THE INITIAL PAPERWORK PACKET: for **Military Soldiers and Veterans**

SUMMARY LETTER

Thank you for considering examination for uranium contamination through the Uranium Medical Research Center.

We are a non-profit organization. You are applying to a research and public health screening program which may not be of any benefit to your physical health. Your participation is entirely voluntary, and you may withdraw your participation as well as record of your participation at any time. In order to proceed, you will need to choose whether you would like to cover the cost of your own laboratory fees or if you would prefer to wait for available grants. Either way you will need to cover the cost of anything which you place in the mail. There are no fees which benefit the UMRC.

If you consent to being a research participant with UMRC, we will use the numeric data from your uranium analysis in our efforts for scientific publication. As protected healthcare information, your name and private information would not be given to anyone. Your identity pertaining to any publication would be entirely anonymous. Importantly, you may withdraw your participation and our right to utilize your data at any time prior to its publication.

In order to register as a UMRC applicant (the first step in any participation with us) you will need to:

1) Create a registration account – you may modify or delete your information at any time
2) Return the Initial Paperwork Package either through regular mail or by scanning the completed package and posting it as an attachment to your registration account

You will then be contacted:

1) To verify full receipt of your material
2) When (and if) a position to become a research participant is available

You may email us with questions about this process any time at umrcinfo@umrc.net.

If you are re-contacted as a research participant, you will first be asked to provide a 24-hour urine sample. You will be mailed a collection kit with instructions to the address provided in your Initial Paperwork Package. This kit includes a container in which you are asked to collect all urine you pass in a 24-hour period. You are otherwise asked to keep a normal routine and normal diet for this time period.

There are also two possible additional steps to be undertaken following receipt of your 24-hour urine sample. These include:

1) Blood sample taken for analysis of genomic abnormalities
2) Clinical examination at a collaborating medical office

Should you wish to begin the applicant and possible participant process, please complete all necessary paperwork and either mail it to us or post a completed, scanned copy to your registration account. Please do your best to write legibly.

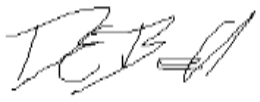
Everything begins with your creation of a UMRC Applicant Registry Account.

Anything mailed to us concerning this registration process should be addressed to:

Uranium Medical Research Center
C/O David E. Bell
PO Box 107, Waterport NY 14571

Any complaints or concerns may be given to the general board of UMRC, based out of the Lakeview Medical Office in Waterport NY, available at 585 682 4274.

Very Sincerely,



David E. Bell, MPH MA (PhD candidate)
Research Coordinator, Uranium Medical Research Center

THE INITIAL PAPERWORK PACKET: **Table of Contents**

This Initial Paperwork Packet is made up of the following items:

1) Contact Sheet
2) Medical and Exposure Survey Form
3) UMRC Rapid Patient Assessment Form
4) Consent Form for Urine Sample Analysis
5) Consent Form for Blood Sample Analysis
6) Consent Form for Results to be Included in Scientific Publication
7) Consent Form for 30 Minute Personal Interview on Your Experience

8) Fatigue Assessment Questionnaire Package (optional)

Along with completing this paperwork, you must create a UMRC Applicant Registration. If you choose to scan your completed paperwork and re-post the packet to your account, please rename the PDF document as follows: **"Your last name, First name – Initial Paperwork Packet."**

Thank You Very Much for Your Interest in Participation.

Form #1: Contact Sheet

Your Name: _____

Preferred title (please circle one): Dr. Mr. Mrs. Ms. Miss Esq. Other: _____

Your Address: _____

Your Telephone Number: _____

Your Email Address: _____

Preferred Method of Contact (please circle one): *Regular Mail* *Telephone* *Email*

Preferred Day of Contact (please circle one): *Week Day* *Weekend Day*

Preferred Time of Contact (please circle one): *Daytime* *Afternoon* *Evening* *Anytime*

Thank You.

Form #2: Medical and Exposure Survey Form
MILITARY SOLDIERS AND VETERANS

PART A: EXPOSURE

1) Have you personally been involved in firing or cleaning-up DU munitions?
(please circle one) **YES** or **NO**

If YES, in what region or country did this occur? _____

during what approximate dates? *(mm/yyyy – mm/yyyy)* _____

2) Were you trained in any way to protect yourself against DU exposure? **YES** or **NO**
Please explain:

_____

_____

3) Have you ever worked closely with DU armored tanks or DU artillery? **YES** or **NO**
Please explain:

_____

_____

_____

4) Were you present at the time DU firing, or DU ordinance recovery or clean-up?
Please explain: **YES** or **NO**

_____

_____

_____

5) Are you are you aware of any other exposure you may have had to DU? **YES** or **NO**
Please explain:

_____

_____

PART B: HEALTH STATUS

6) What is your CHIEF COMPLAINT, or the main MEDICAL reason why you are concerned about possible DU exposure?

