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## **PRIMARY CARE MANAGEMENT AND FOLLOW-UP**

**LTC Patrick G. O'Malley, MD, MPH**  
**Chief, General Internal Medicine Services**  
**Walter Reed Army Medical Center**

In this presentation, we'll review medical management and follow-up of patients with deployment-related health concerns, a critical step in the DoD/VA Post-Deployment Health Clinical Practice Guideline.

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The objectives of this presentation are to:

- (1) Review the key steps in the Guideline
- (2) Define the 3 clinical categories of patients with deployment-related health concerns
- (3) Describe the 3 algorithms in the Guideline, which provide recommendations and decision trees for management and follow-up of each patient category, and
- (4) Identify the tools accompanying the Guideline that have been developed to assist providers and patients in management and follow-up of deployment-related health concerns.

Guideline-based clinical management begins as soon as the patient has been identified as having a health concern related to deployment. This can be at the time of redeployment screening or when the patient is asked the military unique vital sign during routine screening in the primary care clinic.

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The first visit to a primary care setting is typically a 15-minute visit. At this first presentation, the provider initiates a careful evaluation of the patient's chief concern, as for any patient. For this evaluation, the provider would want to include a thorough medical history and order only basic screening tests, as appropriate. The first visit also provides an opportunity for the provider to establish or build on a trusting and credible working relationship with the patient...one that results in increased patient satisfaction with care and adherence to medical advice.

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Establishing an atmosphere of trust is obviously important in all health care visits. But, it's especially critical in deployment health care. In this context, trust is often low on both sides of the clinical encounter. The patient may have heard stories or read media articles that lead them to believe that government provided healthcare is oriented more toward protecting the military than looking after the individual needs of the patient. As a result, they may feel that issues are covered up or overlooked. On the other side, the provider may believe that the patient has ulterior motives, such as seeking compensation or wanting to "get out of" some military obligation. This may not fit with everyone's experience and may have been more common in past contingencies. We hope that emphasis on the importance of trust building will help optimize the management of deployment-related health concerns now and in the future.

This emphasis on trust building is built into every aspect of the post-deployment health guideline. We take the time to review recommendations for building trust as a means of highlighting the importance of these actions in this particular healthcare population. Some actions that you might want to consider in establishing this partnership in a post-deployment context include steps to:

- Acknowledge the patient's concerns and symptoms

- Indicate a commitment to understand the patient's concerns and symptoms
- Encourage open and honest transfer of information that will provide a more comprehensive picture of the patient's concerns and medical history
- Indicate a commitment to allocate sufficient time and resources to resolving the patient's concerns
- Avoid open skepticism or disapproving comments when discussing the patient's concerns that their health problems may be related to a deployment

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During this first visit, the provider will want to ask about the nature of the deployment health concern and may want to offer print handouts or guide the patient to the Deployment Health Clinical Center's website, PDHealth.mil, and to other information sources that may be able to provide the patient with answers to deployment-related questions. We'll talk more about these other health risk communication efforts as we go along.

Many providers have indicated that they would be more effective if they had more time with such patients. So, to allow sufficient time for complete evaluation and discussion of the concerns, the Guideline recommends that the provider schedule a 30-minute follow-up visit, typically within 2 weeks of the first visit. This extended follow-up visit allows time to fully understand the patients concerns, and to provide the full-range of risk communication.

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The time between the first and second visit will also provide an opportunity for clinicians to do any additional research they may need concerning risks and exposures for the patient's specific deployment so they can credibly discuss the concern with the patient.

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During the second visit, the provider continues the evaluation by reviewing laboratory and ancillary test results, medical and deployment history, and exposure information. If a diagnosis can be established, the provider should initiate the appropriate treatment. If a diagnosis cannot be established, other ancillary studies and clinical consultations should be ordered as appropriate, keeping in mind that low-yield testing is not usually a good idea. A 'no stone unturned' approach is usually not medically indicated and often fails to reassure the patient. Another 30-minute follow-up visit should be scheduled during which the success of treatment can be monitored in patients for whom a diagnosis has been established, and the evaluation can be continued following guideline recommendations.

