

**National Family Caregivers Association (NFCA)  
Consumer Survey: Feedback on Medical Equipment labeling/instruction  
information**

**Survey began October 1, 2011 until January 6, 2012**

**Survey administered via NFCA Email Communication to Membership Listserv**

**N=127 respondents**

*Notes: Not all respondents (N=127) answered every question. Respondents had option to answer questions about instructions for 3 pieces of medical equipment. Attrition toward end of survey as number of responses to all questions dwindles.*

**Respondent Demographics:**

- 44% of respondents care for their spouse/partner (n=56)
- 95% of respondents are caring for adult family members (>21 years)
  - 49% respondents care for a family member 65 years+ (n=63)
  - 45% respondents care for family member between ages 21-64 years (n=58)
- 77% care for their family member in their own home (n=99)
- 59% have cared for their family member >5 years (n=76)
- Majority of respondents indicate that they have been using their medical equipment for **3 or more years**.

**Medical Conditions and Equipment Used:**

- Top conditions that respondents indicate their family member has (note: respondent could select all that apply):
  - Other – Free Text (majority responses are Alzheimer’s, Dementia; also old age or post-surgery recovery)
  - Stroke
  - Heart Disease
  - Diabetes
  - Cancer
  - Lung Disease
- Most commonly selected medical equipment respondents use to care for family member include:
  - Other – Free Text (majority responses are Oxygen; also Bi-pap, assistive equipment, i.e. cane, walker, bathroom handrails)
  - Wheelchair
  - Specialty Hospital Bed
  - Blood Glucose Monitor
  - Patient Lift
  - Nebulizer
- Majority of respondents indicate that they have been using their medical equipment for **3 or more years**.

**Most common medical equipment respondents selected to share their experience with the instructions include:**

- Other – Free Text (majority responses are Oxygen; also Bi-pap, assistive equipment, i.e. cane, walker, bathroom handrails)
- Patient Lift
- Wheelchair
- Blood Glucose Monitor
- Specialty Hospital Bed
- Nebulizer

*Note: responses correspond to most common equipment respondents use to care for family member*

- Medical equipment is delivered to respondent's home
  - Other – Free Text (Most common - pharmacy or drug store; respondents also indicate receiving equipment from friends or family).

**Medical Equipment Training (most common responses):**

- Somewhat easy - very easy to learn how to use medical equipment
- Note: seems that there is respondent bias – social desirability bias. Tendency to downplay difficulty with regard to learning, following instructions and using medical equipment, which does not always match free text feedback.*
- Most respondents did receive training on how to use their medical equipment
  - Medical supply company representative is cited most often as the individual who trained respondent how to use equipment (followed by: no training received, home health provider, rehabilitation staff, hospital staff).
  - **Other ways besides training did respondent learn how to use medical equipment:**
    - Learned by trial and error
    - Followed written, paper instructions from manufacturer
    - Searched Internet for instructions
    - Other – Free Text (Most common - verbal instructions, observation and demonstration)

**Medical Equipment Information (most common responses):**

*Note: Many free text responses indicate that respondents don't recall receiving or did not receive instructions with upon receipt of their medical equipment.*

**When manufacturer instructions came with medical equipment, respondents cite:**

- Somewhat easy to follow them, in general.
- Kinds of instructions that came with their equipment are as follows. Top responses:
  - Manual
  - Booklet
  - Information Sheet
- Table of Contents was most helpful in finding information needed in instructions.

- Other – Free Text (respondents indicate the #800 helpline, nurse or company representative is also helpful providing instruction)
- Yes, could quickly and easily find the information needed to troubleshoot in manufacturer’s instructions.
  - Free text comments also indicate that respondents call the #800 helpline for help troubleshooting and that a DVD would be helpful.
- Additional information sources (besides manufacturer’s instructions):
  - Received instructions from medical supply company (#1), Home Health Agency (#2), Hospital (#3)
  - Additional instructions also came in form of a manual, information sheet and booklet.
  - Other – Free Text information sources respondents cite: Verbal instruction, from a friend, pharmacy or #800 helpline.

**ALL OF WHICH DO** simplify/clarify manufacturer’s instructions, when they are provided.

**Using the Instructions (most common responses):**

- Have used instructions when (top 3):
  - Learning to use equipment during training
  - Until respondent felt comfortable using it
  - For information about cleaning
- Those who haven’t ever used the instructions indicate that training was enough
- Instructions do have pictures and diagrams. Mixed reviews as to whether respondents find them helpful. **HOWEVER**, free text fields indicate that pictures, diagrams and other visuals are useful and are suggested for inclusion in instructions.
- Respondents indicate they **don’t** still have the instructions for their equipment. However, this is **INCONSISTENT** because respondents also indicate they keep the instructions as long as they own the equipment.
  - Instructions typically kept in a file or in one place with all medical information.
  - Instructions are found easily, if needed.
- Respondents refer back to instructions when:
  - There is a problem
  - To find a phone number
  - To refresh memory
  - To make sure respondent is using it correctly
- When respondents referred back to instructions, instructions told them what they needed to know. **However, respondents cite that this information isn’t always contained in the manufacturer’s instructions; instead, information comes from other sources, i.e. verbal and from friends.**
- Most important information respondents need to know to use their medical equipment.
  - Other – Free Text comments include:
    - Cleaning information

