

IC Phenotype Workbook

A Gentle Questionnaire to Explore Your IC/BPS Phenotype

At IC Ally, we know that living with Interstitial Cystitis / Bladder Pain Syndrome (IC/BPS) can feel isolating and confusing. This workbook is designed to help you explore your symptom patterns in a structured way, so you feel more prepared and confident when speaking with your clinician.

IC/BPS is complex and often misunderstood. Each person's experience is unique, and understanding which symptom patterns—or phenotypes—might fit you is an important step towards finding the right support and treatment approach.



Educational tool – not a diagnosis. Please use together with a qualified clinician.

Welcome to Your IC Ally Workbook

Welcome. If you're reading this, you're already taking an important step towards understanding your body and advocating for your health. At IC Ally, we believe that you deserve to be heard, believed, and supported throughout your journey with IC/BPS.

This workbook is here to help you notice patterns in your symptoms and prepare for conversations with your healthcare team. IC/BPS is a real, complex condition that affects people in different ways. You might experience bladder-focused symptoms, pelvic muscle pain, widespread discomfort, or a combination of several patterns. All of these experiences are valid.

The term "phenotype" simply means a pattern or grouping of symptoms. In IC/BPS, researchers and clinicians have identified several common phenotypes that help guide treatment approaches. These include bladder-centric patterns, pelvic floor muscle involvement, non-urologic pelvic pain, and systemic or widespread pain patterns.

It's completely normal—and actually quite common—to fit more than one phenotype. Your symptoms might overlap across several categories, and that's okay. This workbook isn't about putting you into a rigid box. Instead, it's about helping you see the bigger picture of your experience and giving you language to describe what you're feeling.

As you work through these pages, remember that there are no "right" or "wrong" answers. Your honest reflections are the most valuable tool you have. Take your time, be gentle with yourself, and know that understanding your patterns is a powerful first step towards finding relief and support.

How to Use This Workbook

01

Base Your Answers on Recent Patterns

Fill this in based on your typical symptoms over the last 4 weeks. Think about what's been "normal" for you recently, rather than focusing only on your very worst or very best days.

03

Be Honest and Specific

There are no "right" or "wrong" answers here. The more honest and specific you can be, the more useful this workbook will be as a communication tool with your clinician.

05

Use the Phenotype Summary

Near the end of the workbook, you'll find pages to pull everything together. Use these to reflect on which phenotype patterns seem to fit your experience most closely.

Remember: this is your workbook. Feel free to add notes in the margins, highlight what feels important, or skip questions that don't apply to you. Make it work for you.

02

Go at Your Own Pace

You don't have to complete this workbook in one sitting. Take breaks when you need them. Some sections might feel more relevant than others, and that's perfectly fine.

04

Note Your Section Scores

At the end of each section, you'll have space to calculate a simple score. These scores help you see which patterns feel strongest for you right now.

06

Bring This to Appointments

This completed workbook is a valuable talking tool. Share it with your clinician to help them understand your experience more fully and guide your care plan together.


Important Safety Note Before You Start

Before you begin working through this questionnaire, we want to make sure you're aware of symptoms that need urgent medical attention. This workbook is designed to help you reflect on chronic, ongoing patterns—but some symptoms require immediate care.

Please seek urgent medical help if you experience any of the following:

- New, severe pain that feels different from your usual symptoms, especially if it comes on suddenly
- Fever, chills, or feeling generally unwell alongside your bladder or pelvic symptoms
- Visible blood in your urine (though small amounts can sometimes occur with IC/BPS, sudden or heavy bleeding needs assessment)
- Complete inability to pass urine or feeling like your bladder won't empty at all
- Severe nausea, vomiting, or pain that radiates to your back or sides
- Any symptoms that feel like a medical emergency or are significantly worse than anything you've experienced before

These symptoms could indicate conditions that require immediate treatment, such as kidney infection, bladder infection, or other urgent issues. Always trust your instincts—if something feels seriously wrong, seek help right away.

