

Thank you for agreeing to participate in our study to understand how patients like you make decisions about planning their future care.

An advance directive, sometimes also called a living will, is designed to provide a written statement of the type of care you would like to receive if you became too sick to make decisions for yourself. It is used to help doctors, family members, and others treat you according to your wishes. In summary:

- An Advance Directive is to be used as a guide for physicians and your loved ones, helping them to make decisions for you.
- An Advance Directive is used only if you cannot make decisions for yourself.
- An Advance Directive can be changed or withdrawn at any time for any reason.

Advance directives are most useful if copies are shared with your loved ones and physicians. If you choose, the research team can help make an advance directive part of your medical record and send it to your family members, helping to ensure that your doctors, nurses, friends, and family members know your wishes, and protecting them from having to make choices for you without your guidance. You are always free to make changes to an advance directive at any time and for any reason.

**1. Would you like to complete an advance directive with the assistance of any person(s) you choose? Please choose only one option below:**

*adq [random1 = 0 (Control)]*

\_\_\_\_\_ Yes, I would like to complete an advance directive.

\_\_\_\_\_ No, I do not wish to complete an advance directive.

Please let the research study personnel know when you have completed this form.

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**1. Would you like to complete an advance directive with the assistance of any person(s) you choose? Please choose only one option below:**

*adq [random1 = 1 (Intervention)]*

\_\_\_\_\_ Yes, I would like to complete a comprehensive version of an advance directive.

\_\_\_\_\_ Yes, I would like to complete an expanded version of an advance directive.

\_\_\_\_\_ Yes, I would like to complete a brief version of an advance directive.

\_\_\_\_\_ No, I do not wish to complete an advance directive.

Please let the research study personnel know when you have completed this form.

### Satisfaction with Decision Instrument

You have just considered whether or not to complete an advance directive. Please answer the following questions about your decision. Please indicate which of the following statements is true for you AT THIS TIME by **circling one number from 1 (strongly disagree) to 5 (strongly agree)**.

		Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
<b>swd1</b>	1. I am satisfied that I am adequately informed about the issues important to my decision.	1	2	3	4	5
<b>swd2</b>	2. The decision I made was the best decision possible for me personally.	1	2	3	4	5
<b>swd3</b>	3. I am satisfied that my decision was consistent with my personal values.	1	2	3	4	5
<b>swd4</b>	4. I expect to successfully carry out the decision I made.	1	2	3	4	5
<b>swd5</b>	5. I am satisfied that this was my decision to make.	1	2	3	4	5
<b>swd6</b>	6. I am satisfied with my decision.	1	2	3	4	5

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# Your Health and Well-Being

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This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. *Thank you for completing this survey!*

For each of the following questions, please mark an ☐ in the one box that best describes your answer.

**1. In general, would you say your health is:**

bsf1, f3sf1

Excellent	Very good	Good	Fair	Poor
▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

**2. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?**

	Yes, limited a lot	Yes, limited a little	No, not limited at all
	▼	▼	▼
a <u>Moderate activities</u> , such as moving a table, pushing bsf2a, f3sf2a a vacuum cleaner, bowling, or playing golf .....	<input type="checkbox"/> 1.....	<input type="checkbox"/> 2.....	<input type="checkbox"/> 3
b <u>Climbing several</u> flights of stairs .....	<input type="checkbox"/> 1.....	<input type="checkbox"/> 2.....	<input type="checkbox"/> 3
bsf2b, f3sf2b			

**3. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
	▼	▼	▼	▼	▼
a <u>Accomplished less</u> than you would like .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b Were limited in the <u>kind</u> of work or other activities .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

bsf3a, f3sf3a

bsf3b, f3sf3b

**4. During the past 4 weeks, how much of the time have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?**

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
	▼	▼	▼	▼	▼
a <u>Accomplished less</u> than you would like .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
b Did work or other activities <u>less carefully than usual</u> .....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5

bsf4a, f3sf4a

bsf4b, f3sf4b

**5. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?**

	Not at all	A little bit	Moderately	Quite a bit	Extremely
	▼	▼	▼	▼	▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	

bsf5, f3sf5

6. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time ▼	Most of the time ▼	Some of the time ▼	A little of the time ▼	None of the time ▼
a Have you felt calm and peaceful?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
bsf6a, f3sf6a					
b Did you have a lot of energy?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
bsf6b, f3sf6b					
c Have you felt downhearted and depressed?.....	<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5
bsf6c, f3sf6c					

7. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting with friends, relatives, etc.)?

