

Attachment A: Survey Questions

Web Survey for Home Medical Device Instructions

The National Family Caregivers Association (NFCA) is working with the Food and Drug Administration (FDA) Center for Devices and Radiological Health (CDRH) to learn what information caregivers need to use medical equipment safely in the home.

This survey asks about your experience with instructions for medical equipment you have used in the home to care for your family member. Your answers will be used to help FDA ensure that the instructions for medical equipment used at home are easily available and understandable to all caregivers.

Your responses will be kept strictly confidential and will not be linked with your name.

Please answer the following questions based on your own experience.

1. Please tell us about the family member you care for in the home. What is his or her relationship to you?
 - Spouse/partner
 - Child
 - Parent
 - Other (please describe)

2. How old is your family member?
 - Under 6 years
 - 6-20 years
 - 21-64 years
 - 65 years or over

3. Where do you care for your family member?
 - In my/our home
 - In my family member's home
 - Other (please describe)

4. How long have you cared for your family member?
 - Less than 2 years
 - 2-5 years
 - More than 5 years

5. Which of the following diseases or conditions does your family member have? Please check all that apply.

- o ALS, also known as Lou Gehrig's disease
- o Birth defects
- o Cancer
- o Cerebral palsy
- o Diabetes (sugar)
- o Heart disease
- o Kidney disease
- o Lung disease
- o Multiple Sclerosis (MS)
- o Parkinson's Disease
- o Spinal cord injury
- o Stroke
- o Traumatic brain injury (head injury)
- o Other (Please specify)

Please tell us what medical equipment you use or have used.

	6. What medical equipment have you used to care for your family member in the home? Please check all that apply.	7. (If checked in Q6) How long have you been using this equipment? Less than 1 year 1-2 years 3 or more years		
Blood glucose monitor (to check blood sugar or sugar, also called a glucometer)				
Nebulizer (breathing machine to deliver medicine to the lungs)				
Patient lift (power or manual)				
Wheelchair (power or manual)				
Specialty bed for pressure ulcers or bed sores (air-fluidized or low-air-loss beds)				
Home dialysis machine (kidney dialysis)				
Infusion or IV pump				
Wound therapy machine (for open wound care)				
Ventilator (breathes for the patient)				
Other (please list)				

I do not use any medical equipment to care for my family member (If checked, skip to Q 40)				
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8. Of the equipment you checked above, please choose up to three to answer more questions about.

- Blood glucose monitor (to check blood sugar or sugar, glucometer)
- Nebulizer (breathing machine to deliver medicine to the lungs)
- Patient lift (power or manual)
- Wheelchair (power or manual)
- Specialty bed for pressure ulcers or bed sores (e.g., air-fluidized or low-air-loss beds)
- Home dialysis machine (kidney dialysis)
- Infusion or IV pump
- Wound therapy machine (for open wound care)
- Ventilator (breathes for the patient)
- Other (Please specify)

The following questions ask about your experience with specific equipment.

9. Where did you receive the equipment?

- It was delivered to my home
- In the hospital/rehab center
- At the doctor's office
- Other (please describe)

10. In your opinion, how easy or difficult was it to learn how to use this equipment?

- Very easy to learn
- Somewhat easy to learn
- Somewhat difficult to learn
- Difficult to learn
- Very difficult to learn

11. Did you receive any training about how to use the equipment?

- Yes
- No (skip Q35)

12. Did manufacturer's instructions come with the equipment?

- Yes (go to Q13)
- No (go to Q17, skip Q19, Q24, Q28, Q29)

- I don't remember

(Note: if manufacturer's instructions did not come with the equipment, Q13-16 will be skipped)

13. What kind of instructions came with the equipment? Please check all that apply.

- A manual
- Several manuals
- A booklet
- Several booklets
- Brochure
- Information sheet
- Checklist
- CD or DVD
- Website link or other Internet source
- Other (please describe)

The following questions ask about the instructions for specific equipment.

14. Which of the following was **most helpful** in finding information you needed in the instructions?

- Table of contents
- Section headings
- Index
- Binder tabs
- Internet website navigation menus
- Other (please describe)

15. If you needed to use the manufacturer's instructions to solve a problem you were having (troubleshooting), could you quickly and easily find information you needed?

- Yes
- No
- Comments:

16. How easy or difficult was it to follow the manufacturer's instructions in general?

- Very easy to follow
- Somewhat easy to follow
- Somewhat difficult to follow
- Difficult to follow
- Very difficult to follow
- Please comment on the ease or difficulty in using manufacturer's instructions: (free text)

17. Did you receive instructions from any of the following sources about how to use the equipment? Please check all that apply.

- The hospital
- The doctor's office
- The home health care agency or home health nurse
- The medical supply company
- The rehab hospital or clinic
- The physical therapist
- Other (please describe)
- I did not receive instructions from any other sources (go to Q 20 and skip Q29)

18. What kind of instructions did you receive from the sources checked above about the equipment? Please check all that apply.

- A manual
- A booklet
- Brochure
- Information sheet
- Checklist
- Other (please describe)

(Note: If they checked No on Q12, Q19 will be skipped)

19. Did the additional instructions simplify the manufacturers' instructions or make them clearer?

- Yes
- No
- Comment:

20. Were there pictures or diagrams in the instructions?

- Yes (Go to Q21)
- No (Go to Q22)

21. Were the pictures or diagrams helpful?

- Yes
- No

22. Do you still have the instructions for the equipment?

- Yes
- No

- I don't know

The following questions ask about the use of the instructions for the specific equipment.

