require us to publish this SSR, we are doing so in accordance with 20 CFR 402.35(b)(1).

Through SSRs, we convey to the public SSA precedential decisions relating to the Federal old-age, survivors, disability, supplemental security income, and special veterans benefits programs. We may base SSRs on determinations or decisions made at all levels of administrative adjudication, Federal court decisions, Commissioner's decisions, opinions of the Office of the General Counsel, or other interpretations of the law and regulations.

Although SSRs do not have the same force and effect as statutes or regulations, they are binding on all components of the Social Security Administration. 20 CFR 402.35(b)(1).

This SSR will remain in effect until we publish a notice in the Federal Register that rescinds it, or we publish a new SSR that replaces or modifies it.

(Catalog of Federal Domestic Assistance, Programs Nos. 96.001, Social Security—Disability Insurance; 96.002, Social Security—Retirement Insurance; 96.004, Social Security—Survivors Insurance; 96.006—Supplemental Security Income.)


Carolyn W. Colvin,

Acting Commissioner of Social Security.

Policy Interpretation Ruling

Titles II and XVI: Evaluating Cases Involving Interstitial Cystitis (IC)

This Social Security Ruling (SSR) rescinds and replaces SSR 02–2p: "Titles II and XVI: Evaluation of Interstitial Cystitis." 1

Purpose: This SSR clarifies our policy on how we develop evidence to establish that a person has a medically determinable impairment (MDI) of IC and how we evaluate this impairment in disability claims and continuing disability reviews under titles II and XVI of the Social Security Act.

DATES: Effective Date: March 18, 2015.

FOR FURTHER INFORMATION CONTACT: Cheryl Williams, Office of Medical Policy, Social Security Administration, 6401 Security Boulevard, Baltimore, Maryland 21235–6401, (410) 965–1020.

SUPPLEMENTARY INFORMATION: Although 5 U.S.C. 552(a)(1) and (a)(2) do not

Introduction

IC is a complex genitourinary disorder involving recurring pain or discomfort in the bladder and pelvic region. The American Urological Association (AUA), National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), and other medical experts may use the terms "interstitial cystitis/painful bladder syndrome (IC/PBS)" and "interstitial cystitis/painful bladder syndrome (IC/PBS)" to describe this disorder because they consider the term "interstitial cystitis" to be synonymous with the terms "bladder pain syndrome" and "painful bladder syndrome." When we refer to IC in this SSR, we include IC/PBS and IC/PBS.

The AUA has developed guidelines providing a clinical framework for diagnosing and treating IC/PBS. These guidelines use a definition of IC accepted by the Society for Urodynamics and Female Urology: "An unpleasant sensation (pain, pressure, discomfort) perceived to be related to the urinary bladder, associated with lower urinary tract symptoms of more than six weeks duration, in the absence of infection or other identifiable causes." 4 NIDDK's National Kidney and Urologic Diseases Information Clearinghouse explains that the term IC/PBS (and IC/PBS) includes all cases of urinary pain unattributed to other causes, such as infection or urinary stones.

5 NIDDK further explains that the term "interstitial cystitis" is used alone (without PBS or BPS) to describe cases of urinary pain that meet all of the IC criteria NIDDK established in 1987 for research purposes. We took into consideration the AUA and NIDDK descriptions of IC when we formulated the criteria in this SSR. For example, we adapted the AUA and NIDDK descriptions to help develop criteria for establishing an MDI of IC.

Except for statutory blindness, we find a person to be "disabled" if he or she is unable to do any substantial gainful activity by reason of a medically determinable physical or mental impairment(s) or combination of impairments that can be expected to result in death or has lasted or can be expected to last for a continuous period of not less than 12 months.

We require an MDI to result from anatomical, physiological, or psychological abnormalities, as shown by medically acceptable clinical and laboratory diagnostic techniques. The Act and our regulations further require that medical evidence establishing an MDI consist of signs, symptoms, and laboratory findings. Thus, we cannot determine that a person who has IC is disabled on the basis of his or her statement of symptoms alone.