	All of the time ▼	Most of the time ▼	Some of the time ▼	A little of the time ▼	None of the time ▼
<input type="checkbox"/> 1	<input type="checkbox"/> 2	<input type="checkbox"/> 3	<input type="checkbox"/> 4	<input type="checkbox"/> 5	
bsf7, f3sf7					

*Thank you for completing these questions!*

# McGILL QUALITY OF LIFE QUESTIONNAIRE

STUDY IDENTIFICATION #: \_\_\_\_\_

DATE: \_\_\_\_\_

## Instructions

*The questions in this questionnaire begin with a statement followed by two opposite answers. Numbers extend from one extreme answer to its opposite.*

*Please circle the number between 0 and 10 which is most true for you.*

*There are no right or wrong answers.*

*Completely honest answers will be most helpful.*

## EXAMPLE:

I am hungry:

**not at all**   0   1   2   3   4   5   6   7   8   9   10   **extremely**

- If you are not even a little bit hungry, you would circle 0.
- If you are a little hungry (you just finished a meal but still have room for dessert), you might circle a 1, 2, or 3.
- If you are feeling moderately hungry (because mealtime is approaching), you might circle a 4, 5, or 6.
- If you are very hungry (because you haven't eaten all day), you might circle a 7, 8, or 9.
- If you are extremely hungry, you would circle 10.

## BEGIN HERE:

IT IS VERY IMPORTANT THAT YOU ANSWER ALL QUESTIONS FOR HOW  
YOU HAVE BEEN FEELING JUST IN THE PAST TWO (2) DAYS.

### **PART A**

Considering all parts of my life - physical, emotional, social, spiritual, and financial - *over the past two (2) days* the quality of my life has been:

**very bad**   0   1   2   3   4   5   6   7   8   9   10   **excellent**

bmqsis, f3mqsis

*Please continue on the next page...*

**PART B: Physical Symptoms or Physical Problems**

- (1) For the questions in Part "B", please list the **PHYSICAL SYMPTOMS OR PROBLEMS** which have been the biggest problem for you over the past **two (2) days**. (Some examples are: pain, tiredness, weakness, nausea, vomiting, constipation, diarrhea, trouble sleeping, shortness of breath, lack of appetite, sweating, immobility. Feel free to refer to others if necessary).
- (2) Circle the number which best shows how big a problem each one has been for you **OVER THE PAST TWO (2) DAYS**.
- (3) If, over the past two (2) days, you had **NO** physical symptoms or problems, or only one or two, answer for each of the ones you have had and write "none" for the extra questions in Part B, then continue with Part C.

1. Over the past two (2) days,  
one troublesome symptom has been: \_\_\_\_\_.

bmq1\_problem, f3mq1\_problem

(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous  
bmq1, f3mq1 problem

2. Over the past two (2) days,  
another troublesome symptom has been: \_\_\_\_\_.

bmq2\_problem, f3mq2\_problem

(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous  
bmq2, f3mq2 problem

3. Over the past two (2) days,  
a third troublesome symptom has been: \_\_\_\_\_.

bmq3\_problem, f3mq3\_problem

(write symptom)