23. When have you used the instructions for the equipment? Please check all that apply.

- Only during training or learning to use the equipment
- Until I felt comfortable using the equipment
- To learn about what the alarms or flashing lights meant
- To learn how to calibrate (part of the set-up procedure) or set up the equipment
- For information about cleaning
- Other (please describe)
- I haven't ever used the instructions (go to Q 24, then skip to Q27--all other answers skip to Q 25)

(Note: if the answer to Q12 is No, Q24 will be skipped)

24. I haven't ever used the instructions because:

- The training was all I needed
- I already knew how to use the equipment
- We don't use the equipment
- Instructions I found on the internet were better
- Someone showed me how to use it
- Other (please describe)

25. Once you learned to use the equipment, when have you referred back to the instructions?

- To check and make sure we were continuing to use it correctly
- Every time I use the equipment
- To learn more details about how it works or to learn
- For troubleshooting, or when something didn't work right, or there was a problem
- To learn new features or how to do something new
- To refresh my memory if we haven't used it in a while
- To find out more about battery life or other battery information
- To find a phone number to call when we have a problem

26. Did the instructions tell you what you needed to know when you referred back to them?

- Yes
- No
- Please add any additional comments:

27. What is the most important information that you need to know about using the equipment? (Free text response)

(Note: If the answer to Q12 is no, Q28-9 will be skipped)

28. Is that information contained in the manufacturer's instructions?

- Yes
- No
- I don't know
- Comments:

(Note if they answered Q17 with "I did not receive instructions from any other sources, Q29 will be skipped)

29. Is that information contained in the instructions you received from other sources?

- Yes
- No
- I don't know
- Comments:

30. Where do you turn when you need help or information about the device? I turn to (please check all that apply):

- Instructions on the equipment
- Instructions that came with the equipment
- The Internet
- The manufacturer (company phone number)
- The doctor
- The home health nurse
- The family member I care for
- Support associations (such as NFCA and others)
- The medical supply company (the supplier)
- The hospital
- The rehab center
- Friends or others with the same condition or equipment
- Other (please describe)

31. Would a short version or "quick start" set of instructions be helpful for you to use?

- Yes
- No (skip to Q 33)

32. What type of information would you want to see in this short version or "quick start?" Please describe.

33. Where would it be most helpful for you to find instructions for this equipment?
Please check all that apply.

- On paper (instruction manual, brochure, quick start guide)
- On the equipment itself, such as on a screen or a label
- On-line (Internet or a website)
- Electronic (DVD, CD)
- By phone with a company representative or a home health nurse, etc.
- Other (Please describe)

34. When is the best time to receive written instructions about use of the equipment?
Please rank in order of importance (with 1 being the best or most important time and 6 being the worst or least important time).

- At the hospital
- On delivery of the equipment at home
- During the first home health visit
- When being trained on the equipment
- When first using the equipment
- Other (Please describe)

For the following questions, think about any *training* you may have received about how to use the equipment.

35. Who trained you or taught you how to use the equipment? Please check all that apply.

- Hospital staff (such as nurse, physical therapist)
- Rehab center staff (such as nurse or physical therapist)
- Medical Supply Company rep
- Manufacturer's representative
- Home health provider (such as nurse or physical therapist)
- My doctor or the doctor's office staff
- The family member that I care for

(Note: If answered No to Q11-Were they trained, Q36 will be skipped)

36. In what other ways (besides training) did you learn to use the equipment? Please check all that apply.

- I followed written, paper instructions from the manufacturer
- I followed written, paper instructions from another source
- I searched the Internet for instructions and followed them
- I watched a video on the Internet, such as a YouTube video
- I learned by trial and error
- I learned how to use it from a friend/support group

- Other (please describe)

37. Please add any other comments you would like to share about information and instructions that came with the medical equipment you use:

NOTE: Questions 9-37 will repeat about each device checked in question 8 (up to 2 more devices, and can include devices listed in “other”).

The following questions ask about the written instructions for all of the medical equipment that you use to care for your family member at home.

38. How long do you keep instructions?

- As long as I own the equipment
- Until I don't need them any more
- I just look them up on the Internet
- I lose them as soon as I get them.
- I put them in a special place so I don't lose them.
- I don't know.
- Other (please comment)

39. Where do you keep instructions?

- With the equipment
- In a file and I know where they are
- In a file and I don't know where they are
- In a basket with all the medical information
- I don't know, I can't find them when I need them
- Other (please describe)

Final Questions

40. Now please think about any other medical equipment that you use. What comments do you have about the instructions for the other equipment? (Free text response)

41. How comfortable are you with using computers?

- Very comfortable
- Somewhat comfortable
- Not very comfortable
- Not comfortable at all

42. If the FDA created a searchable website that contained instructions for medical equipment used in the home, do you think you would make use of it?

- Yes
- No
- Comments:

43. What final comments do you have about instructions for any medical equipment that that you have needed or used as a caregiver?

Thank you very much for participating in this important survey.