 **Core Disclaimer:** This workbook is informational only. It cannot diagnose IC/BPS or determine your phenotype. It is designed to support conversations with a qualified clinician, not to replace personalised medical advice. Please discuss your answers and any concerns with your healthcare provider.

Now that we've covered safety, you're ready to begin exploring your symptom patterns. Take a deep breath, and let's start with a broad overview of what you're experiencing.

Step 1: Your Symptom Snapshot

Overview

Let's start with the big picture. This section helps you capture what daily life with your bladder and pelvic symptoms looks like right now. Think about your typical experience over the past 4 weeks, not just your very worst or best moments.

For each symptom below, rate both how severe it typically feels (on a scale from 0 to 10, where 0 is "not present" and 10 is "the worst imaginable") and how frequently you experience it.

Common Symptoms Checklist

Symptom	Severity (0-10)	Frequency
Need to urinate very frequently during the day	_____	Never / Occasionally / Often / Always
Wake up multiple times at night to urinate	_____	Never / Occasionally / Often / Always
Sudden, urgent need to urinate that's hard to delay	_____	Never / Occasionally / Often / Always
Pain or discomfort as bladder fills	_____	Never / Occasionally / Often / Always
Pain, burning, or stinging while urinating	_____	Never / Occasionally / Often / Always
Pain or discomfort immediately after urinating	_____	Never / Occasionally / Often / Always
Pressure or heaviness in the pelvic area	_____	Never / Occasionally / Often / Always
Burning sensation in bladder or pelvic area	_____	Never / Occasionally / Often / Always

Step 1: Your Symptom Snapshot (continued)

Symptom	Severity (0-10)	Frequency
Pain with sexual activity or penetration	_____	Never / Occasionally / Often / Always
Pain in vulva, vagina, or external genital area	_____	Never / Occasionally / Often / Always
Pain in urethra (where urine exits)	_____	Never / Occasionally / Often / Always
Discomfort or cramping in pelvic floor muscles	_____	Never / Occasionally / Often / Always
Lower back pain connected to pelvic symptoms	_____	Never / Occasionally / Often / Always
Hip or inner thigh pain or tightness	_____	Never / Occasionally / Often / Always
General pelvic discomfort that's hard to describe	_____	Never / Occasionally / Often / Always

Your Top 3 Most Bothersome Symptoms

From everything you've noted above, which three symptoms bother you the most or have the biggest impact on your daily life? Write them here:

1. _____
2. _____
3. _____

Step 1: Reflection

Take a moment to reflect on what you've just documented. Sometimes simply seeing our symptoms written down can help us notice patterns we hadn't recognised before.

Reflection Prompts

What surprised you as you filled this in?

What feels most important for your clinician to know right now?

Is there anything about your symptoms that feels difficult to put into words?

Remember, this overview is just the beginning. In the sections that follow, we'll explore specific symptom patterns in more detail to help you understand which phenotypes might be most relevant to your experience.

Step 2: Bladder-Focused Symptoms

Some people notice that their symptoms closely track what the bladder is doing—filling, stretching, and emptying. This section explores how strongly your symptoms seem tied to the bladder itself rather than to muscles, nerves, or other structures in the pelvis.

A bladder-centric phenotype might involve symptoms that clearly worsen as the bladder fills and improve after emptying, or pain that feels concentrated in the bladder area. Some people with this pattern have visible bladder lesions (called Hunner lesions), though many don't.

Frequency Questions

On a typical day, how many times do you urinate?

- Fewer than 8 times
- 8-10 times
- 11-15 times
- 16-20 times
- More than 20 times

On a typical night, how many times do you wake to urinate?

- 0 times
- 1-2 times
- 3-4 times
- 5 or more times

Urgency

How would you describe the urgency you feel?