_____

7) Please list your 3 greatest health concerns, listed in order of impact on your current life.

a) _____

b) _____

c) _____

8) How healthy would you rank yourself, on a scale of 1 to 10? *(please circle a number)*

Near Death ---------- Perfect Health

0 1 2 3 4 5 6 7 8 9 10

9) In the next 1 to 3 years, do you expect your health to . . . *(please circle one)*

Get much worse Get a little worse Stay the same Get a little better Get much better

10) Have you suffered from any of the following conditions since your service?

(Either officially diagnosed or non-diagnosed)

Category I:

____ Cancer *(any type)*

____ Child with fetal anomaly *(birth defect, stillbirth, miscarriage; if male then with any sexual partner)*

____ Chronic fatigue or otherwise extreme bodily pain or weakness

____ Central Nervous Disorder *(involving problems with coordination, motor function, concentration, memory loss, or dizziness)*

Category II:

___ Persistent skin rash or irritation

___ Respiratory problems

___ Unusual gastrointestinal pains or problems

___ Muscle or joint pain

___ Kidney or urinary tract problem *(including pain with urination)*

___ Unusual tooth or hair loss

___ Headaches or migraines

____ Sexual dysfunction *(including ejaculation pain)*

___ Sleep disorder ___ Post-Traumatic Stress Disorder ____ High anxiety ___ Depression

Other mental health disorder:

_____

11) Have you been medically diagnosed with any of the conditions listed above? *(From either Category I or II)* Please list.

Diagnosis: Date of diagnosis (*mm/yyyy*):

_____ _____

_____ _____

_____ _____

_____ _____

_____ _____

12) Are you interested in medical examination for uranium contamination? YES or NO

13) Please describe anything else you believe is important about **1) your exposure history, 2) your medical condition,** or **3) your reason for interest in uranium analysis**

_____

_____

_____

_____

_____

_____

_____

_____

Form #3: UMRC Rapid Patient Assessment Form
For Possible Internal Contamination with Uranium Isotopes

Please check (√) and then count your number of symptoms.

Minutes or Days Following Bombing Exposure

1) Nose bleeds or runny nose _____
2) Irritation and stinging sensations in throat, nasal passages, mouth _____
3) Skin and/or eyes irritated and burning _____
4) Skin and/or eyes burning when water is applied _____
5) Dry, upper respiratory cough _____
6) Cold and flu like symptoms lasting for weeks _____

Number of Symptoms: _____

Extended Symptoms Following Bombing or Possible Exposure to Contaminated Areas

1) Unusual tiredness, fatigue, weakness (disabling fatigue) _____
2) Intermittent fevers _____
3) Sweating at night _____
4) Headaches _____
5) Recurring or continuous pain in joints _____
6) Recurring nerve, muscle and soft tissue pain _____
7) Short-term memory loss, inconsistent memory capacity _____
8) Mental confusion and disorientation _____
9) Depression and loss of initiative _____
10) Chest pain _____
11) Chronic cold or flu, persistent with respiratory symptoms _____
12) Asthma, chronic bronchitis _____
13) Frequent or persistent unproductive, dry cough _____
14) Pain in the neck, basal skull area, cervical column _____
15) Lower-back, kidney pain _____
16) Stinging sensation when urinating, ejaculating _____
17) Unexplained stomach pain and/or gastrointestinal problems _____

Number of Symptoms: _____

Chronic or Progressive Symptoms

1) Chronic, progressive and repeating symptoms listed above _____
2) Progressive kidney pain and discomfort _____
3) Sexual dysfunction _____
4) Miscarriages _____
5) Birth defects _____
6) Infant children unexplainably ill, weak and lethargic _____
7) Increasing number of family and or community health problems _____
8) Sense of never seeming to get well or defeated immune system (progressive and repeating poor health) _____

Number of Symptoms: _____

Total Number of Symptoms in Rapid Patient Assessment: _____

Form #4: Consent Form for Urine Sample Analysis

This research asks that you provide a 24-hour urine sample.

If you consent to this analysis, you will be mailed a collection jar(s) for this urine, and instructions which reminded you to collect all urine in any 24-hour period while keeping normal diet and activity.