In this SSR, we explain that IC, when accompanied by appropriate symptoms and medical signs or laboratory findings, is an MDI that can be the basis for a finding of "disability." We also explain how we evaluate IC in disability claims.

Policy Interpretation

IC constitutes an MDI when producing appropriate symptoms and medical signs or laboratory findings, and may result in a disabling impairment. There are some signs and findings that could indicate IC, but there are no specific signs or findings that are universally accepted. However, for our program purposes, we are choosing to rely upon certain signs and findings to establish the existence of an MDI of IC. Once we establish that a person has an MDI of IC by taking into consideration these signs or findings, we use the sequential evaluation process to determine whether the person is disabled. This policy interpretation clarifies how our adjudicators should apply our regulations in establishing an MDI of IC and determining disability under titles II and XVI of the Act.

1. What is IC?

A. IC is a complex genitourinary disorder resulting in recurring pain or discomfort in the bladder and pelvic region. The AUA and other medical experts characterize IC, in part, as an unpleasant sensation (pain, pressure, discomfort) perceived to be related to the urinary bladder, associated with lower urinary tract symptoms of more than six weeks duration, in the absence of infection or other identifiable causes. IC is most common in women and sometimes occurs before age 18. It is not unusual for people to have prodromal [early predictive] symptoms years or decades before they get IC.

B. In accordance with the AUA guidelines, a physician should make a diagnosis of IC only after reviewing the person's medical history and conducting a physical examination. The physician should also conduct laboratory tests to rule out certain medical conditions that may result in the same or similar symptoms. For example, the AUA guidelines recommend a basic laboratory evaluation.

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7 We adapted the AUA and NIDDK descriptions of IC, which are mainly symptom-based, because the Act and our regulations require a claimant to establish by objective medical evidence (that is, medical signs and laboratory findings) that he or she has a medically determinable impairment. See 223(d)(3)(A) and 1614(a)(3)(D) of the Act, 20 CFR 404.1560 and 416.908, and SSR 90–4p. Titles II and XVI: Symptoms, Medically Determinable Physical and Mental Impairments, and Exercitional and Nonexercitional Limitations, 61 FR 34388 (1996) (also available at: http://www.seq.gov/OI_Home/RuleEng/ d161/S90-4p-d161.html).
8 See 20 CFR 404.1565 and 416.905.
9 See sections 223(d)(3) and 1614(a)(3)(D) of the Act, 20 CFR 404.1560 and 416.908.
examination that includes urinalysis and urine culture. NIDDK notes that diagnostic tests physicians may also use to rule out other conditions include cystoscopy, biopsy of the bladder wall and urethra, distention of the bladder under anesthesia, and, in men, culture of prostate secretions.12

C. IC may co-occur with fibromyalgia, chronic fatigue syndrome, irritable bowel syndrome, inflammatory bowel disease, vulvodynia, chronic headaches, Sjogren’s syndrome, endometriosis, or systemic lupus erythematosus.

D. Treatments for IC are mostly directed at symptom control. They include, but are not limited to: Changes in diet; physical therapy and pelvic floor strengthening exercises; stress management; bladder distention; bladder instillation; oral drugs, such as prescription drugs indicated for IC (for example, Elmiron and dimethyl sulfoxide), antidepressants, antihistamines, antacids, anticoagulants, and narcotic analgesics; transcutaneous electrical nerve stimulation; and surgery, such as substitution cystoplasty or urinary diversion with or without cystectomy. Treatment is not effective for everyone because response varies among patients.

II. How does a person establish an MDI of IC?

A. General

1. A person can establish that he or she has an MDI of IC by providing appropriate evidence from an acceptable medical source.13 A licensed physician (a medical or osteopathic doctor) is the only acceptable medical source who can provide evidence establishing an MDI of IC. This acceptable medical source often is the person’s treating source(s) who makes the diagnosis of IC. A treating source(s) may be the person’s own physician or other acceptable medical source who provides, or has provided, medical evaluation or treatment and who has, or has had, an ongoing treatment relationship with the person.14

2. We generally will rely on the judgment of a licensed physician who has made a diagnosis of IC.

Evidence must document that this physician reviewed the person’s medical history and conducted a physical examination, and that his or her diagnosis is not inconsistent with the other substantial evidence in the person’s case record.15 However, we cannot rely on the physician’s diagnosis alone to establish an MDI of IC. The physician may make a diagnosis of IC based only on the person’s reported symptoms, after examining the person and ruling out other diseases that could cause the symptoms. Thus, as previously mentioned, there must also be medical signs or laboratory findings to establish an MDI of IC.

