Introduction

This document is the first to be published in a series of “Savvy Health Care Consumer Series” excerpted with permission from Be a Savvy Health Care Consumer, Your Life May Depend on It!, 5TH Edition, Kailes Publications, 2003. Future guides planned for publication include:

■ Visit Strategies
■ Maintaining Your Medical Records And Health Information
■ Be Informed

These guides offer practical and easy-to-use tools and information to help you work on taking charge of or remaining in charge of your health care. This series encourages you to take greater responsibility for your own health, wellness and health services. Savvy health care consumerism means knowing how to work effectively with the health care system and successfully advocating for your needs as well as the needs of family members and significant others.

Medicine is at best an imprecise art. That’s why it’s important to be active and knowledgeable in the process of seeking and receiving health care. While having confidence in providers is important, the “provider always knows best” belief can be harmful.

Today’s health care environment is undergoing massive and rapid change that has far-reaching effects on all consumers. As you experience a leaner, meaner and less flexible health care system, it is more important then ever before that you sharpen your self-advocacy skills. People are finding they must learn how to be effective advocates or they may have to do without essential care. Being passive can be dangerous to your health.

This information may seem overwhelming at first and preparation can seem like a lot of work. It is, and taking charge does take time and effort. Do a little at a time. The important thing is to start. This information can be used and mastered in small pieces. The more you do the more confident you will be. The payoff for using this information may save your life.

These guides are for you if:

■ You use health care providers.
■ You want to take charge of your health care.
■ You live with a disability or a variety of health-related conditions, and are interested in using a number of disability-specific strategies and examples integrated throughout the guide.
■ You advocate with and/or for someone else.

June Isaacson Kailes
Disability Policy Consultant and Associate Director
Center for Disability Issues and the Health Professions at Western University of Health Sciences, Pomona, California

Note to reader: The term "provider" is used throughout this guide to reflect a broad group of people who provide health services. Providers include, but are not limited to, physicians. Providers also include technicians and therapists as well as an array of professionals who are specialists in complementary or alternative approaches to medical practices. Being a savvy health care consumer means employing the skills and strategies discussed in this guide with a variety of these health care providers.
Emergency Health Information

It is good practice to carry on you at all times emergency health information containing your critical health information and emergency contacts. An alternative would be to wear a Medic Alert tag or bracelet (see Resources). These bracelets can be engraved with the type of disability or any medical condition of importance. An 800 number keeps your current medication, diagnosis, etc., on file. You can order these from your local pharmacy.

Emergency health information communicates to emergency and rescue personnel what they need to know about you if they find you unconscious, confused, in shock, or just unable to provide information. Make multiple copies of this information to keep in your: emergency supply kits, car, work space, wallet (fold and place behind driver's license or official identification card), wheelchair pack, etc. (Kailles 1996)

Why You Should Carry Emergency Health Information

The care you receive in emergency situations depends on how much information doctors and other emergency personnel have at the time of the emergency. In emergency rooms you may be unable to give a full medical history and may not have someone with you to provide it. (Lollar 1994) p. 72-73 Sometimes emergency personnel only have seconds to make decisions about your care.

Review and update this information whenever your medications or other information changes, but no less than twice a year.

Tips on Completing Emergency Health Information

When completing your emergency health information (forms included at back of this guide) be sure and include:

Disability/Conditions emergency personnel might need to know about (if you are not sure, list it):

Examples:

• Epilepsy, heart condition, high blood pressure, respiratory problem, HIV positive.
• My disability, due to a head injury, sometimes makes me appear confused or drunk.
• I have a psychiatric disability. In an emergency, I may become confused or overwhelmed. Help me find a quiet corner and I should be fine in about 10 minutes. If this does not happen, give me one pill (name of medication) located in my (purse, wallet, pocket, etc.).
• I have diabetes. If I lose consciousness or my behavior appears peculiar, I may be having a reaction associated with my diabetes. If I can swallow, give me sugar in some form such as candy, syrup, cola or a beverage that contains sugar like orange juice. If my breath smells fruity, don’t give me anything to eat and make sure I get medical help.
• Multiple Chemical sensitivities: I react to....... my reaction is....... do this........ (these conditions may not be commonly understood by emergency personnel and therefore explanations should be detailed and specific).
Medications: If you take medication that cannot be interrupted without serious consequences, make sure this is stated clearly and include:

- Prescriptions,
- Dosage,
- Times taken,
- When first prescribed and how long you have been on the drug,
- Other details regarding specifications of administration/regimen, i.e., insulin

**Example:**

- I take Lithium and my blood level needs to be checked every______.