Most medical care proceeds from the notion that the patient is seeking care for disease, and treatment is based first and foremost on diagnosis of disease. In a post-deployment context, this aspect of care is obviously important, but it frequently fails to provide a basis for addressing the wide range of other reasons that patients seek care. In primary care settings, only one in three symptoms are medically explained. In a post-deployment health care context, medically unexplained symptoms often become the focus of questions and concerns regarding military, environmental, and psychosocial exposures encountered during deployment. Addressing these questions and concerns may require providers to look beyond disease to issues that might otherwise create patient disability, mistrust, suspicion, and dissatisfaction with care. This can lead to frustrating patient encounters. So, the Guideline attempts to offer alternative ways of assessing and managing these patients.

Once a patient indicates a health concern that is deployment-related (or when the clinician identifies a deployment-related health issue that the patient had not previously recognized), the Guideline prompts the clinician to assess the patient's information needs and how those needs relate to the patient's clinical state.

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In this approach, the patient with deployment-related concerns is “triaged”, if you will, to one of three major clinical categories based on the presence or absence of illness, symptoms, or disease. These categories are:

(1) The patient with deployment-related health concerns who denies symptoms or illness, or “Asymptomatic Concerned Patient” for short

(2) The patient with a well-defined disease who is concerned the disease may be related to deployment, and

(3) Those patients with persistent symptoms lacking a clear medical explanation and who are concerned that the symptoms may be related to deployment.

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The Guideline prescribes a stepped approach to patient education based on the patient’s clinical category, recognizing that some patients may need more attention than others.

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Let’s start with a discussion of the “asymptomatic concerned” patient. Algorithm A1 of the Guideline was developed to address this type of patient.

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After the Gulf War, ten percent of patients identified themselves as healthy but just wanted to ask questions or just wanted to have their name “included on the list” of those with concerns. These concerns may be expressed in the form of questions about illness, exposure, or recent media coverage regarding a deployment-related topic. The questions can vary widely. For example, the patient who is getting deployed to Iraq and has a concern about the side effects of a medicine that is given for malaria prophylaxis. Or the woman who returns from deployment to Kosovo and wonders whether depleted uranium munitions might be a cause of future birth defects and a possible reason to defer pregnancy. A non-deployed family member may also express a health concern that is related to reproduction or the possibility of a contagious illness. In addition, he or she may seek information and reassurance regarding changes or symptoms that have been observed in a spouse who has been deployed.

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In terms of risk communication at this step, providers need to be sure that they validate the patient’s decision to bring this concern to them, reassure the patient, and reinforce the patient-provider partnership. The next step is to try to answer the patient’s questions.

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Patient education is one of the most important responsibilities of the clinician. It is facilitated by attention to the individual patient’s expectations and beliefs about illness and the consequences of exposures, which may differ greatly from patient to patient.

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The goals of the clinician should include attempting to understand the patient’s beliefs, informing the patient about scientific information which directly pertains to his or her concerns, and establishing a collaborative and negotiated understanding upon which further communication and work can be based. Getting other members of the healthcare team involved may also be helpful

since some types of patient education may be more effectively provided by other healthcare team members or in a group setting.

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The Guideline suggests one avenue of information for the provider is the Deployment Health Clinical Center website, PDHealth.mil. The patient can also be referred to PDHealth.mil for information.

After identifying the type and extent of the patient's deployment-related health concern and providing reassurance and education, it's a good idea to follow-up to determine whether the patient continues to be concerned. Patients may leave the first visit with lingering questions that they were afraid to ask or forgot to ask. Focus groups with patients tell us that they are often reluctant to ask questions they feel may be considered "silly" until they trust the provider to take them seriously. A second visit may allow those unasked questions to emerge. A second patient contact should be made within two to four weeks of the initial visit. Contact should be made by telephone or in person, if possible. Even if the health concern does not persist, the clinician should reiterate that time is available for additional discussions regarding current or future concerns. In this way, you reinforce the open, caring, provider-patient relationship. This practice also allows the patient time to digest the information provided during the appointment. Upon further consideration, the patient might think of additional questions or need clarification of specific issues that were presented by the clinician, so the patient should be provided with information on how to contact the provider.