3. If we cannot establish that a person has an MDI of IC, but there is evidence of another MDI, we will not evaluate the impairment under this SRR. Instead, we will evaluate it under the rules that apply for that impairment.

B. Symptoms. IC symptoms may vary in incidence, duration, and severity from person to person, and even in the same person. For example, a woman’s symptoms may worsen around the time of menstruation. Symptoms of IC include, but are not limited to:

1. Pain. People who have IC report chronic bladder and pelvic pain, pressure, and discomfort. This pain may range from mild discomfort to extreme distress. The intensity of the pain may increase as the bladder fills and decrease as it empties. In addition to bladder and pelvic pain, people with IC may experience vaginal, testicular, penile, low back, or thigh pain.

2. Urinary urgency and frequency. People who have IC may report an urgent need to urinate (urgency) or a frequent need to urinate (frequency), or both. Some people with severe cases of IC may need to void as often as 60 times per day, including nighttime urinary frequency (nocturia) with associated sleep disruption.16

We use the term "not inconsistent" to indicate that a diagnosis of IC need not be supported directly by all the other evidence (that is, it does not have to be consistent with all the other evidence) as long as there is no other substantial evidence in the case record that contradicts or conflicts with the diagnosis. Whether a diagnosis of IC is "not inconsistent" with the other substantial evidence is a judgment that adjudicators must make in each case. In situations in which the diagnosis of IC is inconsistent with the other substantial evidence in the person’s case record, the adjudicator may determine that the diagnosis is not entitled to "controlling weight" in establishing whether the person has an MDI of IC. An adjudicator should not reject the diagnosis, but instead must weight it using all of the factors provided in 20 CFR 404.1527 and 408.227. See SSR 96–2p, Titled II and XVI. Giving Controlling Weight to Treating Source Medical Opinions, 61 FR 34392 2006 (also available at: http://www.ssa.gov/security/D_PDF_Home/ cgi/printed/SST96-02-d1.HTM).

C. Medical signs. Medical signs can support a diagnosis of IC and help establish the MDI. These signs include the following, which can be detected during a medical procedure that stretches the bladder with fluid (cystoscopy under anesthesia with bladder distention):

1. Fibrosis (bladder-wall stiffening);
2. Diffuse glomerulations (pinpoint bleeding caused by recurrent irritation) on the bladder wall; and
3. Hunner’s ulcers (patches of broken skin) on the bladder wall.

D. Laboratory findings. Laboratory test findings can also support a diagnosis of IC. We will make every reasonable effort to obtain the results of appropriate laboratory testing. However, we will not purchase complex, costly, or invasive tests. Some laboratory tests and findings are more widely used and accepted than others. The following laboratory findings can help establish an MDI of IC:

1. Repeated sterile urine cultures while IC symptoms continue;
2. Positive potassium sensitivity test (Parson’s test); and
3. Antiproliferative factor (APF) accumulation in the urine.17

E. Other signs and findings. Because of the ongoing research into the etiology and manifestations of IC, the medical criteria discussed above are only examples of signs and laboratory findings that help establish an MDI of IC; they are not all-inclusive. As medical research advances regarding IC, we may rely on other signs and laboratory findings to help establish an MDI of IC. For example, gene studies are exploring whether there are various

http://kidney.niddk.nih.gov/KID Diseases/pubs/infastinocystitis/index.aspx As used by the NIDDK, the word "severe" is not meant in the same sense that we use the word to describe a severe impairment at the second step of our sequential evaluation process.

We will not purchase this procedure to establish an MDI of IC because it is an invasive procedure.

Hunner’s ulcers are rare and may be present in only 5–10 percent of individuals with IC.