The first risks associated with the collection of this sample may include some psychological discomfort in collection and mailing of the sample. More importantly, you may experience a high emotional reaction if your urine sample tests positive for uranium. Although we are committed to explaining our findings, we are not a counseling service and we are not equipped to assist you in the case of a high emotional reaction.

This step of research will only be taken if you acknowledge these and any other potential risks, and choose to not hold UMRC responsible if you experience any adverse reactions. You must knowingly consent to participate in this research. YOUR PARTICIPATION IS ENTIRELY VOLUNTARY, and you may discontinue your participation with UMRC at any time, with no penalty or loss of benefit to which you are otherwise entitled. Upon your request, any data which can be associated will also be withdrawn.

Mandatory INFORMED CONSENT questions:

Do you have any significant language or mental handicap, so that you can only understand this form with the help of others?

_____ Yes, I have either a language or mental handicap so that I can only understand this form with the assistance of someone else.

_____ No, I do not have any language or mental handicap. I also understand the purpose of this form.

Are you younger than 18 years old?

_____ Yes, I am 17 years old or younger

_____ No, I am 18 years old or older

If you answered "Yes" to either question, we will contact you about additional consent requirements.

If you consent to your urine being analyzed for uranium content, please sign below:

_____ _____

Your Signature **Date**

Form #5: Consent Form for Blood Sample Analysis

This research asks that you provide a small blood sample (less than 50 mL).

If you consent to this analysis, you will be required to find a qualified healthcare professional to draw this sample, and you will be asked to ship your sample in a refrigerated package the same day to our participating genomic laboratory. While all participants will be asked for urine samples to assess uranium content, only some participants will also be asked for blood samples.

The purpose of collecting your blood sample is to assess genomic breaks and abnormalities using spectral karyotype imaging (SKY) test. If you are selected for this stage of research, which is secondary to the uranium urine assessment, you will be notified and given further instructions.

As with urine analysis, there are risks associated with the collection and analysis or your blood for the SKY test. There is some physical discomfort associated with the needle necessary to draw your blood sample. In addition, there is a very slight chance of infection if the site of blood draw is not kept sufficiently clean. Finally, you may experience a high emotional reaction if your blood sample tests positive for genomic abnormalities. Although we are committed to explaining our findings, we are not a counseling service and we are not equipped to assist you in the case of a high emotional reaction.

This step of research will only be taken if you acknowledge these and any other potential risks, and choose to not hold UMRC responsible if you experience any adverse reactions. You must knowingly consent to participate in this research. YOUR PARTICIPATION IS ENTIRELY VOLUNTARY, and you may discontinue your participation with UMRC at any time, with no penalty or loss of benefit to which you are otherwise entitled. Upon your request, any data which can be associated will also be withdrawn.

Mandatory INFORMED CONSENT questions:

Do you have any significant language or mental handicap, so that you can only understand this form with the help of others?

_____ Yes, I have either a language or mental handicap so that I can only understand this form with the assistance of someone else.

_____ No, I do not have any language or mental handicap. I also understand the purpose of this form.

Are you younger than 18 years old?

_____ Yes, I am 17 years old or younger

_____ No, I am 18 years old or older

If answered "Yes" to either question, we will contact you about additional consent requirements.

If you consent to your blood being analyzed for genomic abnormality, please sign below:

_____ _____

Your Signature **Date**

Form #6: Consent Form for 30 Minute Personal Interview on Your Experience

This research asks that you spend approximately 30 minutes talking with a UMRC research associate to get a better understanding of both your medical and exposure histories. While useful in terms of contributing to your biological assessment, the purpose of this interview is more sociological and is meant to better understand and document your personal experience. In essence, this interview is a short representation of your personal story concerning possible uranium contamination. While review of the medical and exposure survey form (Form #2) is the basis for this interview, the interview will emphasize what you want to emphasize.

Researchers conducting the Personal Interview may have several issues of particular interest in mind. This will be further explained to you at the beginning of the interview, along with qualifications and experience of the interviewer. Some of the research interests of UMRC faculty include sociology of class and ethnicity, the role of culture in medicine, and desires or frustrations associated with counseling. Depending on your preference and availability, this interview may be done either in person or over the telephone.

It is possible that some interview questions may evoke strong emotional or political feelings. Discussion of these issues might increase such feelings or your general level of anxiety. We are not a counseling service and we are not equipped to assist you in the case of a high emotional reaction.

You are under no obligation to complete the interview, and are free to end it at any time. You are also free to not answer any particular question you do not wish to answer. Refusing to answer or withdrawing your participation will involve no penalty or loss of benefit to which you are otherwise entitled. Upon your request, any data which can be associated will also be withdrawn. This step of research will only be taken if you acknowledge these and any other potential risks, and choose to not hold UMRC responsible if you experience any adverse reactions. You must knowingly consent to participate in this research. YOUR PARTICIPATION IS ENTIRELY VOLUNTARY.