Rate from 0 (no urgency) to 10 (severe urgency that's impossible to delay): ____

When you feel the urge to urinate, can you usually delay it?

- Yes, easily for 30+ minutes
- Sometimes, for 10-30 minutes
- Rarely, for less than 10 minutes
- No, I must go immediately

Step 2: Bladder-Focused Symptoms (continued)

Pain Related to Bladder Filling and Emptying

Do you experience pain or discomfort as your bladder fills?

Rate from 0 (no pain) to 10 (worst imaginable): ____

Frequency: Never Occasionally Often Always

Do you experience pain or discomfort while urinating?

Rate from 0 (no pain) to 10 (worst imaginable): ____

Frequency: Never Occasionally Often Always

Do you experience pain or discomfort immediately after urinating?

Rate from 0 (no pain) to 10 (worst imaginable): ____

Frequency: Never Occasionally Often Always

Changes After Emptying

After you empty your bladder, what typically happens to your pain or discomfort?

☐ It improves significantly

☐ It improves a little

☐ It stays about the same

☐ It actually gets worse

☐ It's unpredictable

Bladder Capacity

Do you feel like your bladder can only hold small amounts of urine before you feel a strong need to go?

☐ Yes, definitely—my bladder feels very small

☐ Sometimes

☐ Not really—I can usually hold a normal amount

☐ Not sure

Step 2: Food, Drink, and Bladder Triggers

Dietary Triggers

Many people with IC/BPS notice that certain foods or drinks affect their symptoms. Tick any that tend to trigger or worsen your bladder symptoms:

- ☐ Acidic foods (citrus, tomatoes)
- ☐ Caffeine (coffee, tea, fizzy drinks)
- ☐ Alcohol
- ☐ Chocolate
- ☐ Spicy foods
- ☐ Artificial sweeteners
- ☐ Carbonated drinks
- ☐ Other: _____

Blood in Urine

Have you ever noticed visible blood in your urine (not during menstruation)?

- ☐ Yes, on multiple occasions
- ☐ Yes, once or twice
- ☐ Never
- ☐ Not sure

Note: If you're experiencing blood in your urine now, please speak with a clinician promptly for assessment.

Notes on Food and Drink Triggers

Use this space to note any patterns you've noticed between what you eat or drink and your symptoms:



Bladder-Focused Score

Review your answers in this section. Consider: How many of your symptoms are clearly linked to bladder filling and emptying? How strong is that connection?

My Bladder-Focused Score feels:

- Low** – Most of my symptoms don't seem directly tied to bladder filling/emptyin
- Medium** – Some symptoms are bladder-related, but I also notice other patterns
- High** – Most of my symptoms clearly track with my bladder state

A higher bladder-focused score may suggest a more bladder-centric pattern, but this is not a diagnosis. It simply highlights an area to explore with your clinician.

Step 3: Pelvic Floor and Muscle-Related Pain

For many people, tight or overworked pelvic muscles play a significant role in pain. This is sometimes called myofascial pain. The pelvic floor is a group of muscles that support your bladder, bowel, and reproductive organs. When these muscles become tense, go into spasm, or develop trigger points (sensitive spots), they can cause pain in the pelvis, hips, lower back, and even down the inner thighs.

This section looks at muscle-based pain patterns. You might notice these symptoms alongside bladder symptoms, or they might feel separate. Both are common in IC/BPS.

Muscle Tightness and Spasm

Do you experience sensations of tightness, spasm, or cramp-like feelings in your pelvic floor muscles?

Rate from 0 (none) to 10 (severe): ____

Frequency: Never Occasionally Often Always

Do you have tightness or pain in your hips or hip flexors?

Rate from 0 (none) to 10 (severe): ____

Frequency: Never Occasionally Often Always

Do you experience lower back pain that seems connected to your pelvic symptoms?

Rate from 0 (none) to 10 (severe): ____

Frequency: Never Occasionally Often Always

Do you have pain or tightness in your inner thighs?