Although validated by some studies, the potassium sensitivity test is not yet recommended for routine clinical use and can be painful for the patient. We will not purchase this procedure to establish an MDI of IC because it is an invasive procedure.

Physicians do not routinely measure APF.
subtypes of IC. Thus, we may document the existence of IC as an MDI with medical signs and laboratory findings other than those listed above, provided such evidence is consistent with medically accepted clinical practice and the other evidence in the case record.

F. Mental conditions. People who have IC may report ongoing mental conditions directly associated with their IC. For example, a person may report having anxiety or depression associated with IC symptoms of chronic bladder and pelvic pain, and urinary urgency, frequency, or both. When these mental conditions are documented by mental status examination(s) or psychological testing, they may constitute medical signs or (in the case of psychological testing) laboratory findings that help establish an MDI of IC.

III. How do we document IC?

A. General. In cases of alleged IC, we generally need to have longitudinal evidence because symptoms, signs, and laboratory findings of IC may fluctuate in frequency and severity and may continue over a period of months or years.

1. Longitudinal clinical records reflecting ongoing medical evaluation and treatment from the person’s medical sources, especially treating sources, are extremely helpful in documenting the presence of any signs or laboratory findings, as well as the person’s limitations over time. The longitudinal record should contain medical observations, information about treatment, the person’s response to treatment, and a detailed description of how the impairment affects the person’s ability to function.

2. In addition to obtaining evidence from a physician, we may request evidence from other acceptable medical sources, such as psychologists, both to determine whether the person has another MDI(s) and to evaluate the severity and functional effects of IC in combination with other impairments the person may have. Under our regulations and SSR 06-03p, we also may consider evidence from other medical sources we do not consider acceptable medical sources to help us evaluate the severity and functional effects of the impairment(s). Nurse practitioners, physician assistants, and physical therapists are examples of other medical sources.

3. Information from nonmedical sources can also help us evaluate the severity of a person’s IC.

23 This information may help us assess the person’s ability to function day-to-day and over time. It may also help us when we make findings about credibility of the person’s allegations about symptoms and their effects. Examples of nonmedical sources include:

- Spouses, parents, siblings, other relatives, neighbors, friends, and clergy;
- Past employers, rehabilitation counselors, and teachers;
- Statements from SSA and State agency personnel who interviewed the person.

4. Before we make a determination whether or not the person is disabled, we will make every reasonable effort to develop his or her complete medical history and help the person get medical reports from his or her medical sources. Generally, we will request evidence from the person’s medical sources for the 12-month period preceding the month of application unless there is reason to believe that development of an earlier period is necessary, or unless the alleged onset of disability is less than 12 months before the date of application.

5. When the alleged onset of disability secondary to IC occurred less than 12 months before adjudication, we must evaluate the medical evidence and project the degree of impairment severity that is likely to exist at the end of 12 months. Information about the person’s treatment and response to treatment, including any medical source opinions about the person’s prognosis at the end of 12 months, helps us decide whether to expect an MDI of IC to be of disabling severity for at least 12 consecutive months.

B. What do we do if there is insufficient evidence to determine whether the person has an MDI of IC or is disabled?

1. When there is insufficient evidence for us to determine whether the person has an MDI of IC or is disabled, we may take one or more actions to try to resolve the insufficiency:

- We may request the person’s treating or other source(s) to see if the information we need is available;
- We may request additional existing records from treating or other sources;
- We may ask the person or others for more information; or
- We may purchase a consultative examination (CE) at our expense.

2. When we are unable to resolve an insufficiency in the evidence, and we need to determine whether the person has an MDI of IC or is disabled, we may make a determination or decision based on the evidence we have.

C. How do we resolve conflicts in the evidence? Conflicting evidence in the medical record is not unusual in cases of IC due to the complicated diagnostic process involved. We will consider conflicting medical evidence in accordance with our rules.

IV. How do we evaluate a person’s statements about his or her symptoms and functional limitations?

Generally, we follow a two-step symptom evaluation process:

A. First step of the symptom evaluation process. There must be medical signs or laboratory findings that show the person has an MDI(s) which we could reasonably expect to produce the pain or other symptoms alleged. If we find that a person has an MDI that we could reasonably expect to produce the alleged symptoms, the first step of our two-step process for evaluating symptoms is satisfied.