Mandatory INFORMED CONSENT questions:

Do you have any significant language or mental handicap, so that you can only understand this form with the help of others?

_____ Yes, I have either a language or mental handicap so that I can only understand this form with the assistance of someone else.

_____ No, I do not have any language or mental handicap. I also understand the purpose of this form.

Are you younger than 18 years old?

_____ Yes, I am 17 years old or younger

_____ No, I am 18 years old or older

If answered "Yes" to either question, we will contact you about additional consent requirements.

If you consent to your blood being analyzed for genomic abnormality, please sign below:

_____ _____

Your Signature **Date**

CHECK here if it is OK to audio record this interview: _____

Form #7: Consent Form for Results to be Included in Scientific Publication

The UMRC is a research organization interested in using your results for the purpose of scientific publication and scrutiny.

Your confidentiality will be strictly maintained. Only non-identifiable or numeric data concerning you would ever be published.

If you consent to allowing publication of both biological and sociological data pertaining to you, you may be benefiting the development of science and other people suffering in similar ways to you, but there is unlikely to be any other direct benefit to you.

We will only publish data concerning you if you knowingly consent to our use of your numeric or non-identifiable personal data. YOUR PARTICIPATION IN OUR RESEARCH IS ENTIRELY VOLUNTARY, and you may discontinue your participation with UMRC at any time, with no penalty or loss of benefit to which you are otherwise entitled. Upon your request, any data which can be associated will also be withdrawn.

Mandatory INFORMED CONSENT questions:

Do you have any significant language or mental handicap, so that you can only understand this form with the help of others?

_____ Yes, I have either a language or mental handicap so that I can only understand this form with the assistance of someone else.

_____ No, I do not have any language or mental handicap. I also understand the purpose of this form.

Are you younger than 18 years old?

_____ Yes, I am 17 years old or younger

_____ No, I am 18 years old or older

If you answered "Yes" to either question, we will contact you about additional consent requirements.

If you consent to non-identifiable (anonymous) data pertaining to you being included in scientific publication, please sign below:

_____ _____

Your Signature **Date**

Form #8: Fatigue Assessment Questionnaire Package (optional)

PLEASE COMPLETE ONLY
IF YOU SUFFER FROM FATIGUE OR BODILY WEAKNESS
TO A POINT WHERE YOUR QUALITY OF LIFE
IS NEGATIVELY AFFECTED

To study participants: The following questionnaires are designed to document the clinical state of persons with Gulf War illness, chronic fatigue syndrome, fibromyalgia, and related conditions. While somewhat tedious to fill out, they allow for severity scoring on particular aspects and are helpful for clinical studies. If you do decided to fill in these questionnaires, please try to be complete in filling out all questions.

The following questionnaires are included:

1) Hours of Daily Activity
2) Visual Analog Scales
3) Partial SF-36 Health Survey
4) Orthostatic Grading Scale
5) Bell Activity Scale
6) McGill Pain Questionnaire
7) Pittsburgh Sleep Quality Index
8) Fisk Fatigue Impact Scale

1) HOURS OF DAILY ACTIVITY

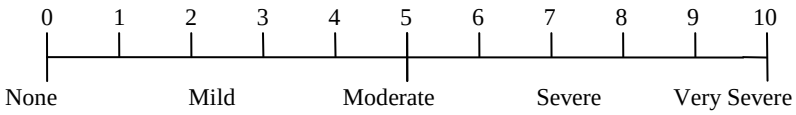
Estimate how much time you spent in each of the activities listed on a good day, an average day and a bad day over the past month. Total for each column should be 24 Hrs.

	Good Day	Average Day	Bad Day
Sleep	_____Hrs	_____Hrs	_____Hrs
Rest (i.e. TV)	_____Hrs	_____Hrs	_____Hrs
Light Activity	_____Hrs	_____Hrs	_____Hrs
Moderate Activity	_____Hrs	_____Hrs	_____Hrs
Exercise	_____Hrs	_____Hrs	_____Hrs
	24 Hrs	**24 Hrs**	**24 Hrs**

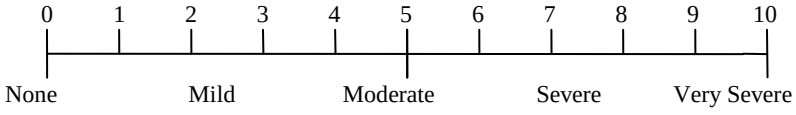
2) VISUAL ANALOGUE SCORES FOR 9 SYMPTOMS

Please mark on the scale the degree to which each symptom has affected you in the past month. If the symptom varies day-to-day, mark an average severity.

