) Crisped Rice

Fruits/juices (Choose 2-4 servings per day)

Canned applesauce, pears, peaches, cherries, or pineapple

Fish/meat (4 oz. per day) Choose from:

Canned tuna, Chicken, Turkey in water

Frozen or shelf stable non-dairy creamer (4 oz per day)

#### Sweets

Choose from: marshmallows, honey, sugar, jelly

Assorted candies (jelly beans, sourballs, mints, hard candies)

Vegetables (1/2 cup/day)

Choose from canned: low sodium green beans, asparagus, or carrots

Fats (Choose 6 or more servings per day)

Margarine\* Oil (olive or vegetable)

Mayonnaise (perishable after opening)\*

\*Individual mayonnaise or margarine packets are recommended to avoid spoilage

Other Beverages (Limit to 1/2 cup/day in addition to meal plan)

1 gallon of spring water, ginger ale or lemon-lime soda

Cranberry juice or powdered juice mix (Kool-Aid, Tang)

## Other

Herbal seasoning, garlic powder, breath spray, chewing gum, fresh or reconstituted lemon juice

## Adult Renal Diabetic Diet 3-day Meal Plan for Emergencies

The sample meal plan given contains approximately 43 grams of protein, 1200 mgs sodium, 1300 mgs potassium, 675 mgs phosphorus, 190 grams carbohydrate, and 1700 calories. You can adjust menus to fit your individual taste with the help of your dietitian. These meal plans are stricter than your normal renal-diabetic diet to keep poisons from building up in your blood.

Day 1

Breakfast	Lunch	Dinner
½ cup non-dairy creamer	2 slices white bread	2 slices white bread
<sup>3</sup> / <sub>4</sub> cup dry cereal	2 oz unsalted tuna fish*	2 oz unsalted chicken*
½ cup drained pineapple (canned in juice)	1 ½ tblsp margarine, oil or mayonnaise*	1 ½ tblsp margarine, oil or mayonnaise*
	½ cup low sodium green beans	½ cup drained peaches (canned in juice)
	½ cup cranberry juice**	½ cup cranberry juice**
	Afternoon Snack	Evening Snack
	½ cup applesauce	¹/4 cup cranberry juice**
	(sugar free)	5 vanilla wafers or 3 graham crackers or 6 unsalted crackers
		1tsp margarine and 1 ½ tsp jelly

Day 2

Breakfast	Lunch	Dinner
½ cup non-dairy creamer	2 slices white bread	2 slices white bread
<sup>3</sup> / <sub>4</sub> cup dry cereal	2 oz unsalted turkey*	2 oz unsalted chicken*
½ cup drained peaches (canned in juice)	1 ½ tblsp margarine, oil or mayonnaise*	1 ½ tblsp margarine, oil or mayonnaise*
	4 spears low sodium asparagus	½ cup drained pears
	½ cup cranberry juice**	½ cup cranberry juice**
	Afternoon Snack	Evening Snack
	½ cup applesauce	½ cup cranberry juice**
(sugar	(sugar free)	5 vanilla wafers or 3 graham crackers or 6 unsalted crackers
		1tsp margarine and 1 ½ tsp jelly

<sup>\*</sup>If unable to keep food chilled in refrigerator, after opening, keep packed in cooler with ice or snow and discard at the end of the day.

<sup>\*\*</sup>Low calorie cranberry juice

## Day 3

Breakfast	Lunch	Dinner
½ cup non-dairy creamer	2 slices white bread	2 slices white bread
³⁄4 cup dry cereal	2 oz unsalted tuna fish*	2 oz unsalted turkey*
½ cup drained peaches (canned in juice)	1 ½ tblsp margarine, oil or mayonnaise*	1 ½ tblsp margarine, oil or mayonnaise*
	4 spears low sodium carrots	½ cup drained cherries (canned in juice)
	½ cup cranberry juice**	½ cup cranberry juice**
	Afternoon Snack	Evening Snack
	½ cup applesauce (sugar free)	5 vanilla wafers or 3 graham crackers or 6 unsalted crackers
		1tsp margarine and 1 ½ tsp jelly

<sup>\*</sup>If unable to keep food chilled in refrigerator, after opening, keep packed in cooler with ice or snow and discard at the end of the day.

## Suggested Grocery List for Emergency Adult Renal Diabetic Diet

Bread/cereal (Choose 5 servings per day)

White Bread Dry Cereal (sweetened preferred)

Vanilla Wafers Puffed Wheat
Graham Crackers Puffed Rice
Unsalted Crackers (plain) Crisped Rice

Fruits (Choose 3 servings per day canned in own juices)

Applesauce, pears, peaches, pineapple, cherries

Fish/meat (Choose 4 ounces per day)

Canned Tuna in water

Canned Chicken in water

Canned Turkey in water

<u>Vegetables</u> (1 serving per day)

Choose from canned: low sodium asparagus, green beans or carrots

Frozen or shelf stable non-dairy creamer (4 ounces per day)

Fats (10 servings per day)

Margarine\*\* Oil (olive or vegetable)

Mayonnaise (perishable after opening)\*\*

\*\*Individual mayonnaise or margarine packets are recommended to avoid spoilage

<u>High Caloric Foods</u> (Choose 3 servings per day and if needed 1 serving to raise blood sugar)