B. Second step of the symptom evaluation process. After finding that the MDI could reasonably be expected to produce the alleged symptoms, we evaluate the intensity and persistence of the person’s symptoms and determine the extent to which they limit the person’s functional capacity for work. In evaluating the intensity, persistence, and functionally limiting effects of symptoms, we consider all of the evidence in the case record, including the person’s daily activities.

21 See 20 CFR 404.1528 and 416.926.
23 See 20 CFR 404.1513(d)(2-4) and 416.913(d)(2-4), and also SSR 06-03p.
24 See 20 CFR 404.1512(d) and 416.912(d).
25 To meet the statutory requirement for “disability,” a person must have been unable to engage in any substantial gainful activity because of any medically determinable physical or mental impairment that is expected to result in death or that has lasted or can be expected to last for a continuous period of not less than 12 months. Thus, the existence of an impairment(s) for 12 continuous months is not controlling; rather, it is the existence of a disabling impairment that has lasted or can be expected to last for at least 12 months that meets the duration requirement of the Act. See 20 CFR 404.1509 and 416.909.
26 See 20 CFR 404.1520(b)(b) and 416.920(b)(b).
27 See 20 CFR 404.1520(b)(3), and 416.920(b)(3).
28 See 20 CFR 404.1520(d) and 416.920(d).
29 See 20 CFR 404.1520(b) and 416.920(b).
30 See 20 CFR 404.1520, 416.920, and 416.924.
medications or other treatments the person uses, or has used, to alleviate symptoms; the nature and frequency of the person's attempts to obtain medical treatment for symptoms; and statements by other people about the person's symptoms. We will make a finding about the extent to which symptoms, such as pain, affect his or her capacity to perform basic work activities. When we need additional information to assess the person's statements about symptoms and their effects, we will make every reasonable effort to obtain available information that could shed light on the person's statements.

V. How do we find a person disabled based on an MDI of IC?

Once we establish that a person has an MDI of IC, we will consider this MDI in the sequential evaluation process to determine whether the person is disabled. As we explain in section VI below, we consider the severity of the impairment, whether the impairment meets or medically equals the requirements of a listed impairment, and whether the impairment prevents the person from doing his or her past relevant work or other work that exists in significant numbers in the national economy.

VI. How do we use the sequential evaluation process to evaluate IC?

We adjudicate claims involving IC using the sequential evaluation process, just as we do for any impairment. Once we find that an MDI(s) exists (see section II), we must establish the severity of the impairment(s) based on the totality of signs, symptoms, and laboratory findings, and the effects of the impairment(s), including any related symptoms, on the person's ability to function. Additionally, several other disorders may share characteristics similar to those of IC. When there is evidence of the potential presence of another disorder that may adequately explain the person's symptoms, it may be necessary to pursue additional medical or other development. As mentioned, if we cannot find that the person has an MDI of IC but there is evidence of another MDI, we will not evaluate the impairment under this SSR. Instead, we will evaluate it under the rules that apply for that impairment. A. Step 1. We consider the person's work activity. If a person with IC is engaged in substantial gainful activity, we will find that he or she is not disabled.

B. Step 2. If we find that a person with IC has an MDI that meets the duration requirement and the person alleges pain and other symptoms consistent with IC, we must consider these symptoms in deciding whether the person's impairment is "severe" at step 2 of the sequential evaluation process, and at any later steps reached in the sequential evaluation process. If we find that the person's pain, urinary urgency or urinary frequency, or other symptoms have more than a minimal effect on a person's ability to perform basic work activities, we must find that the person has a "severe" impairment.