Rate from 0 (none) to 10 (severe): ____

Frequency: Never Occasionally Often Always

Step 3: Positions, Activities, and Internal Discomfort

Pain with Different Positions and Activities

Do you experience pain or discomfort with sitting for long periods?

- Yes, always
- Yes, often
- Sometimes
- Rarely
- No

Does standing for extended periods worsen your pelvic or muscle pain?

- Yes, always
- Yes, often
- Sometimes
- Rarely
- No

Do walking or other exercise activities trigger or worsen muscle-related pain?

- Yes, always
- Yes, often
- Sometimes
- Rarely
- No

Do you experience pain or increased muscle tension with bowel movements?

- Yes, always
- Yes, often
- Sometimes
- Rarely
- No

Internal Exam or Penetration

If applicable to you: Do you experience significant pain or discomfort with internal vaginal examinations or tampon use?

- Yes, severe pain
- Yes, moderate pain
- Mild discomfort
- No pain
- Not applicable to me

Pelvic Sensations

Do you have sensations of heaviness, pressure, or feeling like there's a "golf ball" or "knot" in your pelvic area?

- Yes, very much so
- Yes, sometimes
- Rarely
- No, not really

Body Outline for Muscle Tension

When you print this page, use the space below to draw or shade areas where your muscles often feel tight, tender, or in spasm. Focus on the pelvis, hips, lower back, and inner thighs.

[Space for body diagram marking]

Step 3: Pelvic Floor and Myofascial Score

Now take a moment to review your answers from Step 3. Consider how much muscle tension, tightness, and position-related pain feature in your experience.

Pelvic Floor / Myofascial Score

Think about: How prominent are muscle-related symptoms for you? Do your symptoms worsen with sitting, standing, or activities that engage the pelvic floor?

My Pelvic Floor / Myofascial Score feels:

Low – Muscle-related symptoms aren't a major part of my experience

Medium – I notice some muscle tension and position-related pain, but it's not the main issue

High – Muscle tightness, spasm, and myofascial pain are a significant part of my symptoms

A higher score here may suggest a myofascial or pelvic floor-driven pattern. This can sometimes respond well to pelvic floor physiotherapy, gentle stretching, stress management, and other muscle-focused approaches. Your clinician can help you explore whether this might be helpful for you.

Additional Notes

Is there anything else about muscle-related pain or pelvic floor symptoms that feels important to mention?

Step 4: Non-Urologic Pelvic Pain

Not all pelvic pain comes directly from the bladder. This step looks at pain that feels more focused on the vulva, vagina, urethra (the tube where urine exits), perineum (the area between the genitals and anus), rectum, or tailbone. These symptoms might be present alongside bladder issues, or they might be your primary concern.

Non-urologic pelvic pain can be related to nerve sensitivity, pelvic floor tension, or inflammation in tissues outside the bladder itself. Understanding where your pain is centred can help guide treatment options.

Pain Locations

For each area below, indicate whether you experience pain there, and if so, how intense and frequent it is.

Location	Intensity (0-10)	Frequency
Vulva (external genital area)	_____	Never / Occasionally / Often / Always
Vagina (internal)	_____	Never / Occasionally / Often / Always
Urethra (opening where urine exits)	_____	Never / Occasionally / Often / Always
Perineum (between genitals and anus)	_____	Never / Occasionally / Often / Always
Rectum or anal area	_____	Never / Occasionally / Often / Always
Tailbone (coccyx)	_____	Never / Occasionally / Often / Always
Other pelvic location: _____	_____	Never / Occasionally / Often / Always

Step 4: Triggers and Bladder Connection

Activities and Triggers

Do you experience pain with sexual activity or penetration?

- Yes, severe pain that prevents activity
- Yes, moderate pain during or after
- Mild discomfort
- No
- Not applicable to me

Does wearing tight clothing (such as jeans, underwear, or tights) worsen your pelvic pain?