Honey (1 Tablespoon=1 serving) Jelly (1 Tablespoon=1 serving)

Sugar (4 teaspoons=1 serving) Low calorie Cranberry Juice (1/2 cup)

Powered Drink Mix (1/2 cup, mixed) Carbonated Beverages (1/2 cup)

<sup>\*\*</sup>Low calorie cranberry juice

Other Beverages (Limit to 1/2 cup/day in addition to meal plan)

1 gallon of Spring Water

Diet lemon-lime carbonated beverage or Diet ginger ale

Other (seasoning and fluid control aids)

Breath spray, fresh or reconstituted lemon juice, herbal seasoning, garlic powder, sugarless gum, sugar free hard candies (as desired)

#### Adult Diabetic Menu Pattern

Breakfast	Lunch	Dinner
1 milk substitute (½ cup)	2 starches	2 starches
1 starch	2 meats	2 meats
1 fruit	4 ½ fat	4 ½ fat
	1 vegetable	1 fruit
	1 high calorie	½ high calorie
	Afternoon Snack	Evening Snack
	1 fruit	1 starch
		1 fat
		1 high calorie

## Pediatric Renal Diet 3-day Meal Plan for Emergencies

Serving sizes vary according to the age of the child. As always, food consistency and choking hazards need to be considered on an individual basis. For children who still drink formula, the meal plan should be adjusted for the child to drink formula instead of the other beverages listed. Formula should be prepared one bottle at a time as needed. Adjust the amount of food according to the age of the child. For children who are still on formula, give formula instead of juices. You are encouraged to discuss portion sizes as well as food preferences and substitutions with your renal nutritionist. It is necessary to limit fluids even more than before.

Day 1

Breakfast	Lunch	Dinner	
non-dairy creamer	white bread	white bread	
dry cereal	unsalted canned tuna*	unsalted chicken*	
sugar	low sodium mayonnaise or margarine	low sodium mayonnaise or margarine	
cup drained pineapple	low sodium canned green beans	canned pears	
	Kool-Aid or Tang	cranberry juice	
Morning Snack	Afternoon Snack	Bedtime Snack	
candy (see Sweets list)	applesauce	graham cracker	
	marshmallows	jelly	
		candy (see Sweets list)	

<sup>\*</sup> If unable to keep food chilled in refrigerator after opening, keep packed in cooler with ice or snow and discard at the end of the day.

#### **Pediatric Renal Diet**

## Day 2

Breakfast	Lunch	Dinner
non-dairy creamer	unsalted turkey sandwich*	white bread
Cream of Wheat	low sodium mayonnaise or margarine	unsalted chicken*
sugar	low sodium canned carrots	low sodium mayonnaise or margarine
canned drained peaches	Kool-Aid or Tang	canned cherries
		cranberry juice
Morning Snack	Afternoon Snack	Bedtime Snack
sugar wafers	unsalted pretzels	vanilla wafers
ginger ale	candy (see Sweets list)	candy (see Sweets list)

# Day 3

Breakfast	Lunch	Dinner
non-dairy creamer	unsalted turkey sandwich*	unsalted turkey sandwich*
dry cereal	low sodium mayonnaise or margarine	low sodium mayonnaise or margarine
sugar	canned pineapple	low sodium canned corn
white bread	ginger ale	cranberry juice
jelly		unsalted turkey sandwich*
Morning Snack	Afternoon Snack	Bedtime Snack
applesauce	unsalted pretzels	canned drained peaches
candy (see Sweets List)	Kool-Aid or Tang	graham crackers

<sup>\*</sup> If unable to keep food chilled in refrigerator after opening, keep packed in cooler with ice or snow and discard at the end of the day.

## **Suggested Grocery List for Emergency Pediatric Renal Diet**

## Bread/cereal/starches

Sliced white bread (May substitute white rice, noodles, spaghetti, Dry cereal (sweetened preferred) macaroni, or unsalted crackers for white bread)

Puffed rice Sugar wafers (or sugar cookies)

Crisped rice Vanilla wafers
(Cream of Wheat, Cream of Rice, Graham crackers and Farina can be substituted) Unsalted pretzels

## Fruits/juices

Canned (sweetened or in syrup) applesauce, pears, peaches, pineapple or cherries

#### Fish/meat/poultry

Canned unsalted tuna, chicken, turkey (preferably small cans)

#### Frozen or shelf stable liquid non-dairy creamer

## Sweets

Marshmallows, sugar, jelly, honey, hard candy, gum drops, jelly beans, sourballs, mints, etc.

#### **Vegetables**

Canned low sodium green beans, carrots, corn (Canned mushrooms or asparagus can be substituted if preferred)

#### <u>Fats</u>

Low sodium mayonnaise and margarine (preferably individual packets or very small jars to avoid spoilage) and oil

#### Other beverages

Spring water, ginger ale, lemon lime soda (no cola drinks), cranberry juice, Kool-Aid (no grape flavor), Tang

#### **Other**

Herbal seasonings, garlic powder, onion powder, breath spray, chewing gum, fresh or reconstituted lemon juice

#### Formula

Powdered formula (prepare one bottle at a time as needed)

The dietary suggestions and menu plans are from, ESRD Network 4, Inc., Emergency Preparedness Resource for Dialysis Patients (2005). Please consult your physician and/or renal nutritionist before following any of the dietary suggestions in this guidebook.