no problem 0 1 2 3 4 5 6 7 8 9 10 tremendous  
bmq3, f3mq3 problem

*Please continue on the next page...*



4. Over the past two (2) days I have felt:

bmq4, f3mq4

**physically** 0 1 2 3 4 5 6 7 8 9 10 **physically**  
**terrible** **well**

**PART C** Please choose the number which best describes your feelings and thoughts  
**OVER THE PAST TWO (2) DAYS.**

5. Over the past two (2) days, I have been depressed:

bmq5, f3mq5

**not at all** 0 1 2 3 4 5 6 7 8 9 10 **extremely**

6. Over the past two (2) days, I have been nervous or worried:

bmq6, f3mq6

**not at all** 0 1 2 3 4 5 6 7 8 9 10 **extremely**

7. Over the past two (2) days, how much of the time did you feel sad?

bmq7, f3mq7

**never** 0 1 2 3 4 5 6 7 8 9 10 **always**

8. Over the past two (2) days, when I thought of the future, I was:

bmq8, f3mq8

**not afraid** 0 1 2 3 4 5 6 7 8 9 10 **terrified**

9. Over the past two (2) days, my life has been:

bmq9, f3mq9

**utterly** 0 1 2 3 4 5 6 7 8 9 10 **very**  
**meaningless** **purposeful**  
**and without** **and**  
**purpose** **meaningful**

10. Over the past two (2) days, when I thought about my whole life, I felt that in achieving life goals I have:

bmq10, f3mq10

**made no** 0 1 2 3 4 5 6 7 8 9 10 **progressed**  
**progress** **to complete**  
**whatsoever** **fulfillment**

*Please continue on the next page...*

11. Over the past two (2) days, when I thought about my life, I felt that my life to this point has been:

bmq11, f3mq11

<b>completely worthless</b>	0	1	2	3	4	5	6	7	8	9	10	<b>very worthwhile</b>
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12. Over the past two (2) days, I have felt that I have:

bmq12, f3mq12

<b>no control over my life</b>	0	1	2	3	4	5	6	7	8	9	10	<b>complete control over my life</b>
--	---	---	---	---	---	---	---	---	---	---	----	--

13. Over the past two (2) days, I felt good about myself as a person.

bmq13, f3mq13

<b>completely disagree</b>	0	1	2	3	4	5	6	7	8	9	10	<b>completely agree</b>
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14. To me, the past two (2) days were:

bmq14, f3mq14

<b>a burden</b>	0	1	2	3	4	5	6	7	8	9	10	<b>a gift</b>
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15. Over the past two (2) days, the world has been:

bmq15, f3mq15

<b>an impersonal unfeeling place</b>	0	1	2	3	4	5	6	7	8	9	10	<b>caring and responsive to my needs</b>
--	---	---	---	---	---	---	---	---	---	---	----	--

16. Over the past two (2) days, I have felt supported:

bmq16, f3mq16

<b>not at all</b>	0	1	2	3	4	5	6	7	8	9	10	<b>completely</b>
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*Please continue on the next page...*

**Demographic and Clinical information** (all will be kept confidential and secure and will not be shared):

**1. What is your gender?**

**gender** ☐ Male  
☐ Female

**2. What is your date of birth? (mm/dd/yyyy)**

(omitted)

**3. What is your social security number?**

(omitted)

**4. Please provide your phone number(s):**

Home: \_\_\_\_\_

Work: \_\_\_\_\_

Mobile: \_\_\_\_\_

(omitted)

**5. Please provide your address:**

Number/Street: \_\_\_\_\_

City/State: \_\_\_\_\_

Zip Code: \_\_\_\_\_

(omitted)

**6. What is your marital status?**

**marital** ☐ Widowed  
☐ Married/Partnered  
☐ Never married  
☐ Divorced  
☐ Separated

**7. Please specify your ethnicity:**

**ethnic** ☐ Hispanic or Latino  
☐ Not Hispanic or Latino

**8. Please specify your race:**

**race** ☐ American Indian or Alaskan Native  
☐ Asian  
☐ Native Hawaiian or Other Pacific Islander  
☐ Black or African-American  
☐ White or Caucasian  
☐ Other

**9. What is the highest level of education you have completed?**

**educ** ☐ Less than High School  
☐ High School/GED  
☐ Some College  
☐ College Degree  
☐ Post-College Degree (MA, Professional degree, PhD)

**10. What is your combined annual household income?**

**income** ☐ Less than \$30,000  
☐ \$30,000-\$39,999  
☐ \$40,000-\$49,999  
☐ \$50,000-\$59,999  
☐ \$60,000-\$69,999  
☐ \$70,000-\$79,999  
☐ \$80,000-\$89,999  
☐ \$90,000-\$99,999  
☐ \$100,000 or more