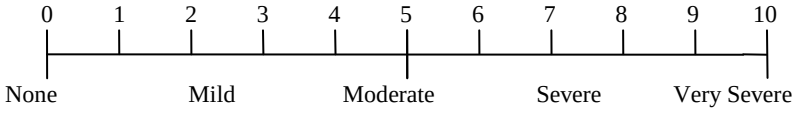
Fatigue



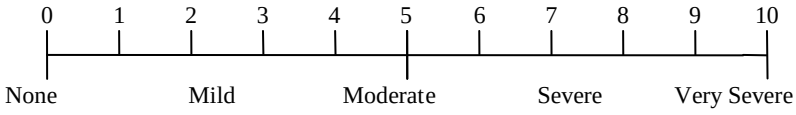
Impaired memory or concentration



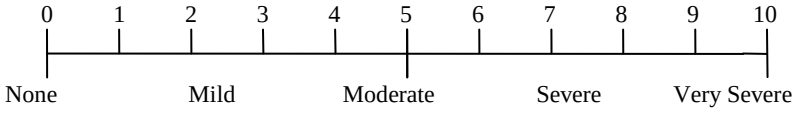
Recurrent sore throat



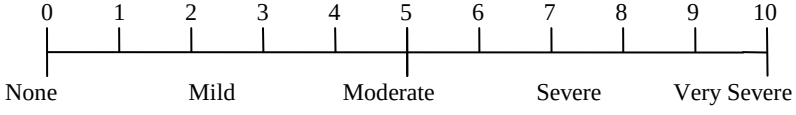
Tenderness in the lymph nodes



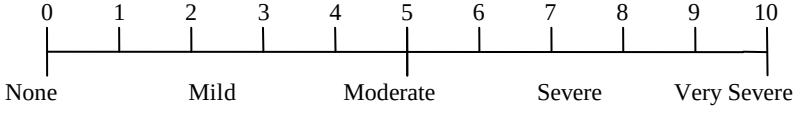
Muscle tenderness or pain



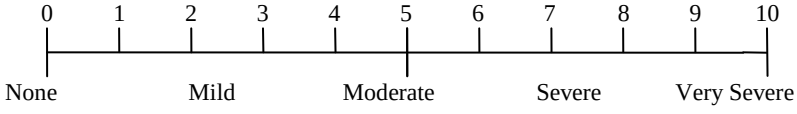
Joint pain



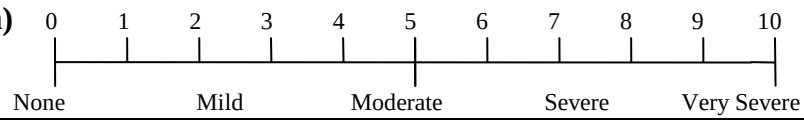
Headache



Disturbed sleep, waking unrefreshed



Post-exertional malaise (Tiredness the day after exertion)



3) MODIFIED PARTIAL SF36 HEALTH SURVEY

Adapted from Rand Corporation and available online for noncommercial purposes at http://www.rand.org/health/surveys_tools/mos/mos_core_36item_survey.html

INSTRUCTIONS: This set of questions 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. Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is: (please check one line)

____ Excellent ____ Very Good ____ Good ____ Fair ____ Poor

2. Compared to one year ago, how would you rate your health in general now? (please check one line)

____ Much better than one year ago
____ Somewhat better than one year ago
____ About the same as one year ago
____ Somewhat worse now than one year ago
____ Much worse now than one year ago

3. 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? (please check one line for each part)

Activities	Significantly Limited	Slightly Limited	Not Limited At All
3a. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	_____	_____	_____
3b. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	_____	_____	_____
3c. Lifting or carrying groceries	_____	_____	_____
3d. Climbing **several** flights of stairs	_____	_____	_____
3e. Climbing **one** flight of stairs	_____	_____	_____
3f. Bending, kneeling, or stooping	_____	_____	_____
3g. Walking **more than one mile**	_____	_____	_____
3h. Walking **several blocks**	_____	_____	_____
3i. Walking **one block**	_____	_____	_____
3j. Bathing or dressing yourself	_____	_____	_____

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health? (please circle YES or NO)

4a. Cut down on the **amount of time** you spent on work or other activities	YES	NO
4b. Accomplished less than you would like	YES	NO
4c. Were **limited** in the **kind** of work or other activities	YES	NO
4d. Had **difficulty** performing the work or other activities (for example it took extra effort)	YES	NO