# **Dialysis Patient Information Form**

Date /		
Patient Name:		_ DOB//
Address:		
City:	State:	Zip:
Phone:	Social Security #	//
Neighbor or Emergency Contact:		
Name:		
Relationship to you:		
Address:		
City:	State:	Zip:
Phone:		
Medicare Number:		
Other Insurance:		
Policy Number:		
Your Dialysis Center:		
Address:		
City:	State:	Zip:
Phone:		
Head Nurse:		
Nephrologist:	Phon	e:
Usual Source of Transportation/Needs:		

# **Dialysis Treatment Information Form**

If you need to go to another facility or if your treatment information is destroyed or unavailable, this information will help your caregivers provide you with the appropriate treatment. Your nurse or doctor can help complete this form. It should be updated as changes occur.

Date Completed:	
Primary ESRD Diagnosis:	
Allergies:	
Medications:	
Type of Treatment: Center Hemodialysis	CAPD
Home Hemodialysis	CCPD
Dialysis Prescription	
Dialyzer:	_ Dialysate:
Hours per Run:	_ Times per Week:
Dry Weight:	_ Average Weight Gain:
Heparinization:	
Access Site:	Needle Size:
Blood Flow Rate:	
Re-Use: YesNo	Lidocaine: Yes No
HBsAg Status:	Blood Type:
Special Needs/Problems:	

# Peritoneal Dialysis Information: CAPD

System:	Number of Exchanges:	
Fill Volume:	Estimated Dry Weight:	
Exchange Information Percentage of Dextrose (based on weight	ht increase):	
1–2 lbs. 1.5%	3–5 lbs. 3.5%	
2–3 lbs. 2.5%	3–5 lbs. 4.25%	
Low Calcium 3.5 mEq/L Dianeal:		
Reg. Calcium 3.5 mEq/L Dianeal:		
Dianeal PD 2 Magnesium 0.5:		
Peritonitis Is patient trained to do IP antibiotics? Yes Does patient have antibiotic at home? Yes		
Name of antibiotic:		
Diabetic: Yes No Insulin:	IP SQ	
Specify amount insulin used: SQ Dose		
Evening Dose		
Sliding scale for insulin (attach if available	·):	
Usual dose of insulin per bag:		
1.5% 3.5%	6	
2.5%4.25	5%	
Additional Information:		

# Peritoneal Dialysis Information: CCPD

Type of Cycler:		
Night Time Total Liters Delivered		Hours of Therapy:
Fill Volume per Cycle	Fill	Time:
Dwell Time:	Drain Time:	
Daytime Dwell: Yes No	Daytime Volume:	
Exchange Information Percentage of Dextrose (based on	weight increase):	
1–2 lbs. 1.5%	3–5 lbs. 3.5% _	
2–3 lbs. 2.5%	3–5 lbs. 4.25%	
Low Calcium 3.5 mEq/L Dianeal:		
Reg. Calcium 3.5 mEq/L Dianeal:		
Dianeal PD 2 Magnesium 0.5:		
<b>Peritonitis</b> Is patient trained to do IP antibiotic	s? Yes No	-
Does patient have antibiotic at hom	e? Yes No	-
Name of antibiotic:		
Diabetic: Yes No In	sulin: IP	SQ
Specify amount insulin used: SQ Do	ose	Evening Dose
Sliding scale for insulin (attach if av	ailable):	
Usual dose of insulin per bag:		
1.5%	3.5%	
2.5%	4.25%	
Additional Information:		

## Sources for Additional Kidney Disease/Dialysis Information

## National Kidney Foundation of Kentucky

http://www.nkfk.org/ 1-800-737-5433

## National Kidney Disease Education Program

http://www.nkdep.nih.gov/patients 1-866-4-KIDNEY (1-866-454-3639)

## ESRD Network 9/10 (Illinois, Indiana, Ohio, & Kentucky)

http://www.therenalnetwork.org 317-257-8265

## 7. Osteoporosis, Arthritis and Bone Diseases

## Osteoporosis

Osteoporosis is a disease that thins and weakens the bones to the point that they become fragile and break easily. In the U.S., 10 million people already have osteoporosis. Millions more have low bone mass, or **osteopenia**, placing them at increased risk for more serious bone loss and subsequent fractures. Osteoporosis can strike at any age, but it is most common among older people, especially older women. Of the 10 million Americans with osteoporosis, 80 percent are women.

#### What are the Symptoms of Osteoporosis?

Osteoporosis is often called "silent" because bone loss occurs without symptoms. People may not know that they have osteoporosis until a sudden strain, bump or fall causes a bone to break. Women and men with osteoporosis most often break bones in the hip, spine and wrist. But any fracture in an older person could be a warning sign that the bone is weaker than optimal.

Some people may be unaware that they have already experienced one or more spine fractures. Height loss of one inch or more may be the first sign that someone has experienced spine fractures due to osteoporosis. Multiple spine fractures can cause a curved spine, stooped posture, back pain and back fatigue. Women and men who have had a fracture are at high risk of experiencing another one. A fracture over the age of 45 or several fractures before that age may be a warning sign that a person has already developed osteoporosis.