Allergies (sensitivities):

- Penicillin or other antibiotics
- Adhesive tape
- Morphine, Codeine, Demerol or other narcotics
- Latex
- Novocain or other anesthetics
- Iodine or Methiolate
- Aspirin, Emperin or other pain remedies
- Sun exposure
- Detergents, fabric softeners
- Sulfa drugs
- Tetanus, antitoxin or other serums
- Pesticides
- Eggs, milk, chocolate or other foods
- Insect bites, bee stings
- Environmental sensitivities
- Other:

**Examples:**

- Diesel exhaust can kill me. Do not put me in or near idling emergency vehicles.
- I can speak when provided with clean air and low electromagnetic fields. Take me to fresh air and turn off electrical equipment.

Immunization (shots) and Dates:

**Examples:**

- Flu,
- Pneumonia/Pneumococcal,
- Tetanus/diphtheria,
- Polio (IPV or OPV),
- Measles-mumps-rubella (MMR),
- H. influenzae type b (HIB),
- (Chicken Pox) Vericella,
- Hepatitis A,
- Hepatitis B,
- Rubella 9.

**Communication / Devices / Equipment / Other**

Communication (or a speech-related disability) examples:

With a communication or speech-related disability, list specific communication needs:

- I speak using an artificial larynx, if it is not available, I can write notes to communicate.
- If (under stress after seizure), I may not make sense for a while. Leave me alone for 10-15 minutes, my mind should clear.
- I speak slowly, softly and my speech is not clear. Find a quiet place for us to communicate. Be patient! Ask me to repeat or spell out what I am saying if you do not understand me!
- I use a (word board, augmentative communication device, etc.) to communicate. In an emergency, I can point to words and letters.
- I cannot read. I communicate using an augmentative communication device. I can point to simple pictures on a sheet which you will find in my wallet or emergency supply kit.
• I may have difficulty understanding what you are telling me, please speak slowly and use simple language.

• My primary language is ASL (American Sign Language). I am deaf, not fluent in English, I will need an ASL interpreter. I read only very simple English. Try using gestures.

• I am hard of hearing. Get my attention before speaking to me. Look at me when you speak so I can speechread.

**Equipment examples:**

• Motorized wheelchair
• Suction machine
• Home dialysis
• Respirator
• Cochlear implant
• Indwelling catheter

**Other examples:**

• I need specific help with: walking, eating, standing, dressing, transferring, etc.

• I need assistance with walking. The best way to assist is to allow me to hang onto your arm for balance.

• I am blind, please tell me what you are doing before doing it. I read Braille and I need paper work read to me.

• I have a panic condition. If I panic and appear very anxious, speak to me calmly and slowly. Be patient. Ask me if I need my medication and I will direct you. You may need to ask me more than once. Please stay with me until I calm down.

• I use a respirator full time, but I can breathe without it for up to 15 minutes.

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**Resources**

MedicAlert - http://www.medicalert.org

**References**


**Sample Emergency Health Information**

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<th>Emergency Health Information</th>
<th>Date: 6/20/02</th>
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**Name**  
Jane Ready

**Address**  
11 Prepared Place  
City: Savvy  
State: CA  
Zip: 90001

**CONTACT METHOD**  
**HOME**  
Phone: 310-555-9999  
Cell: 310-555-9998  
Pager: 888-555-6666  
Fax: 310-555-9996  
E-mail: Jr@beready.org

**WORK**  
Phone: 909-555-6666  
Fax: 310-555-6668  
E-mail: Healthcall@one-of-a-kind.com

**Birth Date**  
7/7/77

**Blood Type**  
B+

**Social Security No.**  
555-55-5555

**Health Plan**  
Blue Cross

**Individual #:** 010101-09009  
**Group #:** 010203-00006

**Emergency Contact:**  
**Husband - Bob**

**Address**  
Same as above  
City: Same as above  
State: Same as above  
Zip: Same as above

**CONTACT METHOD**  
**HOME**  
Phone: Same as above  
Cell: 310-555-9993  
Pager: 888-555-6667  
Fax: Same as above  
E-mail: b.r@beready.org