- Yes, definitely
- Sometimes
- Rarely
- No

Does sitting on certain surfaces (like bicycle seats, hard chairs, or narrow seats) trigger pain in these pelvic areas?

- Yes, always
- Often
- Sometimes
- No

Connection to Urination

When you urinate, does it clearly change the pain in these non-bladder pelvic areas?

- Yes, urinating makes this pain better
- Yes, urinating makes this pain worse
- No change—this pain feels separate from bladder function
- Not sure / It's complicated



Non-Urologic Pelvic Pain Score

Reflect on your answers above. How much of your pain feels concentrated in areas outside the bladder itself?

My Non-Urologic Pelvic Pain Score feels:

Low – Most of my pain is bladder-focused; these other areas aren't a major issue

Medium – I have some pain in these areas, but bladder symptoms dominate

High – Pain in vulva, vagina, urethra, or other pelvic areas is a significant part of my experience

If this score is higher, it may point towards pelvic pain that isn't driven mainly by bladder filling or emptying. This might need a slightly different focus in your care plan, such as addressing nerve sensitivity, pelvic floor dysfunction, or localised inflammation.

Step 5: Whole-Body Symptoms and Overlaps

Some people experience IC/BPS alongside widespread pain, fatigue, digestive issues, headaches, or other conditions. This is sometimes called a systemic pattern, meaning your nervous system and body are more widely involved. This doesn't mean your symptoms are "in your head" or not real—it simply shows that pain and sensitivity can affect multiple body systems.

Understanding the bigger picture of your whole-body health can be really helpful, because treatments that support your nervous system, sleep, stress levels, and overall wellbeing may improve your pelvic symptoms too.

Widespread Pain

Do you experience pain in multiple areas of your body beyond your pelvis? (For example: shoulders, neck, jaw, arms, legs, back)

- ☐ Yes, in many areas (more than 5 areas)
- ☐ Yes, in several areas (3-5 areas)
- ☐ Yes, in 1-2 areas
- ☐ No, my pain is mainly pelvic

If yes, rate the intensity of this widespread pain:

From 0 (no pain) to 10 (worst imaginable): ____

Fatigue and Sleep

How often do you feel fatigued or exhausted, even after a full night's rest?

- ☐ Always or almost always
- ☐ Often (most days)
- ☐ Sometimes (a few times a week)
- ☐ Rarely
- ☐ Never

How would you describe your sleep quality?

- ☐ Very poor—I rarely feel rested
- ☐ Poor—I often wake feeling unrefreshed
- ☐ Fair—some nights are okay, some aren't
- ☐ Good—I usually feel reasonably rested
- ☐ Excellent—I consistently sleep well

Cognitive Symptoms

Do you experience "brain fog," difficulty concentrating, or memory problems?

- ☐ Yes, severely—it affects my daily function
- ☐ Yes, moderately
- ☐ Occasionally
- ☐ Rarely
- ☐ No

Step 5: Gut Symptoms and Other Conditions

Digestive Symptoms

Do you experience symptoms that sound like Irritable Bowel Syndrome (IBS)?

Such as abdominal pain, cramping, bloating, diarrhoea, constipation, or a mix of these.

- Yes, frequently
- Yes, sometimes
- Rarely
- No

Headaches

Do you have frequent headaches or migraines?

- Yes, migraines (severe, throbbing, often with nausea or light sensitivity)
- Yes, frequent tension headaches
- Occasionally
- Rarely
- No

Overlapping Diagnoses

Have you been diagnosed with, or do you suspect you have, any of these conditions alongside IC/BPS? Tick all that apply:

- Fibromyalgia
- Chronic fatigue syndrome (ME/CFS)
- Irritable Bowel Syndrome (IBS)
- Endometriosis
- Temporomandibular joint disorder (TMJ/TMD)
- Migraine
- Anxiety or depression
- Ehlers-Danlos Syndrome or joint hypermobility
- Chronic regional pain syndrome
- Vulvodynia
- Other chronic pain condition: _____

Body Map for Widespread Pain

When you print this page, use the space below to shade or mark any areas outside your pelvis that often feel painful or extra sensitive.