It is important to prevent falls among individuals with osteoporosis because their bones break easily. Falls can be prevented by having the person begin a regular exercise program, reviewing medications, checking vision and making the environment safer. Environments can be made safer by removing clutter and things that can be easily tripped over, providing appropriate lighting and making stairs and bathrooms safer by installing grab bars and handrails.

#### What Causes Osteoporosis?

The following factors can put you at risk for developing osteoporosis, but there are also steps you can take to prevent it.

- **Gender**. Women are at higher risk for osteoporosis than men. They have smaller bones and lose bone more rapidly than men do because of hormone changes that occur after menopause.
- **Age**. Because bones become thinner with age, the older you are, the greater your risk of osteoporosis.
- **Ethnicity**. Caucasian and Asian women are at the highest risk for osteoporosis. African-American and Hispanic women are also at risk, but less so.
- **Family History**. Osteoporosis tends to run in families. If a family member has osteoporosis or breaks a bone, there is a greater chance that you will too.
- **History of Previous Fracture**. People who have had a fracture are at high risk of having another.
- **Diet**. Getting too little calcium over your lifetime can increase your risk for osteoporosis. Not getting enough vitamin D either from your diet, supplements, or sunlight can also increase your risk for osteoporosis. Vitamin D is important because it helps the body absorb calcium. An overall diet adequate in protein and other vitamins and minerals is also essential for bone health.

- **Physical activity**. Not exercising and being inactive or staying in bed for long periods can increase your risk of developing osteoporosis. Like muscles, bones become stronger with exercise.
- **Smoking**. Smokers may absorb less calcium from their diets. In addition, women who smoke have lower levels of estrogen in their bodies.
- **Medications**. Some commonly used medicines can cause loss of bone mass. These include a type of steroid called glucocorticoids, which are used to control diseases such as arthritis and asthma; some antiseizure drugs; some medicines that treat endometriosis; and some cancer drugs. Using too much thyroid hormone for an underactive thyroid can also be a problem. Talk to your doctor about the medications you are taking and what you can do to protect your bones.
- Low body weight. Women who are thin and small-boned are at greater risk for osteoporosis.

#### How do Doctor's Diagnose Osteoporosis?

People over the age of 45 who have experienced a fracture should talk to their doctor about getting evaluated for osteoporosis. The test used to diagnose osteoporosis is called a bone density test. This test is a measure of how strong or dense your bones are and can help your doctor predict your risk for having a fracture.

#### How is Osteoporosis Treated?

Although there is no cure for osteoporosis, it can be treated. The goal of treatment is to prevent fractures. A balanced diet rich in calcium, adequate vitamin D, a regular exercise program and fall prevention are all important for maintaining bone health.

Several medications are available for the treatment of osteoporosis. If treatment is stopped or your doctor's recommendations regarding your osteoporosis are not followed, you run the risk of further loss of bone density and an increased risk of fractures. For younger people, a fracture may simply involve wearing a cast for a few weeks while it heals. In older adults, fractures cause more consequences:

- It may take 2-3 months for pain to resolve.
- With hip fractures, as many as 50 percent of patients do not regain their pre-fracture function after 1 year.
- About 25 percent of women will spend some time in a nursing home after a hip fracture.
- About 10-20 percent of hip fracture patients will die within 1 year of the fracture.

#### **Arthritis**

Arthritis literally means joint inflammation, and it can affect joints in any part of the body. Joints are places in the body where two bones meet. Many people use the term arthritis to refer to rheumatic diseases; however, the different kinds of arthritis comprise just a portion of the rheumatic diseases. Many forms of arthritis cause swelling, redness, heat and pain.

• Osteoarthritis is the most common form of arthritis among older people. Osteoarthritis occurs when cartilage, the tissue that cushions the ends of the bones within the joints, breaks down and wears away. In some cases, all of the cartilage may wear away, leaving bones that rub up against each other.

The disease affects both men and women. Before age 45, osteoarthritis is more common in men than in women. After age 45, osteoarthritis is more common in women. By age 65, more than half of the population has x-ray evidence of osteoarthritis in at least one joint. Osteoarthritis affects only joints, not internal organs.

• Rheumatoid arthritis not only affects the joints, but may also attack tissue in the skin, lungs, eyes and blood vessels. People with rheumatoid arthritis may feel sick, tired and sometimes feverish. Rheumatoid arthritis is classified as an autoimmune disease. An autoimmune disease occurs when the immune system turns against parts of the body it is designed to protect. Rheumatoid arthritis generally occurs in a symmetrical pattern. This means that if one knee or hand is involved, the other one is too. It can occur at any age, but usually begins during a person's most productive years. Rheumatoid arthritis occurs much more frequently in women than in men. About two to three times as many women as men have the disease.

#### What are the Symptoms of Arthritis?

Different types of arthritis have different symptoms. In general, people with most forms of arthritis have pain and stiffness in their joints.

Osteoarthritis usually develops slowly and can occur in any joint, but often occurs in weight bearing joints. Other symptoms include:

- Joints may ache after physical work or exercise
- Most often occurs in the hands, hips, knees, neck or low back
- Joint pain, swelling and tenderness
- Stiffness after getting out of bed
- A crunching feeling or sound of bone rubbing on bone

Not everyone with osteoarthritis feels pain, however. In fact, only a third of people with x-ray evidence of osteoarthritis report pain or other symptoms.