- What it is used for
- General operation and troubleshooting information
- Where to get replacement parts
- Storage information
- Emergency contact information
- Alarm information – what they mean
- Assembly information
- Battery information
- Calibration information
- Care and maintenance information

*Note: Many responses also include 'gripes' about the specific equipment(s) respondents use.*

### **Respondent Preferences about Instructions (most common responses):**

- Most helpful ways respondents cite to find instructions include (top responses):
  - Paper instructions (manual, brochure, quick start guide)
  - information on equipment itself
  - online, and
  - by phone with a company representative or home health nurse
- Respondents turn to the following sources when they need help or information about their equipment:
  - Medical supply company
  - The Internet
  - Instructions that came with or are on the equipment
  - Friends or others with same condition/equipment
- **YES - A short version or 'quick start' would be helpful**
  - Information for inclusion in 'quick start' includes provided in Free Text fields:
    - Basic information, i.e. set up and troubleshooting
    - How-to instructions
    - Cleaning instructions
    - 'Do's and Don't's'
    - Step-by-step instructions
    - Short descriptions
    - Diagrams
    - Laminated cards on equipment with basic information
    - 800# helpline
    - Checklists
    - Large fonts
- Best time to receive written instructions → On delivery of equipment at home
- Worst time to receive written instructions → At the hospital

### **MISC FEEDBACK:**

- 65% of respondents indicate they are very comfortable with using computers (n=83)

- 70% of respondents indicate they would make use of a ‘searchable website that contained instructions for medical equipment used in the home’ (n=90)
  - If FDA created a searchable website, Free Text comments include:
    - Need for videos on website, which supplement the written instructions
    - Diagrams/pictures
    - Easy to print

**Miscellaneous Comments from NFCA Respondents about instructions (edited for grammar and clarity):**

- A DVD would be great & could include more detailed situations
- Instructions should be in text, illustration with a DVD. They should include very detailed use, care and ownership instructions to include keeping the wheels free of pet hair and other components of (power) chairs being clean such as when a patient goes to a barbershop...the chair needs to be cleaned of hair bits. Special populations patients who use wheelchairs do not always comprehend the manufacturer's written instructions. A DVD would be helpful.
- Again, I think the best way to train someone how to use a lift is with video that includes a running narration, captions, and actual footage.
- Instructions should be brief- maybe the person who wrote the instructions should have to operate the pump using only the directions he/she wrote.
- It's frustrating that the medical supply companies do not provide instruction manuals for the equipment they deliver, & sometimes are not trained to instruct the patient further than basic instructions.
- Most instructions are written in black and white, it would be more helpful if the instructions were colored coded such as red for most important, green for follow-thru, yellow for caution, and blue for other
- Not very good - medical supply company acted as middleman / manufacturer tended to refer me back to them - they wanted to sell / replace new mattress when it wasn't necessary according to a tech I spoke to
- Pictures help a lot. Words can be confusing. People have different disabilities and pictures enable you to see a "person" inside the lift and judge how your family member would fit.
- The manuals and booklets were voluminous and were not read at all. I didn't perceive that there was any useful information for daily use. (Power chair) Same with the manual chairs, except less voluminous. They were sterile and uninviting without color pictures of the chairs in use. All in all, the written matter seems to be designed to just comply with regulations and not help the user. And some accidents happened that could have possibly been avoided with pictures of bad use and proper use - in a user friendly way.
- There should be a law that insists on text and illustrated instructions be delivered and signed for and permanently attached to the equipment.
- If you use several kinds of medical equipment, it would be helpful if the instructions were on the equipment itself, and they were as brief as possible. Unless the caregiver is extremely organized, dealing with more than one set of instructions and more than one piece of equipment can become frustrating, adding more stress to an already stressful situation
- Quick start instructions are the best for time saving and getting to use the equipment right away. A more comprehensive manual would be good for reference.
- So many things fall through the cracks. I am overwhelmed with my set of circumstances to begin with, these issues may seem insignificant, but the stress one feels in the responsibility in keeping someone alive & as comfortable as possible, should not have to endure the struggles of issues with equipment.
- Some products come with photos that take a person through step by step in the usage and care of that piece of medical equipment. That is very useful to refer back to. DVDs that do that are great too.

- Would like pictographs on decals on all equipment. Having a quick set of instructions hanging from the equipment in a heavy plastic holder would be nice too. We could all use a little extra while caregiving to make our loved ones' lives better.
- A law should be put into action that ALL equipment MUST include the written instructions with contact information AND a DVD for us visual people to be included so we don't have to spend hours on the Internet trying to find instructions for our PARTICULAR model's instructions! We don't have time for that!
- A website WITH downloadable material, such as .pdf documents would be helpful. Downloadable videos would be even more helpful to special populations or persons who do not comprehend written instructions very well.
- I think 'cheat sheets' or 'quick reference' guides are the most useful if done in a user friendly way. I have used a 'passport' format in the past with great results due to its compactness, interest factor, and bullet format with pictures. That could be stored in almost any equipment.