Overview
Full body layout guide

Front View
Profile proportions and posture

Overview

Back View
Posterior muscle and bone points



Step 5: Systemic and Widespread Score

Take a moment to review your answers from Step 5. Think about how much your symptoms extend beyond your pelvis and affect your whole body and overall wellbeing.

Systemic / Widespread Score

Consider: Do you have pain in multiple body areas? Are fatigue, sleep problems, brain fog, digestive issues, or headaches a significant part of your daily experience?

My Systemic / Widespread Score feels:

Low – My symptoms are mostly limited to my pelvis; I don't have much whole-body involvement

Medium – I have some fatigue or other systemic symptoms, but they're not overwhelming

High – Widespread pain, fatigue, and other whole-body symptoms are a major part of my experience

A higher score can suggest a more systemic pain pattern. This doesn't mean your pain is "all in your head"—it simply shows that your nervous system and body are more widely involved. Treatments that support your overall nervous system health, such as stress management, sleep support, gentle movement, nutrition, and sometimes medications that calm nerve sensitivity, may be helpful alongside pelvic-focused therapies.

Reflection

What connections, if any, have you noticed between your pelvic symptoms and your whole-body symptoms?

Step 6: How IC/BPS Affects Your Life

Your symptoms are only part of the story. How they affect your sleep, work, relationships, and sense of self matters just as much. Understanding the impact of IC/BPS on your life helps you and your clinician see the full picture and prioritise what support you need most.

Life Impact Ratings

For each area below, rate how much IC/BPS currently affects it, from 0 (no impact at all) to 10 (completely prevents me from functioning in this area).

Life Area	Impact (0-10)
Sleep quality and quantity	—
Work, study, or career	—
Social life and friendships	—
Intimate relationships and sexual life	—
Family relationships and responsibilities	—
Physical activity and exercise	—
Hobbies and enjoyable activities	—
Mood and emotional wellbeing	—
Sense of identity and self-esteem	—
Financial stability (due to medical costs, reduced work capacity)	—

Step 6: Describing Your Daily Experience and Flares

Beyond numbers and ratings, sometimes it helps to describe your experience in your own words. Use the prompts below to paint a picture of what life with IC/BPS looks like for you.

A Typical Day

A typical day with my symptoms looks like...

(For example: How do your symptoms affect your morning routine? Do you need to plan activities around toilet access? How do symptoms change throughout the day?)

When You're in a Flare

When I'm in a flare, I usually notice...

(Describe what changes during a flare. Are symptoms more intense? Do you need to stay home? What does a flare day feel like?)

Common Triggers

Things that often trigger a flare for me are...

(For example: certain foods, stress, physical activity, hormonal changes, lack of sleep, sexual activity, travel, specific postures)

Step 6: Impact Score and Priorities

Now review the impact ratings you gave on the previous pages. This helps you—and your clinician—understand where IC/BPS is affecting your life most significantly.



Impact Score

Think about the overall burden IC/BPS places on your daily life across sleep, work, relationships, mood, and activities.

Overall, the impact of IC/BPS on my life feels:

Low burden – I can manage most activities without major disruption

Medium burden – I have to make adjustments, but I can still do many things

High burden – IC/BPS significantly limits what I can do and how I live

What Matters Most

If my clinician could help with just one impact area first, I'd choose...

- Sleep
- Work or study
- Social life
- Intimate relationships
- Physical activity
- Mood and emotional wellbeing
- Pain intensity
- Urgency and frequency
- Other: _____

What You Wish Others Understood

One thing I wish more people understood about my life with IC/BPS is...