Rheumatoid arthritis is characterized by inflammation of the joint lining. This inflammation causes warmth, redness, swelling and pain around the joints. A person also feels sick, tired and sometimes feverish. Rheumatoid arthritis generally occurs in a symmetrical pattern. If one knee or hand is affected, the other one is also likely to be affected.

#### What Causes Arthritis?

The causes of arthritis are not fully understood. Researchers suspect that osteoarthritis is caused by a combination of factors in the body and the environment. The chance of developing osteoarthritis increases with age. Osteoarthritis often results from years of wear and tear on joints. This wear and tear mostly affects the cartilage, the tissue that cushions the ends of bones within the joint. Osteoarthritis occurs when the cartilage begins to fray, wear away and decay. Putting too much stress on a joint that has been previously injured, improper alignment of joints, and excess weight all may lead to the development of osteoarthritis.

Rheumatoid arthritis results from the interaction of many factors such as genes, hormones and the environment. Research suggests that a person's genetic makeup is an important part of the picture, but not the whole story. Some evidence shows that infectious agents, such as viruses and bacteria, may trigger rheumatoid arthritis in people with an inherited tendency to develop the disease. However, a specific agent or agents are not yet known.

#### How do Doctors Diagnose Arthritis?

To make a diagnosis, most doctors use a combination of methods and tests including a complete medical history, a physical examination x-rays and laboratory tests. Rheumatoid arthritis can be difficult to diagnose in its early stages for several reasons. First, there is no single test for the disease. In addition, symptoms differ from person to person and can be more severe in some people than in others. Also, symptoms of rheumatoid arthritis can be similar to those of other types of arthritis and joint conditions, and it may take some time to rule out other conditions. Finally, the full range of symptoms develops over time, and only a few symptoms may be present in the early stages.

#### How is Arthritis Treated?

Although there is no cure for most forms of arthritis, various therapies can help patients manage symptoms and improve their overall quality of life.

#### Osteoarthritis

Osteoarthritis treatment plans often include ways to manage pain and improve function. Current treatments for osteoarthritis can relieve symptoms such as pain and disability, but right now there are no treatments that can cure osteoarthritis.

- Exercise can decrease pain, increase flexibility and help you maintain a healthy weight. The amount and form of exercise will depend on which joints are involved, how stable the joints are, whether or not the joint is swollen and whether a joint replacement has already been done.
- **Heat or ice** you can use warm towels, hot packs or a warm bath or shower. In some cases, cold packs such as a bag of ice or frozen vegetables wrapped in a towel can relieve pain or numb the sore area. A doctor or physical therapist can recommend if heat or cold is the best treatment. For osteoarthritis in the knee, wearing insoles or cushioned shoes may reduce joint stress.
- **Medications** doctors usually start with acetaminophen because the side effects are minimal, then non-steroidal anti-inflammatory drugs such as ibuprofen and naproxen may be used. Corticosteroids, hyaluronic acid and topical creams are also used.
- **Protection and support of joints** some people use canes and splints to protect and to take pressure off the joints. Splints or braces are used to provide extra support for weakened joints.
- **Surgery** helps relieve the pain and disability of osteoarthritis. A doctor may perform surgery to smooth out, fuse, or reposition bones or to replace joints.

#### **Rheumatoid Arthritis**

Treatments for rheumatoid arthritis can help relieve your pain, reduce swelling, slow down or help prevent joint damage, increase your ability to function and improve your sense of well-being. Exercise, medication, and in some cases, surgery are common treatments for rheumatoid arthritis. People with rheumatoid arthritis need a good balance between rest and exercise; they should rest more when the disease is active and exercise more when it is not.

An overall nutritious diet with the right amount of calories, protein and calcium is important. Some people need to be careful about drinking alcoholic beverages because of the medications they take for rheumatoid arthritis. Reducing stress also is important. Doing relaxation exercises and taking part in support groups are two ways to help reduce stress.

Most people who have rheumatoid arthritis take medications. Some drugs only provide relief for pain, others reduce inflammation. Still others, called disease-modifying anti-rheumatic drugs or DMARDs, can often slow the course of the disease. Steroids, which are also called corticosteroids, are another type of drug used to reduce inflammation for people with rheumatoid arthritis. Early treatment with powerful drugs and drug combinations instead of single drugs may help prevent the disease from progressing and greatly reduce joint damage.

In some cases, a doctor will recommend surgery to restore function or relieve pain in a damaged joint. Surgery may also improve a person's ability to perform daily activities. Joint replacement and tendon reconstruction are two types of surgery available to patients with severe joint damage.

No matter what type of arthritis you have, the goal of treatment is to reduce pain and improve daily functioning. It is important that treatment recommendations be followed. This may be difficult to do in a disaster situation, but following your treatment plan can go a long way in maintaining your quality of life.