**WORK**  
Phone: 818-777-5555  
Fax: 818-777-5553  
E-mail: Bob.ready@safety.com

**Primary Care Provider:**  
Henrietta Housecall

**Address**  
12 Primary Care Place  
City: Healthville  
State: California  
Zip: 90001

**Phone:** 310-555-2345  
**Fax:** 310-555-2346  
**E-mail:** HH@telecompetent.net

**Disability/Conditions:**  
Cerebral palsy, Diabetes, Low vision, Epilepsy

**Medication:**  
Dilantin 300 mg, Lantus - insulin

**Allergies:**  
penicillin; sensitive to antibiotic “e-mycin” (stomach upset, headache, diarrhea)

**Immunizations**  
**Dates**  
**Immunizations**  
**Dates**

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**Communication / Devices / Equipment / Other:**  
Motorized scooter; I need assistance with walking. The best way to assist me is to allow me to hang onto your arm for balance. I speak slowly, softly and my speech is not clear. Find a quiet place for us to communicate. Be patient! Ask me to repeat or spell out what I am saying if you cannot understand me.
About the Guide’s Sponsor

The Center for Disability Issues and the Health Professions (CDIHP), established in 1998, at Western University of Health Sciences, in Pomona, California, works to enhance health professions education, and to improve access for people with disabilities to health, health education and health care services. CDIHP focuses on:

- Improving the capabilities of health care providers to meet the needs of people with disabilities.
- Increasing the number of qualified individuals with disabilities who pursue careers in the health professions.
- Supporting people with disabilities in becoming more vocal and active participants in their health care.
- Conducting and disseminating research on community based health education, prevention and health care services for people with disabilities.
- Sponsoring educational activities and curriculum development for health professionals working with people with disabilities. The Center also conducts applied research to develop continuing education programs for current health care providers. These activities are designed to improve health care delivery through advocating basic changes in social and policy issues affecting the health of people with disabilities.

To learn more visit http://www.cdihp.org

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Pomona, California 91766-1854
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TTY 909.469.5520
Fax 909.469.5503
E-mail jik@pacbell.net
About the Guide’s Author

June Isaacson Kailes, a disability rights advocate, is one of the original national leaders in the independent living movement. June is the Associate Director of the Center for Disability Issues and the Health Professions at Western University of Health Sciences, Pomona, California. June also operates a disability consulting practice and consults, writes and trains on: ADA implementation, advocacy training and skills building; health, wellness and aging with disability; developing and analyzing disability-related public policy; planning barrier free meetings, disability diversity training, reaching the disability market; customer service and product design, disaster preparedness for people with disabilities and incorporating universal design and usability principles into existing and new environments.

June publishes widely on disability-related topics including numerous articles, books, book chapters and training manuals including: A Guide to Planning Accessible Meetings, Be a Savvy Health Care Consumer – Your Life May Depend on It!, Health, Wellness, and Aging with Disability, and Americans with Disabilities Act Compliance Guide for Organizations. June has received many awards and has delivered hundreds of keynote addresses, workshops and seminars. She writes and speaks from practical “hands-on” experience.

June is also well known for her national and international work in disaster preparedness for people with disabilities. California Office of Emergency Safety distributes her publication Living and Lasting on Shaky Ground: An Earthquake Preparedness Guide for People with Disabilities, and Creating a Disaster- Resistant Infrastructure for People at Risk Including People with Disabilities is used and published in several countries. Her most recent book Emergency Evacuation Preparedness Guide For People with Disabilities and Other Activity Limitations is available at http://www.cdihp.org/evacuationpdf.htm.

As a presidential appointee to the United States Access Board, she served as its chair and vice chair. She also served on the boards of the National Council of Independent Living (NCIL) and the California Foundation of Independent Living (CFILC) and was the executive director of the Westside Center for Independent Living (WCIL) in Los Angeles. To learn more about June, visit www.jik.com.
Please Tell Us What You Think

Please tell us what you think about this guide.

The guide was: □ Easy to understand    □ Hard to understand

The information was: □ Too much        □ Too little            □ Just the right amount

More information should have been given about:

Less information should have been given about:

I would recommend this guide to another person: □ Yes    □ No

I received this guide from:
□ A disability-related organization    □ Center for Disability Issues and the Health Professions
□ A family member or friend            □ Other (please explain): ________________________________

I am a (check all that apply):
□ Person with a disability or activity limitation
□ Service professional                  □ Emergency professional
□ Service or Emergency Volunteer        □ Other: ________________________________

How far did you go in school?
□ 8th grade or less                      □ Some high school
□ High school graduate                   □ Some college
□ College graduate                       □ Graduate school

How did you or how do you plan to use this guide?

Other comments:

Optional:
Name __________________________________________
Address _________________________________________
Phone __________________ Fax _________________ E-mail __________________________

May we quote you? □ Yes    □ No
# Emergency Health Information

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Sometimes emergency personnel only have seconds to make decisions about your care.