Pulling It Together: Phenotype Summary

You've worked through a lot of questions about your symptoms, triggers, and life impact. Now it's time to pull everything together and see which phenotype patterns feel strongest for you.

Remember: most people don't fit neatly into just one phenotype. It's completely normal to identify with several patterns. This summary is a starting point for conversations with your clinician, not a final diagnosis or label.

Your Phenotype Summary Table

Phenotype Pattern	Your Score Band	How well this fits your experience
Bladder-Focused / Bladder-Centric	Low Medium High	Not at all Somewhat Very much
Pelvic Floor / Myofascial Pain	Low Medium High	Not at all Somewhat Very much
Non-Urologic Pelvic Pain	Low Medium High	Not at all Somewhat Very much
Systemic / Widespread Pain	Low Medium High	Not at all Somewhat Very much

Take a moment to look at this table. Which rows have higher scores or stronger "fits"? Those are the patterns that might be most relevant to your experience right now. It's also okay if multiple patterns feel relevant—that's very common with IC/BPS.

Reflection on Your Phenotype Patterns

Now that you've reviewed your scores, let's dig a bit deeper. Use these prompts to reflect on what you've discovered about your symptom patterns.

Guided Reflection


Which phenotype(s) seem strongest for you right now?

Do you notice any patterns between your symptoms and things like stress, hormones, diet, movement, or sleep?

What feels like the most important next step in your care?

(For example: seeing a pelvic floor physiotherapist, exploring medication options, working on stress management, getting better diagnostic tests, finding a more supportive clinician, learning more about diet, etc.)

Is there anything about your phenotype patterns that surprised you or gave you new insight?

 **Remember:** Most people have a **mix** of patterns rather than a perfect fit with just one phenotype. This workbook is a starting point for conversations, not a final label. Your experience is unique, and the goal is to help your clinician understand you better so you can work together on a care plan that addresses your specific needs.

My IC Ally Appointment Summary

This page is designed as a one-page summary you can bring to your next appointment. It distills your workbook answers into the most important points to share with your clinician. You can even tear it out or photocopy it if you prefer to keep the rest of your workbook private.

My Top 5 Symptoms Right Now Are:

- 1. _____
- 2. _____
- 3. _____
- 4. _____
- 5. _____

The Phenotype Patterns That Seem to Fit Me Most Are:

My Biggest Questions for My Clinician Are:

- 1. _____
- 2. _____
- 3. _____

Topics I'd Like to Explore or Discuss:

- Diagnostic tests or further investigations
- Referral to pelvic floor physiotherapy
- Systemic pain management or whole-body support
- Medication options or changes
- Creating a flare management plan
- Dietary or lifestyle strategies
- Mental health and emotional support
- Sexual health and intimacy concerns
- Other: _____

You can take this page to your appointment to help your clinician quickly understand what matters most to you right now.

Understanding Phenotype-Guided Treatment

Now that you have a clearer sense of which phenotype patterns might fit you, it can be helpful to understand how this knowledge can guide treatment. Different phenotypes often respond better to different approaches, though there's significant overlap.

Bladder-Centric Phenotype

People with a bladder-focused pattern might benefit from bladder instillations, oral medications that reduce inflammation in the bladder lining, dietary modifications, and sometimes procedures like hydrodistention or treatment of Hunner lesions if present.

Pelvic Floor / Myofascial Phenotype

Pelvic floor physiotherapy is often the cornerstone of treatment for this pattern. Other helpful approaches might include trigger point release, relaxation techniques, gentle stretching exercises, and addressing posture and movement patterns.

Non-Urologic Pelvic Pain

Treatment often focuses on nerve pain management, topical therapies for vulvar or urethral pain, addressing inflammation in specific tissues, and sometimes specialist referral to vulvovaginal specialists or pain medicine clinicians.

Systemic / Widespread Pattern

A whole-body approach is usually most helpful. This might include medications that calm central nervous system sensitivity, sleep support, stress management, gentle movement like yoga or swimming, nutrition, and treating overlapping conditions.