## Sources for Additional Osteoporosis, Arthritis and Bone Disease Information

## Osteoporosis

## **National Osteoporosis Foundation**

http://www.nof.org 1-800-231-4222

#### Kentucky Cabinet for Health and Family Services

http://chfs.ky.gov/dph/ach/cd/osteo.htm

#### National Women's Health Information Center

http://www.4women.gov/FAQ/osteopor.htm 1-800-994-9962

#### Arthritis

#### **Arthritis Foundation**

http://www.arthritis.org/arthritis-is.php 1-800-283-7800

#### **Arthritis Foundation Ohio River Valley Chapter**

http://ww2.arthritis.org/communities/chapters/Chapter.asp?Chapid=65 1-800-383-6843

#### Kentucky Cabinet for Health and Family Services

http://chfs.ky.gov/dph/ach/cd/arthritis.htm

# 8. Parkinson's Disease, Alzheimer's Disease and Other Neurological Disorders

#### Parkinson's Disease

Parkinson's disease is a movement disorder that impairs motor skills, speech and other functions. As many as one million Americans suffer from Parkinson's disease. While approximately 15 percent of people with Parkinson's are diagnosed before the age of 50, incidence increases with age.

#### What are the Symptoms of Parkinson's Disease?

It is important to realize that not every person with Parkinson's develops all signs or symptoms of the disease. For example, some people experience tremor as the primary symptom, while others may not have tremor but do have balance problems. Also, for some people the disease progresses quickly, and in others it does not. The following are descriptions of the most common primary symptoms of Parkinson's disease:

- Slight **tremor** in the hand or foot on one side of the body, or less commonly in the jaw or face.
- Stiffness or inflexibility of the muscles also called rigidity. **Rigidity** can cause pain, cramping and a decreased range of motion.
- Slowing of movements is also called **bradykinesia**. People who have bradykinesia may walk with short, shuffling steps.
- Impaired balance and coordination: People with Parkinson's disease often experience instability when standing or impaired balance and coordination. People with balance problems may have difficulty making turns or abrupt movements. They may go through periods of "freezing," which is when a person feels stuck to the ground and finds it difficult to start walking.

The following is a list of secondary symptoms of Parkinson's disease:

- Speech changes
- Small, cramped handwriting
- Loss of facial expression or "masking"
- Difficulty swallowing
- Drooling
- Pain
- Dementia or confusion
- Sleep disturbances
- Constipation
- Skin problems

- Depression
- · Fear or anxiety
- Memory difficulties and slowed thinking
- Sexual dysfunction
- Urinary problems
- Fatigue and aching
- Loss of energy
- Compulsive behavior
- Cramping

#### What Causes Parkinson's?

The cause of Parkinson's disease is unknown. It is known that it affects cells called neurons that are located in a small area at the base of the brain called the substantia nigra. These neurons normally make a chemical called dopamine. Dopamine is one of the chemicals needed to help the brain function smoothly and control movement of the body. Dopamine helps nerve impulses to transmit messages to muscles, resulting in what we know as normal body movement.

Parkinson's disease results when neurons die and less dopamine is made. When the supply of dopamine is decreased by approximately 50 - 60 percent, symptoms of Parkinson's begin to start. Over time, as more neurons are lost and the supply of dopamine is lower and lower, symptoms become more severe. The cause of the cell death that leads to Parkinson's disease is unknown.

#### How do Doctors Diagnose Parkinson's?

An accurate diagnosis of Parkinson's disease can be difficult to make. Today, there is no specific diagnostic test that can be used to confirm the disease. However, an MRI scan or blood tests can be used to rule out other disorders that have some symptoms similar to Parkinson's. Diagnosis is made by a physician based on a physical examination of the patient, focused on the body movement symptoms that are associated with Parkinson's, along with the patient's medical history.

#### How is Parkinson's Treated?

Parkinson's is mainly treated with medications. If they do not work, sometimes surgery helps some symptoms. The goal of treatment is to balance the chemicals dopamine and acetylcholine found in the brain. A very common medication is levodopa, or L-dopa. It is a chemical the brain needs to make dopamine. It breaks down very quickly in the brain, and patients often take other medications to prevent this. Other medications are given that act just like dopamine in the brain and some counteract acetylcholine. Most medications usually work well at first. Over time, doses and combinations of medications may need to be changed for best results.

Parkinson's medications do have side effects including nausea, depression, dry mouth and blurred vision. After a patient has been taking medications for a while, he or she might start to have jerky movements in the face or arms. This is called dyskinesia. The medications can also make a person go from having good mobility to almost no mobility. This is called "on-off phenomena"

Physical and occupational therapy can help with posture, walking and fine movements. Sometimes changing medication combinations or dosages makes symptoms better. If medications do not help, surgery may be an option. Surgery for Parkinson's either destroys or stimulates parts of the brain.

It is very dangerous to stop or change medications without discussing it with your doctor. Interrupting the prescribed treatment schedule can cause a worsening of symptoms, and possibly new ones. The symptoms can lead to a decrease in functioning. It may be difficult to keep to your dosing schedule during a disaster, but it is important to do so in order to manage your symptoms and maintain your quality of life.

#### Alzheimer's Disease

Alzheimer's disease is a type of dementia, which causes nerve cells in the brain to die. The disease affects memory, thinking, personality and behavior. Scientists think that up to 4.5 million people in the U.S. suffer from Alzheimer's disease. The disease usually begins after age 65 and risk goes up with age. While younger people also may get Alzheimer's disease, it is much less common. About 5 percent of men and women ages 65 to 74 have Alzheimer's disease, and nearly half of those age 85 and older may have the disease. It is important to note, however, that Alzheimer's disease is not a normal part of aging.

#### What are the Symptoms of Alzheimer's?

Alzheimer's disease begins slowly. At first, the only symptom may be mild forgetfulness. People in the early stages of Alzheimer's disease may have trouble remembering recent events, activities, or the names of familiar people or things. Simple math problems may become hard to solve. Such difficulties may be a bother, but usually they are not serious enough to cause alarm.