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (i.e. feeling depressed or anxious)? (please circle YES or NO)

5a. Cut down on the **amount of time** you spent on work or other activities	YES	NO
5b. Accomplished less than you would like	YES	NO
5c. Did not do work or other activities as **carefully** as usual	YES	NO

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with normal social activities with family, friends, or other groups? (please check one)
____ Not at all ____ Slightly ____ Moderately ____ Quite a bit ____ Extremely

7. How much physical pain have you had during the past 4 weeks? (please check one)
____ None ____ Very mild ____ Mild ____ Moderate ____ Severe ____ Very severe

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? (please check one)
____ Not at all ____ Slightly ____ Moderately ____ Quite a bit ____ Extremely

9. These questions are about how you feel and how things have been with you during the past 4 weeks. Please give the one answer that is closest to the way you have been feeling for each item.

(please circle one number for each line)	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9a. Did you feel full of life?	1	2	3	4	5	6
9b. Have you been a very nervous person?	1	2	3	4	5	6
9c. Have you felt so down in the dumps	1	2	3	4	5	6
that nothing could cheer you up?	1	2	3	4	5	6
9d. Have you felt calm and peaceful?	1	2	3	4	5	6
9e. Did you have a lot of energy?	1	2	3	4	5	6
9f. Have you felt downhearted and blue?	1	2	3	4	5	6
9g. Did you feel worn out?	1	2	3	4	5	6
9h. Have you been a happy person?	1	2	3	4	5	6
9i. Did you feel tired?	1	2	3	4	5	6

10. 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 time ___ Most of time ___ Some of time ___ A little of time ___ None of time

11. How TRUE or FALSE is each statement? (please circle one number for each line)

	Definitely true	Mostly true	Do not know	Mostly false	Definitely false
11a. I seem to get sick a little easier					
than other people	1	2	3	4	5
11b. I am as healthy as anybody I know	1	2	3	4	5
11c. I expect my health to get worse	1	2	3	4	5
11d. My health is excellent	1	2	3	4	5

4) MODIFIED ORTHOSTATIC GRADING SCALE

Adapted from Schrezenmaier C, Gehrking J, Hines S, Low P, Benrud-Larson L, Sandroni P. Evaluation of orthostatic hypotension: relationship of a new self-report instrument to laboratory-based measures. Mayo Clin Proc. 2005; 80(3):330-4.

Please circle the number in each category which best reflects your degree of orthostatic symptoms. (Orthostatic symptoms include weakness, light-headedness, nausea, malaise, and fatigue.)

1. Frequency of orthostatic symptoms

0. I never or rarely experience orthostatic symptoms when I stand up.
1. I sometimes experience orthostatic symptoms when I stand up.
2. I often experience orthostatic symptoms when I stand up.
3. I usually experience orthostatic symptoms when I stand up.
4. I always experience orthostatic symptoms when I stand up.

2. Severity of orthostatic symptoms

0. I do not experience orthostatic symptoms when I stand up.
1. I experience mild orthostatic symptoms when I stand up.
2. I experience moderate orthostatic symptoms when I stand up, and sometimes have to sit back down for relief.
3. I experience severe orthostatic symptoms when I stand up, and frequently have to sit back down for relief.
4. I experience severe orthostatic symptoms when I stand up, and regularly faint if I do not sit back down.

3. Conditions under which orthostatic symptoms occur

0. I never or rarely experience orthostatic symptoms under any circumstances.
1. I sometimes experience orthostatic symptoms under certain conditions, such as prolonged standing, a meal, exertion such as walking, or when exposed to heat as in a hot day, hot bath, or hot shower.
2. I often experience orthostatic symptoms under certain conditions, such as prolonged standing, a meal, exertion such as walking, or when exposed to heat as in a hot day, hot bath, or hot shower.
3. I usually experience orthostatic symptoms under certain conditions, such as prolonged standing, a meal, exertion such as walking, or when exposed to heat as in a hot day, hot bath, or hot shower.
4. I always experience orthostatic symptoms when I stand up; the specific conditions do not matter.

4. Activities of daily living (i.e. work, chores, dressing, bathing, etc.)

0. My orthostatic symptoms do not interfere with activities of daily living
1. My orthostatic symptoms mildly interfere with activities of daily living
2. My orthostatic symptoms moderately interfere with activities of daily living
3. My orthostatic symptoms severely interfere with activities of daily living
4. My orthostatic symptoms severely interfere with activities of daily living, and I am bed or wheelchair bound because of my symptoms.

