

## Copy of page:

Thank you for taking part in this survey. It should take about 5 minutes to complete.

We would like to collect some information about you and your conditions, or the conditions of the person you care for. Please also tell us about people you have cared for in the past.

If you care for more than one person please feel free to complete the survey more than once.

None of the information you provide in the survey will be identifiable personally.

We may share anonymous information with other organisations and groups.

### **\*1. Do you have a long-term medical condition or disability, or are you directly involved in caring for someone who has?**

- Yes, I have a long-term medical condition or disability
- Yes, I care for someone with a long-term medical condition or disability
- Yes, I am a healthcare professional involved in caring for people with long-term medical conditions or disabilities
- Other
- No, I don't have long-term medical condition or disability, and I am not directly involved in caring for someone who has

**\*2. Please let us know if the person with the long-term medical condition or disability you care for is male or female :**

- Male
- Female
- Rather not say

**\*3. Are you male or female?**

- Male
- Female
- Rather not say

**\*4. How old are you? Or if you are completing this survey as a carer, how old is the person you care for?**

- 0-5 years
- 6-17 years
- 18-34 years
- 35-64 years
- 65 years or older

**\*5. People who have long-term medical conditions or disabilities often have difficulty with normal day-to-day activities that other people take for granted.**

**Which of the following do you or the person you care for have difficulty with, or have experienced difficulty with in the past? Please tick all that apply.**

- Preparing your own drinks, meals and snacks
- Eating without assistance
- Swallowing
- Managing food restrictions (e.g. sugar, fat, salt, other)
- Managing fluid restrictions (e.g. having to drink a lot or not being allowed to drink much)
- Walking without assistance
- Going up or down stairs
- Grooming (e.g. combing your hair, putting on make-up, shaving)
- Dressing yourself
- Doing housework yourself (e.g. cleaning, washing clothes, hovering, washing up)
- Managing money (e.g. handling money, cards or writing cheques)
- Bathing/showering
- Going to the toilet by yourself
- Continence
- Brushing your teeth
- Getting into bed
- Sleeping
- Moving around in bed
- Getting up
- No difficulties with any of the listed activities

**\*6. Other difficulties you might have could relate directly to your condition, communications or family and work.**

**Which of the following do you or the person you care for have difficulty with, or have experienced difficulty with in the past? Please tick all that apply.**

- Getting to and/or from the hospital/doctor's surgery
- Getting around the hospital or doctor's surgery during your visit, or waiting for your appointment at the hospital or doctor's surgery
- Swallowing medication
- Opening medication packs
- Applying creams or ointments
- Knowing which medication to take or when to take it
- Remembering to take your medication
- Managing pain
- Monitoring my condition
- Doing the exercises suggested by my therapist
- Using a phone
- Using a computer or tablet
- Reading
- Speaking
- Writing
- Hearing
- Summoning help in emergencies
- Caring for dependent children
- Ensuring my family and carers understand my changing needs
- Caring for pets
- Working the hours I would like
- My condition prevents me from working at all
- I am currently between jobs
- No difficulties with any of the listed activities
- Other

Other, please let us know what else you struggle with

**\*7. We would now like you to think about devices you might use to help you manage your condition or symptoms such as catheters, prostheses, walking aids, dialysis machines, glucose monitors, rehabilitation aids or any other devices not included in this list.**

**Do you use any devices to help manage your condition or symptoms?**

Yes

No

Other (please specify)

**\*8. Could you give us a little more detail about what types of devices you use?**



**\*9. If you could change your device, what changes would you make?**

**For example, you might prefer it to be more discrete, better to look at, lighter or less bulky, portable, easier to clean or change the batteries, or have bigger buttons. Perhaps you'd prefer a different material where it touches your skin?**

**If applicable please tell us about several devices - Please be clear about which improvements are for which device.**

**\*10. Which of the following long-term medical conditions do you have, or does the person you care for have?**

- Cancer
- Kidney disease
- Cardiovascular condition
- Lung condition/COPD
- Diabetes
- Parkinson's
- Dementia
- Stroke
- Mental health issues
- Other
- None

Other (Please specify your condition/disability)

**11. NIHR Devices for Dignity have a limited number of places available at a patient-led event taking place later this year. If you would like to know more or wish to be considered for one of the patient or carer places available at this event please provide a telephone number or email address so that we can contact you and provide more information.**

**Further information about the event can be found here:**

**<http://www.devicesfordignity.org.uk/ppc/patient-led-event>**

**12. We will never share your contact details with any other organisation, but if you would like us to email a summary of the results from this survey and other messages that you may be interested in from us, please provide your email address below:**