However, in the middle stages, forgetfulness begins to interfere with daily activities. People may forget the way home or find it hard to cope with daily life. Such symptoms are more easily noticed and become serious enough to cause people with Alzheimer's disease or their family members to seek medical help.

People in the later stages of Alzheimer's disease may forget how to do basic tasks, like brushing their teeth or combing their hair. They can no longer think clearly. They begin to have problems speaking, understanding, reading or writing. Later on, people with Alzheimer's disease may become anxious, agitated or aggressive or wander away from home. Eventually, patients need total care.

#### What Causes Alzheimer's?

Scientists do not yet fully understand what causes Alzheimer's disease, but they have found brain changes in people with the disease. What causes the changes is still unknown. There probably is not one single cause, but several factors that affect each person differently.

- **Age** the most important known risk factor for Alzheimer's disease. The number of people with the disease doubles every 5 years beyond age 65.
- **Family history** Scientists believe that genetics may play a role in the causes of Alzheimer's disease. For example, early-onset familial Alzheimer's disease, a rare form of Alzheimer's disease that occurs between the ages of 30 and 60, is inherited.
- Other risk factors like high blood pressure, high cholesterol and low levels of the vitamin folate may also increase the risk of Alzheimer's.

Researchers are also investigating the possibility that physical, mental and social activities may protect against Alzheimer's.

## How do Doctors Diagnose Alzheimer's?

Doctors use several tools to diagnose Alzheimer's disease:

- A complete medical history including questions about any difficulties carrying out daily activities
- Medical tests, such as tests of blood, urine or spinal fluid
- Tests to measure memory, problem solving, attention, counting and language
- Brain scans that allow the doctor to look at a picture of the brain to see if anything does not look normal

Sometimes, these test results help the doctor find other possible causes of the person's symptoms. For example, thyroid problems, drug reactions, depression, brain tumors and blood vessel disease in the brain can cause symptoms similar to those of Alzheimer's. Some of these other conditions can be treated successfully.

#### How is Alzheimer's Treated?

There is no known cure for Alzheimer's, but there are treatments that can prevent some symptoms from getting worse for a limited time. For some people in the early and middle stages of the disease, there are drugs that may help prevent some symptoms from becoming worse for a limited time. Also, some medicines may help control behavioral symptoms of Alzheimer's disease such as sleeplessness, agitation, wandering, anxiety and depression. Treating these symptoms often makes patients more comfortable and makes their care easier for caregivers.

Family members and friends can assist people in the early stages of Alzheimer's in continuing their daily routines, physical activities, and social contacts. People with Alzheimer's should be kept up-to-date about the details of their lives, such as the time of day, where they live and what is happening at home or in the world. Memory aids may help in the day-to-day living of patients in the earlier stages of Alzheimer's. Some families find that a big calendar, a list of daily plans, notes about simple safety measures and written directions describing how to use common household items are very useful aids.

#### Alzheimer's Disease (additional information)

- Extra identification items such as clothing tags, wallet cards or ID jewelry (bracelets, necklace, dog tags, etc.)
- Consider enrolling your loved one in the Alzheimer's Safe Return® program.
- A recent photo of your loved one in case he/she wanders away in the commotion.
- A pillow, toy or something else to hug
- Lotion or other items that can help soothe an agitated individual
- Make sure other care attendants that help you also have copies of your loved one's dementia medical history, physician information, and family contacts.
- See Section 3: Dementia and Memory Loss for more information about caring for a loved one with dementia in a disaster situation.

## **Multiple Sclerosis (MS)**

Multiple Sclerosis (MS) is a disease that affects the brain and spinal cord. Many different areas of the brain and spinal cord may be involved. Patches of the areas of the brain and spinal cord affected become hardened (sclerosed) with scar tissue. A normal nerve fiber is surrounded by a fatty substance called myelin, which is like insulation protecting electrical wires. Myelin helps messages travel smoothly along the nerve fiber. When myelin breaks down, scar tissue forms which prevents messages from flowing smoothly along the nerve. Messages can become completely blocked and body functions such as speaking, moving and seeing are affected.

#### What are the Symptoms of MS?

The symptoms vary depending on the area where the scar patches occur. Symptoms may occur in any combination, and may be mild to severe, including:

- Poor balance
- Poor coordination
- Mood swings
- Shaking of the hand(s)
- Unusual fatigue
- Double or blurry vision
- Slurred speech
- Muscle cramps or spasms
- Difficulty walking

- Forgetfulness or confusion
- Numbness or tingly feelings like "pins and needles"
- Involuntary (uncontrolled) rapid movements of the eyes
- Weakness of an arm or leg, which may lead to paralysis or inability to move if the disease is severe

#### What Causes MS?

The cause of MS is not known. There are many theories including that MS may be an auto-immune reaction. One theory is that MS may be caused by a virus that stays in the body for months or years before symptoms appear. Another theory is that MS may be caused by a combination of viral infection and immune reaction. The virus takes over body cells. The immune system then attacks these cells or the wall of the virus.