C. Step 3. When we find that a person with IC has a severe MDI, we must proceed to step three and consider the medical severity of the impairment(s). At this step, we consider whether a person's impairment(s) meets or equals in severity one of the impairments in the Listing of Impairments. IC is not a listed impairment; therefore, we cannot find that a person with IC alone has an impairment that meets a listing. However, we will compare the specific findings in each case to any pertinent listing to determine whether medical equivalence may exist. We also may find medical equivalence if the person has multiple impairments, including IC, none of which meets or medically equals the requirements of a listing, but the combination of impairments is medically equivalent in severity to a listed impairment. In cases in which a person with IC has psychological manifestations related to IC, we must consider whether the person's impairment meets or equals the severity of any impairment in the mental disorders listings (see section III).

D. Steps 4 and 5. For those impairments that do not meet or medically equal the severity of a listing, we must make an assessment of the person's residual functional capacity (RFC). The RFC assessment must be based on all the relevant evidence in the record. In assessing RFC related to an MDI of IC, we must consider all of the person's impairment-related symptoms in deciding how such symptoms may affect functional capacity. For example, many people with IC have chronic pelvic pain, which can affect the ability to focus and sustain attention on the task at hand. Nocturia may disrupt sleeping patterns and lead to drowsiness and lack of mental clarity during the day. Urinary frequency can necessitate trips to the bathroom as often as every 10 to 15 minutes, day and night. Consequently, some individuals with IC essentially may confine themselves to their homes. After we consider such impairment-related symptoms and we make our RFC assessment, our evaluation must proceed to the fourth step of the sequential evaluation process, unless an expedited process applies. If necessary, we then proceed to the fifth step of the sequential evaluation process. If we do not use an expedited process, we must determine whether the person's impairment(s) precludes the performance of past relevant work (unless we determine that there was no past relevant work). If we determine that the person's impairment(s) precludes performance of past relevant work or there was no past relevant work, we must make a finding about the person's ability to perform other work. We must apply the usual vocational considerations in determining the person's ability to perform other work.

[38] See 20 CFR 404.1545(a) and 416.945(a), and also SSR 96-8p; Titles II and XVI: Assessing Residual Functional Capacity in Initial Claims, 61 FR 34474 (1996) (also available at http://www.ssa.gov/Opp_Home/rulings/di/01/SSR96-08-di-01.html). Our RFC assessments consider the person's maximum ability to do sustained work activities in an ordinary work setting on a regular and continuous basis. Generally, a "regular and continuous basis" means eight hours a day, for five days a week, or an equivalent work schedule of 40 hours per week. In cases involving IC, chronic fatigue may affect the person's physical and mental ability to sustain work activity, and this may be especially true in cases involving urinary frequency.

[39] See 20 CFR 404.1529(d) and 416.929(d), and SSR 96-7p.

[40] See 20 CFR 404.1520(b) and 416.920(b).

[41] The fourth and fifth steps of the sequential evaluation process are not applicable to claims for benefits under title XVI for people under age 18. See 20 CFR 416.624.

1. Pain and other symptoms associated with IC may result in exertional limitations that prevent a person from doing a full range of unskilled work in one or more of the exertional categories in appendix 2 of subpart P of part 404 (appendix 2). People with IC may also have nonexertional physical or mental limitations because of their pain or other symptoms. Some may have environmental restrictions, which are also nonexertional.

2. Exertional and nonexertional limitations resulting from IC may affect the person’s ability to perform routine movement and necessary physical activity in the work environment, such as sitting, standing, walking, lifting, carrying, pushing, and pulling. These limitations may also affect the person’s ability to do postural functions, such as climbing, balancing, stooping, and crouching, or they may affect the person’s ability to tolerate extreme heat, humidity, or hazards.

3. Adjudicators must be alert to the possibility that there may be exertional or nonexertional (for example, postural or environmental) limitations that exceed a person’s occupational base sufficiently to preclude the use of a rule in appendix 2 to direct a decision. In such cases, adjudicators must use the rules in appendix 2 as a framework for decision-making and may need to consult a vocational resource.

E. Continuing disability reviews. In those cases in which we find that a person has a disability based on IC, we will conduct an appropriate continuing disability review as required by law.

For this review, we take into account relevant individual case facts, such as the combined severity of other chronic or static impairments, and the person’s vocational factors.

Effective Date: This SSR is effective on March 18, 2015.


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