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Chapter 3 WHERE AND HOW TO GET HELP

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I. Both DoD and the VA recently concluded two research trials:

The first study was based on a controversial theory that a microbial infection (mycoplasma) may be at the root of Gulf War veterans symptoms, is an 18-month study involving a trial of doxycycline or a placebo. Patients were considered to have GWI if they have at least two of three symptoms (fatigue, musculoskeletal pain, neurocognitive dysfunction) that began after August 1990 and that have lasted more than six months and up to the present. Patients who tested positive for *Mycoplasma fermentors*, *Mycoplasma Genitalium*, and/or *Mycoplasma pneumoniae* at baseline were eligible to enroll. Patients assigned doxycycline received 200 mg/day. All patients were provided with a potent sun block preparation for protection from common drug-related photosensitivity.

Findings from the VA antibiotic treatment trial appeared to confirm a high (40%) rate of mycoplasma positivity among ill Gulf War veterans. The study, oddly, defined the primary outcome to be improvement of over a threshold amount on a specific metric, after completion of the treatment period, rather than just assessing whether a significant difference was present. . There was strongly significant benefit at the 3-month treatment point in the antibiotic treatment group; however benefit lost significance on further follow-up. Additionally, despite a 40% mycoplasma positivity rate in Gulf War veterans at outset, in both antibiotic treatment and placebo groups the overwhelming majority tested mycoplasma negative at study conclusion, a finding that is difficult to understand. (Even under the conservative assumptions that these Gulf War veterans who tested positive at outset were no more likely than others to become infected, and supposing that mycoplasma recovery and re-infection occur randomly in Gulf War veterans so that only 40% are infected at a given time (but not the same 40%), it would still be expected that 40% of those who received placebo would test positive at study conclusion. This was not the case.) <http://www.gulfink.osd.mil/medsearch/Treatment/VA55.shtml>



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The second study primarily funded by DoD, involved exercise and behavior modification using adaptive behavioral techniques. Cognitive behavioral therapy and exercising seem to provide some relief from the symptoms of Gulf War veterans' illnesses. The results of a new study, the first large-scale, multi-centre trial to compare cognitive behavioral therapy (CBT) and exercise in these veterans, appear in the March 19 issue of the Journal of the American Medical Association. There has also been some controversy among veterans over the use of psychosocial treatments such as cognitive behavior therapy in treating GWVI. The scientific evidence suggests that stress and psychiatric illness cannot account for GWVI. Still, cognitive behavioral therapy has been shown to help with other chronic, multi-symptom illnesses such as fibromyalgia and chronic fatigue syndrome. And because there appears to be similarities between GWVI and chronic fatigue syndrome and fibromyalgia, Dr. Ncloa Wray decided to approve a study on the subject.

In the study, 1992 Gulf War veterans who reported having at least two of three symptoms (fatigue, pain and cognitive symptoms) for more than six months were randomly assigned to one of four groups: usual care; usual care plus cognitive behavioral therapy; usual care plus individual aerobic exercise training; and usual care plus cognitive behavioral therapy and aerobic exercise. The study has given the Department of Veterans Affairs enough justification to start implementing similar programs at VA centers around the country. Some 200 physicians in the VA system specialize in Gulf War Veterans' illnesses. Psychologists and psychiatrists who are trained in CBT are already employed by the system. The VA is hopeful the program being adopted will have more success and will treat a broader spectrum of individuals. The study participants tended to be very ill; many more veterans suffer from milder symptoms. Others feel that the benefits will be limited. Cognitive behavioral therapy and aerobic exercise provide only modest relief from symptoms of Gulf War veterans' illnesses. Unfortunately, over 80% of the patients showed no improvement of symptoms after 1 year of either or both treatments.

II. Active duty military

Active duty military personnel with questions or concerns about their service in the Persian Gulf region - contact your commanding officer or call the Department of Defense (DoD) deployment health' Hotline (1-800-796-9699).

III. Gulf War veterans

Gulf War veterans with concerns about their health - contact the nearest VA medical center. The telephone number can be found in the local telephone directory under Department of Veterans Affairs in the "U.S. Government" listings. A Gulf War Registry examination will be offered. Treatment will be provided to eligible veterans. The VA Gulf



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War Information Helpline can also provide the latest information and assistance. The toll-free telephone number is 1-800-PGW-VETS (1-800-749-8387).

A. Gulf War veterans seeking disability compensation

Gulf War veterans seeking **disability compensation** for illnesses incurred in or aggravated by military service contact a veteran service office near you that is well known on this type of claim. Ask other GW vets that has his claim done for who is the best. Do not call the Veterans Benefits Counselor or call the VA Gulf War Information Helpline. They have given out the wrong information 60% + of the time. NEVER DO YOUR CLAIM ALONE. There has been far too many veterans that tried and lost out on years of pay for it.

B. Veterans who have a motor neuron disease

Veterans who have been diagnosed with a motor neuron disease (including **amyotrophic lateral sclerosis** or **Lou Gehrig's disease**) and who were on active duty between August 2, 1990, and July 31, 1991, regardless of whether they actually served in the Gulf War theater of operations (or family/friends of veterans who are deceased or otherwise unable to contact VA) - call 1-877-DIAL-ALS (1-877-342-5257) to participate in a national survey.

IV. Gulf War veterans who **encounter difficulties** at a VA medical facility can contact the "**patient advocate**" at that medical facility for assistance in resolving the problem or the NGWRC at toll free (866) 531-7183.

Representatives of **veterans service organizations**, including the American Legion (1-800-433-3318), Veterans of Foreign Wars of the United States (1-800-VFW-1899), Disabled American Veterans (1-877-426-2838), etc.

V. The VA has the War Related Illness & Injury Study Centers

War-Related Illnesses and Injury Study Centers (WRIISCs)s. They can be contacted at 1-800-749-8387. There are three subsections. Press one for GW illnesses. The centers are located at the Washington DC VA Hospital (in room 3B203) <http://www.warrelatedillness.va.gov> and East Orange VA Medical Center (outside of Newark, NJ) <http://www.warrelatedillness.va.gov/nj> and West Coast - Palo Alto, California <http://www.warrelatedillness.va.gov/WARRELATEDILLNESS/paloalto>

You can call 1-800-722-8340 to the Washington DC location, 1-800-248-8005 for the East Orange Location and 1-888-482-4376 for the Palo Alto location



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You will need a doctor's referral. The doctor needs to call Helen Malaskiewicz at 1-202-273-8463 for the necessary information/forms.

<http://www.warrelatedillness.va.gov/provider/wriisc-provider-home.asp>

The Department of Veterans Affairs has some new programs for Veterans Returning from Operation Iraqi Freedom and Desert Storm. VA has produced a tri-fold that has important information for returning veterans. See -

<http://www.va.gov/environagents/docs/SVABENEFITS.pdf>

More Data on Combat Related Special Compensation program.

<http://www.dod.mil/prhome/crsc.html> The form for applying is located at

<http://www.dod.mil/prhome/docs/form.pdf>

The VA also has information on the Special Health Care Eligibility for Combat Veterans

http://www.va.gov/environagents/docs/Combat_Vets_2-year_health_care_.pdf

<http://www.va.gov/environagents/docs/SpecialHCforCombatVets2.pdf>

The Center for Women Veterans: <http://www.va.gov/womenvet/>

To find a State Veterans Affairs Office: <http://www.va.gov/partners/stateoffice/index.htm>

To get information on reemployment rights and unemployment insurance: <http://www.dol.gov>

For those individuals that are hearing impaired, the TDD number is 800-829-4833.