#### How is MS Diagnosed?

Diagnosing MS may be easy in some cases and difficult in others because early symptoms can be mild and go away without treatment. Symptoms may not reappear for weeks, months or years. MS may have the same symptoms as other diseases and there is no single test that gives a definite diagnosis. To find out if a person has MS, the doctor will order certain tests. However, the diagnosis of MS is always made by the history and physical exam.

#### How is MS Treated?

There is no cure for MS. However, persons with MS can have a satisfactory, productive life even with limitations. MS is not a fatal disease, but a person with MS may be more likely to get a respiratory or urinary tract infection. If these infections are not treated, they can cause death. You can ease symptoms by:

- Leading a healthy lifestyle
- Avoiding extremes of heat and cold
- · Participating in physical therapy which provides exercise programs and muscle retraining
- Taking medications that may help control symptoms or decrease the frequency, duration or intensity of attacks

## ALS (Lou Gehrig's Disease)

Amyotrophic lateral sclerosis (ALS), often referred to as "Lou Gehrig's disease," is a progressive neurodegenerative disease that affects nerve cells in the brain and the spinal cord. Motor neurons reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. The progressive degeneration of the motor neurons in ALS eventually lead to their death. When the motor neurons die, the ability of the brain to initiate and control muscle movement is lost. With voluntary muscle action progressively affected, patients in the later stages of the disease may become totally paralyzed.

#### What are the Symptoms of ALS?

At the onset of ALS the symptoms may be so slight that they are frequently overlooked. With regard to the appearance of symptoms and the progression of the illness, the course of the disease may include the following:

- Muscle weakness in one or more of the following: hands, arms, legs or the muscles of speech, swallowing or breathing
- Twitching (fasciculation) and cramping of muscles, especially those in the hands and feet
- Impairment of the use of the arms and legs
- "Thick speech" and difficulty in projecting the voice
- In more advanced stages, shortness of breath, difficulty in breathing and swallowing

## What Causes ALS?

A-myo-trophic comes from the Greek language. "A" means no or negative. "Myo" refers to muscle, and "Trophic" means nourishment – "No muscle nourishment." When a muscle has no nourishment, it "atrophies" or wastes away. "Lateral" identifies the areas in a person's spinal cord where portions of the nerve cells that signal and control the muscles are located. As this area degenerates it leads to scarring or hardening ("sclerosis") in the region.

As motor neurons degenerate, they can no longer send impulses to the muscle fibers that normally result in muscle movement. Early symptoms of ALS often include increasing muscle weakness,

especially involving the arms and legs, speech, swallowing or breathing. When muscles no longer receive the messages from the motor neurons that they require to function, the muscles begin to atrophy (become smaller). Limbs begin to look "thinner" as muscle tissue atrophies.

#### How do Doctors Diagnose ALS?

ALS is a very difficult disease to diagnose. To date, there is no one test or procedure to ultimately establish the diagnosis of ALS. It is through a clinical examination and series of diagnostic tests, often ruling out other diseases that mimic ALS, that a diagnosis can be established. A comprehensive diagnostic workup includes most, if not all, of the following procedures:

- Electrodiagnostic tests including electomyography (EMG) and nerve conduction velocity (NCV)
- Blood and urine studies including high resolution serum protein electrophoresis, thyroid and parathyroid hormone levels and 24 hour urine collection for heavy metals
- Spinal tap
- X-rays, including magnetic resonance imaging (MRI)
- Myelogram of cervical spine
- Muscle and/or nerve biopsy
- Thorough neurological examination

#### How is ALS Treated?

While there is not a cure or treatment today that halts or reverses ALS, there are therapies that can manage the symptoms of ALS that help people maintain as much independence as possible and prolong survival. It is important to remember that ALS is a quite variable disease; no two people will have the same journey or experiences. There are medically documented cases of people in whom ALS 'burns out,' stops progressing or progresses at a very slow rate. No matter what your individual course or situation may be there are resources that can help.

# Sources for Additional Parkinson's Disease, Alzheimer's Disease and Other Neurological Disorders Information

#### Parkinson's Disease

#### National Parkinson's Foundation

http://www.parkinson.org 1-800-327-4545

### Parkinson's disease Foundation

http://www.pdf.org 1-800-457-6676

## Kentucky Parkinson's Disease Information and Referral Center

http://ukhealthcare.uky.edu/KNI apda\_parkinsons.htm 1-866-554-APDA (2732)

## **Multiple Sclerosis**

## **National MS Society**

http://www.nationalmssociety.org 1-800-344-4867

### ALS (Lou Gehrig's Disease)

http://www.alsa.org/ 1-818-880-9007

#### Alzheimer's Disease

## Alzheimer's Association

http://www.alz.org 1-800-272-3900

#### Alzheimer's Association Safe Return

http://www.alz.org/safereturn 1-888-572-8566

# National Institute on Aging Alzheimer's Disease Education and Referral (ADEAR)

http://www.alzheimers.nia.nih.gov 1-800-438-4380

## **Family Caregiver Alliance**

http://www.caregiver.org 1-800-445-8106

### **Children of Aging Parents**

http://www.caps4caregivers.org 1-800-227-7294

#### **Eldercare Locator**

http://www.eldercare.gov 1-800-677-1116

## **Well Spouse Association**

http://www.wellspouse.org 1-800-838-0879

Visit www.chronicdiseasepreparedness.org or call 1-877-293-7447 and tell them you're

calling about disaster preparedness.