5. Standing time

0. On most occasions, I can stand as long as necessary without experiencing orthostatic symptoms.
1. On most occasions, I can stand more than 15 minutes without experiencing orthostatic symptoms.
2. On most occasions, I can stand from 5 to 14 minutes without experiencing orthostatic symptoms.
3. On most occasions, I can stand from 1 to 4 minutes without experiencing orthostatic symptoms.
4. On most occasions, I can stand less than 1 minute before experiencing orthostatic symptoms.

5) BELL ACTIVITY SCALE

Adapted from Bell DS. The Doctor's Guide to Chronic Fatigue Syndrome. Perseus Books: Reading, MA. 1993.

Please check (√) the level which best describes your activity and symptoms.

_____ **100**. No symptoms at rest or with exercise; normal overall activity; able to work or do house/home work full time without difficulty.

_____ **90**. No symptoms at rest; mild symptoms with vigorous activity; normal overall activity level; able to work full time without difficulty.

_____ **80**. Mild symptoms at rest; symptoms worsened by exertion; minimal activity restriction for activities requiring exertion; able to work full time with difficulty in jobs requiring prolonged standing or exertion.

_____ **70.** Mild symptoms at rest; some daily activity limitation noted; overall functioning close to 90% of expected except for activities requiring exertion; able to work full time.

_____ **60**. Mild to moderate symptoms at rest; daily activity limitation clearly noted; overall functioning 70% to 90%; able to work full time in light activity if hours flexible.

_____ **50**. Moderate symptoms at rest; moderate to severe symptoms with exercise or activity; overall activity level reduced to 70% of expected; unable to perform strenuous activities but able to perform light duties or desk work 4 to 5 hours a day, but requires rest periods.

_____ **40**. Moderate symptoms at rest; overall activity 50% to 70% of previous normal; able to go out of the house for short excursions; unable to perform strenuous activities; able to work sitting down at home 3 to 4 hours per day, but requires rest periods.

_____ **30**. Moderate to severe symptoms at rest; severe symptoms with exercise; overall activity reduced to 50% of expected; usually confined to house; able to perform light activity (desk work) 2 to 3 hours per day but requires rest periods.

_____ **20**. Moderate to severe symptoms at rest; unable to perform strenuous activity; overall activity 30-50% of expected; able to leave house only rarely; confined to bed or couch most of day; unable to concentrate more than 1 hour per day.

_____ **10**. Severe symptoms at rest; bedridden the majority of the time; rare travel outside the house; marked cognitive symptoms preventing concentration.

_____ **0**. Severe symptoms on a continuous basis; bedriddren; unable to care for self.

6) MODIFIED SHORT-FORM McGILL PAIN QUESTIONAIRE

Please check (√) the appropriate level for each pain description.

	NONE	MILD	MODERATE	SEVERE
THROBBING	0) _____	1) _____	2) _____	3) _____
SHOOTING	0) _____	1) _____	2) _____	3) _____
STABBING	0) _____	1) _____	2) _____	3) _____
SHARP	0) _____	1) _____	2) _____	3) _____
CRAMPING	0) _____	1) _____	2) _____	3) _____
GNAWING	0) _____	1) _____	2) _____	3) _____
HOT-BURNING	0) _____	1) _____	2) _____	3) _____
ACHING	0) _____	1) _____	2) _____	3) _____
HEAVY	0) _____	1) _____	2) _____	3) _____
TENDER	0) _____	1) _____	2) _____	3) _____
SPLITTING	0) _____	1) _____	2) _____	3) _____
SICKENING	0) _____	1) _____	2) _____	3) _____
FEARFUL	0) _____	1) _____	2) _____	3) _____
PUNISHING-CRUEL	0) _____	1) _____	2) _____	3) _____
TIRING-EXHAUSTING	0) _____	1) _____	2) _____	3) _____

IN GENERAL – HOW WOULD YOU DESCRIBE YOUR OVERALL PAIN LEVEL?

(A)

NO PAIN ---------- WORST PAIN POSSIBLE

0 1 2 3 4 5 6 7 8 9 10

(B)

No Pain (0) _____ Mild (1-2) _____ Discomforting (3-4) _____

Distressing (5-6) _____ Horrible (7-8) _____ Excruciating (9-10) _____

7) MODIFIED PITTSBURGH SLEEP QUALITY INDEX (PSQI)

Adapted from Buysse D, Reynolds C, Monk T, Berman S, Kupfer D. The Pittsburgh Sleep Quality Index: A new instrument for psychiatric practice and research. Psych. Res. 1989; 28: 193-231.