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If the patient's health concern does persist despite a negative screening work-up, reassurance and education, the clinician should re-evaluate the patient's medical data, address psychosocial issues, and tailor further work-up to the evolution of clinical symptoms. In the asymptomatic patient, special reassurance that they will have access to the care they need should symptoms evolve can be reassuring. Additional educational material should be provided, if indicated.

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Although excessive consultation is explicitly cautioned against (particularly in an asymptomatic patient), consultation sources that may be helpful include, but are not limited to: medical specialists; behavioral health or family services; military preventive medicine or public health; bioenvironmental engineering/environmental sciences/industrial hygiene; reproductive toxicology; genetic counseling; health promotion; health education/health information; and spiritual counseling. Even if the patient is referred to a medical specialist or a community resource, the primary care clinician should continue follow-up to ensure that the patient feels that his or her concerns have been adequately addressed and to avoid the perception that they are being "turfed" to someone else.

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Let's now turn to a discussion of the symptomatic patients who believe their symptoms are deployment-related. If the patient has symptoms, then the determination should be made whether or not the condition has a well-defined diagnosis. A diagnosis is a clinically defined injury or disease based on objective and reproducible clinical findings on examination, laboratory testing, or medical imaging. Virtually all patients who see a clinician receive some kind of diagnostic label. Medicine is firmly based on the notion that proper treatment is based upon recognition of the correct disease with a defined etiology. However for syndromes such as multiple chemical sensitivity, chronic fatigue syndrome, fibromyalgia, temporomandibular disorders, fibrositis, and

irritable bowel syndrome, there is ample evidence of diagnostic overlap and limited evidence to support discrete illnesses with distinct pathophysiologies or natural histories. For most of these and other constellations of persistent physical symptoms, comprehensive biomedical evaluation yields few consistent objective findings and does little to guide clinical management or provide insight into associated functional impairment. Typically, these diagnoses are largely descriptive (such as retropatellar pain syndrome) or based on hypothesized etiology (such as fibromyalgia) rather than a known pathophysiology. The Guideline allows for chronic conditions that may not represent an objectively evident injury or disease, to be placed in a diagnostic category where treatments are based on functional status improvement, rather than on defined injury or disease-based treatment.

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If a diagnosis can be established, then proceed to Algorithm A3. Depending on the problem, the laboratory work-up may need to be continued before beginning the treatment plan, or, a specialty consultation may need to be considered.

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For individuals with a clearly defined illness, disease, or injury, the Guideline provides a basic foundation for medical management. The Guideline is not meant to be prescriptive regarding the basic practice of medicine for defined illness, but is intended to call attention to areas of care that overlap extensively with deployment-related exposures, diseases, and concerns and to address specific communication issues for this category of patient.

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Risk communication techniques at this step include providing additional information about the deployment risks and health concerns related to those risks as well as reinforcing the patient-clinician partnership. In addition to the basic risk communication strategies, the goal of the clinician is to offer illness-specific education regarding prognosis, self-care, and treatment options including relative benefits and risks. This can and should be offered through various sources including PDHealth.mil along with illness-specific websites, tapes, videos, and literature.

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If the clinical evaluation reveals a well-defined diagnosis with a widely accepted treatment protocol and the patient is willing to accept this diagnosis as the cause of his or her signs and symptoms, the clinician should initiate treatment at the local medical treatment facility in accordance with the appropriate disease management guideline.