**trsplnt** **11. Have you received a kidney transplant in the past?** ☐ Yes ☐ No

**trsplntnum** **If yes, please list how many kidney transplants you have received \_\_\_\_\_?**

**trsplntlist** **12. Are you currently listed for a kidney transplant?** ☐ Yes ☐ No ☐ I don't know

**eoldiscussmd** **13. Have you and your doctor discussed any particular wishes you have about the care you would want to receive if you were dying?**  
☐ Yes ☐ No

**eoldiscussfam** **14. Have you and your family discussed any particular wishes you have about the care you would want to receive if you were dying?**  
☐ Yes ☐ No

**15. Please indicate if you have any of the following conditions (mark all that apply):**

(omitted) ☐ Congestive heart failure  
(omitted) ☐ Peripheral vascular disease (for example, toe or leg amputation)  
(omitted) ☐ Cerebrovascular disease (for example, a stroke)  
(omitted) ☐ Diabetes

religion: numbers indicate coded category. Cf. data dictionary.

**16. Please indicate your religion (choose ONE best option):**

- |   |  |
|---|--|
| 6 <input type="checkbox"/> Agnostic                               | 3 <input type="checkbox"/> Jehovah's Witness                     |
| 2 <input type="checkbox"/> Apostolic/New Apostolic                | 4 <input type="checkbox"/> Jewish                                |
| 2 <input type="checkbox"/> Assemblies of God                      | 2 <input type="checkbox"/> Lutheran                              |
| 6 <input type="checkbox"/> Atheist                                | 3 <input type="checkbox"/> Mennonite                             |
| 7 <input type="checkbox"/> Baha'i                                 | 2 <input type="checkbox"/> Methodist/Wesleyan                    |
| 2 <input type="checkbox"/> Baptist                                | 7 <input type="checkbox"/> Mormon/Latter-Day Saints              |
| 7 <input type="checkbox"/> Buddhist                               | 5 <input type="checkbox"/> Muslim                                |
| 1 <input type="checkbox"/> Catholic                               | 7 <input type="checkbox"/> Native American                       |
| 2 <input type="checkbox"/> Christian Reform                       | 6 <input type="checkbox"/> No religion                           |
| 3 <input type="checkbox"/> Christian Science                      | 6 <input type="checkbox"/> Nondenominational                     |
| 3 <input type="checkbox"/> Christian – no denomination supplied   | 1 <input type="checkbox"/> Orthodox (Eastern)                    |
| 2 <input type="checkbox"/> Church of God                          | 7 <input type="checkbox"/> Other unclassified                    |
| 2 <input type="checkbox"/> Church of the Brethren                 | 7 <input type="checkbox"/> Pagan                                 |
| 2 <input type="checkbox"/> Church of the Nazarene                 | 2 <input type="checkbox"/> Pentecostal/Charismatic               |
| 3 <input type="checkbox"/> Churches of Christ                     | 2 <input type="checkbox"/> Presbyterian                          |
| 3 <input type="checkbox"/> Congregational/United Church of Christ | 2 <input type="checkbox"/> Protestant – no denomination supplied |
| 2 <input type="checkbox"/> Disciples of Christ                    | 3 <input type="checkbox"/> Quaker                                |
| 2 <input type="checkbox"/> Episcopalian/Anglican                  | 2 <input type="checkbox"/> Reformed/Dutch Reform                 |
| 2 <input type="checkbox"/> Evangelical/Born Again                 | 7 <input type="checkbox"/> Scientologist                         |
| 2 <input type="checkbox"/> Foursquare Gospel                      | 2 <input type="checkbox"/> Seventh-Day Adventist                 |
| 2 <input type="checkbox"/> Full Gospel                            | 7 <input type="checkbox"/> Sikh                                  |
| 7 <input type="checkbox"/> Hindu                                  | 7 <input type="checkbox"/> Spiritualist                          |
| 2 <input type="checkbox"/> Holiness/Holy                          | 7 <input type="checkbox"/> Taoist                                |
| 7 <input type="checkbox"/> Humanist                               | 7 <input type="checkbox"/> Unitarian/Universalist                |
| 3 <input type="checkbox"/> Independent Christian Church           | 7 <input type="checkbox"/> Wicca                                 |