The following questions relate to your usual sleep habits during the past month only. Your answers indicate the most accurate reply for the majority of days and nights in the past month.

During the past month,

1. At what time do you usually go to bed? _____
2. How long (in minutes) does it usually take you to fall asleep? _____
3. At what time do you usually get up in the morning? _____
4. How many hours of actual sleep do you get on such a night _____
   (This may be different from the number of hours you spend in bed)

5. During the past month, how often have you had trouble sleeping because you . . .	Not during the past month (0)	Less than once per week (1)	Once or twice per week (2)	Three or more times a week (3)
a) Cannot get to sleep within 30 minutes				
b) Wake up in the middle of the night or early morning				
c) Have to get up to use the bathroom				
d) Cannot breathe comfortably				
e) Cough of snore loudly				
f) Feel too cold				
g) Feel too hot				
h) Have bad dreams				
i) Have pain				
j) Other reason (please explain) _____				
6. During the past month, how often have you taken medicine (prescribed or "over the counter") to help sleep?				
7. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?				
8. During the past month, how much of a problem has it been to keep up enthusiasm to get things done?				
9. During the past month, how would you rate your overall sleep quality?	Very Good (0)	Fairly Good (1)	Fairly Bad (2)	Very Bad (3)

8) MODIFIED FISK FATIGUE IMPACT SCALE

Adapted from Fisk J, Ritvo P, Ross L, Haase D, Marrie T, Schlech W. Measuring the functional impact of fatigue: initial validation of the fatigue impact scale. Clin Infect Dis. 1994; Suppl 1:S79-S83.

The following statements are designed to determine how much impact fatigue has had on your life in the past month. Please indicate the most appropriate response for each statement below by circling "0" for no impact at all, "1" for slight impact or problem, "2" for moderate impact, "3" for a big impact, and "4" for a very severe impact or problem.

	None	Small	Moderate	Big	Extreme
1) I feel less alert.	0	1	2	3	4
2) I am more isolated from social contact.	0	1	2	3	4
3) I have to reduce my workload or responsibilities.	0	1	2	3	4
4) I am more moody.	0	1	2	3	4
5) I have difficulty paying attention for a long period.	0	1	2	3	4
6) I feel like I cannot think clearly.	0	1	2	3	4
7) I work less effectively (inside or outside of home)	0	1	2	3	4
8) I have to rely more on others to help me or do things for me.	0	1	2	3	4
9) I have difficulties planning activities ahead of time.	0	1	2	3	4
10) I am more clumsy and uncoordinated.	0	1	2	3	4
11) I find that I am more forgetful.	0	1	2	3	4
12) I am more irritable and more easily angered.	0	1	2	3	4
13) I have to be careful about pacing my physical activities.	0	1	2	3	4
14) I am less motivated to do things that require physical effort.	0	1	2	3	4
15) I am less motivated to engage in social activities.	0	1	2	3	4
16) My ability to travel outside my home is limited.	0	1	2	3	4
17) I have trouble maintaining physical effort for long periods.	0	1	2	3	4
18) I find it difficult to make decisions.	0	1	2	3	4
19) I have few social contacts outside of my own home.	0	1	2	3	4
20) Normal day-to-day events are stressful for me.	0	1	2	3	4
21) I am less motivated to do anything that requires thinking.	0	1	2	3	4
22) I avoid situations that are stressful for me.	0	1	2	3	4
23) My muscles feel much weaker than they should.	0	1	2	3	4
24) My physical discomfort is increased.	0	1	2	3	4
25) I have difficulty dealing with anything new.	0	1	2	3	4
26) I am less able to finish tasks that require thinking.	0	1	2	3	4
27) I feel unable to meet the demands that people place on me.	0	1	2	3	4
28) I am less able to provide financial support.	0	1	2	3	4
29) I engage in less sexual activity.	0	1	2	3	4
30) I find it difficult to organize my thoughts.	0	1	2	3	4
31) I am less able to complete tasks that require physical effort.	0	1	2	3	4
32) I worry about how I look to other people.	0	1	2	3	4
33) I am less able to deal with emotional issues.	0	1	2	3	4
34) I feel slowed down in my thinking.	0	1	2	3	4
35) I find it hard to concentrate.	0	1	2	3	4
36) I have difficulty participating fully in family activities.	0	1	2	3	4
37) I have to limit my physical activities.	0	1	2	3	4
38) I require more frequent and longer periods of rest.	0	1	2	3	4
39) I am unable to provide emotional support to my family.	0	1	2	3	4
40) Minor difficulties seem like major difficulties.	0	1	2	3	4