Some of the specific guidelines that support or complement the Post-Deployment Health Clinical Practice Guideline include the Major Depressive Disorder guideline and a new guideline due out in 2004 for Post-traumatic Stress. Clinical guidance, though not formally established as a guideline, is also available for emerging health concerns from deployments, including Depleted Uranium Exposure, Leishmaniasis, SARS, Malaria prophylaxis, and others.

If the evaluation reveals a diagnosis or disease entity that is newly defined or an effective treatment protocol has not yet been established or approved for the condition, the clinician and patient may benefit from collaboration with a Deployment Health Clinical Center. Collaboration can be in-person, on the phone or through written correspondence depending on the urgency of the patient's condition. Consultation with the center offers the clinician and patient access to practitioners with special expertise and experience, entry into approved clinical trials, and diagnostic testing and evaluation that may not be available locally or at other referral centers. Follow-up with the patient after treatment should be based on the disease-specific guideline.

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We often encounter patients with symptoms for which we cannot find a cause. This takes us into Algorithm A2 of the Guideline. These conditions are referred to as medically unexplained symptoms.

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These patients present with symptoms that remain unexplained after an appropriate medical assessment that includes focused diagnostic testing. We know that these patients are not unique to the post-deployment context. In fact, virtually every discipline in medicine has patients with symptoms that are medically unexplained.

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We highly recommend however that the patient be seen at least twice, with symptom duration of greater than 3 months, before concluding that a recognizable illness or injury cannot be identified.

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The most important message to convey to the patient is the availability of help even though the specific cause of the symptoms has not been identified.

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Many providers and patients alike are surprised to find that there are evidence-based approaches to the management of medically unexplained physical symptoms.

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For these patients, the goal is to maximize overall functional status and improve health-related quality of life rather than treating a single symptom or subset of symptoms. Functional status can be monitored by using the SF-36, which is a simple on-line test of 36 questions that gives an score of overall physical and mental well being and can be used to monitor a patient's progress. Diagnostic testing, invasive procedures, and habit-forming or otherwise disabling medications should be used sparingly and conservatively. The Guideline recommends physical and psychological activation and self-management strategies. And, perhaps the most important thing for this group of patients is consistent longitudinal care involving watchful waiting with regular follow-up on a scheduled rather than "PRN" basis. Getting the family or other support systems involved in the care is also important whenever possible, agreed to by the patient, and otherwise clinically appropriate.

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To assist in management of patients with medically unexplained symptoms, the VA and DoD have developed a separate clinical practice guideline specifically addressing this problem. This guideline is available on the PDHealth.mil website.

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A patient brochure on Medically Unexplained Symptoms is also available for use in patient education.

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The DoD Deployment Health Clinical Center, located at Walter Reed Army Medical Center, stands ready to provide multispecialty assessment and consultation to clinicians and patients around the world. The clinical staff has had years of experience in working with unexplained symptoms in the context of deployment-related health concerns. In addition to consultation, they also accept referrals for tertiary, rehabilitative care for patients with chronic problems that seem unresponsive to other forms of treatment.

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For treatment-refractory patients with deployment-related chronic illness or health concerns accompanied by multiple disabling but medically unexplained symptoms, the Deployment Health Clinical Center offers hands on management assistance in the form of an intensive three-week, multidisciplinary rehabilitation program called the Specialized Care Program. This program is available to all military and family members who continue to have problems after going through Guideline-based care at their local MTF. Military health system clinicians can refer patients who meet the admission criteria to this program. Patients must be ambulatory and able to participate in some exercises since physical conditioning is part of the treatment program.

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I want to highlight that providers can find information on Key Elements of the Guideline

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and Consultation Information, including telephone numbers and e-mail address on the Provider Reference Cards that can be found in the original guideline toolkit or the new Providers Desk Reference Set designed for this guideline. All this information is also available electronically for immediate access on the PDHealth.mil website.

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If you need further information on the Guideline or assistance with deployment-related patient management, you can contact the Deployment Health Clinical Center's Provider Toll Free Helpline, inside the US at 1-866-1627 or DSN 662-6365.