Your clinician can help you develop a personalised treatment plan that addresses your specific phenotype mix. Most people benefit from a combination of approaches rather than a single treatment.

Next Steps, Resources, and Support

Completing this workbook is a significant step. You've taken time to understand your symptoms, recognise patterns, and prepare for meaningful conversations with your healthcare team. At IC Ally, we want you to know: you are not alone, and there is hope.

IC/BPS is a real, complex condition. Research into better treatments and understanding continues to grow. More and more clinicians are becoming skilled at recognising and treating the different phenotypes of IC/BPS. With the right support, many people find significant improvement in their symptoms and quality of life.

Finding Support and Information

There are many organisations and communities dedicated to supporting people with IC/BPS. Whilst we can't provide live links in this printable document, here are some resources to search for:

- **Interstitial Cystitis Association (ICA)** – US-based organisation providing patient education and advocacy
- **Bladder Health UK** – UK-based charity supporting people with bladder conditions
- **International Painful Bladder Foundation (IPBF)** – Global resource for IC/BPS information
- **Pelvic Pain Foundation of Australia** – Resources and support for pelvic pain conditions
- **National Vulvodynia Association** – For those with overlapping vulvar pain
- **Endometriosis UK** – If you also have or suspect endometriosis
- **Chronic Pain Support Groups** – Look for local or online communities

Finding the Right Clinician

Seek out clinicians who:

- Are knowledgeable about IC/BPS and pelvic pain
- Listen to you and believe your experience
- Are willing to consider phenotype-based approaches
- Work collaboratively with you to develop a treatment plan
- Are respectful, compassionate, and evidence-based

Don't be afraid to seek a second opinion if you feel dismissed or unsupported. You deserve quality care.

Self-Care and Flare Management Strategies

Whilst medical treatment is important, self-care and flare management strategies can make a real difference to your day-to-day life with IC/BPS. Everyone is different, but here are some approaches that many people find helpful.



Hydration Balance

Staying well hydrated can help dilute urine and reduce bladder irritation, but drinking too much too quickly can trigger urgency. Find your personal balance.



Dietary Awareness

Many people benefit from avoiding known bladder irritants like caffeine, alcohol, acidic foods, and spicy foods, especially during flares. Keep a food diary to identify your personal triggers.



Stress Management

Stress and anxiety can worsen IC/BPS symptoms. Gentle practices like meditation, deep breathing, or mindfulness can help calm your nervous system.



Heat Therapy

A warm (not hot) heat pack on your lower abdomen or between your legs can soothe pelvic pain and muscle tension. Many people find this helpful during flares.



Gentle Movement

Activities like gentle stretching, yoga, walking, or swimming can help maintain muscle flexibility and reduce tension without aggravating symptoms.



Sleep Hygiene

Prioritising good sleep can help your body heal and reduce overall pain sensitivity. Create a calm bedtime routine and manage night-time frequency as best you can.

Experiment with these strategies and notice what works for you. Keep notes on what helps during flares so you have a personalised toolkit ready.

Emotional Wellbeing and Mental Health

Living with chronic pelvic pain and IC/BPS can take a significant toll on your emotional wellbeing. It's completely normal to feel frustrated, anxious, sad, or even grieving for the life you had before symptoms started. These feelings don't mean you're weak—they're a natural response to living with ongoing pain and disruption.

At IC Ally, we want to emphasise: taking care of your mental health is just as important as treating your physical symptoms. In fact, they're deeply connected. Chronic pain affects mood, and emotional distress can amplify pain signals. Supporting your emotional wellbeing isn't about "thinking positively" to make pain disappear—it's about giving yourself compassionate support whilst navigating a difficult situation.

Signs You Might Benefit from Mental Health Support

- Feeling overwhelmed, hopeless, or unable to cope most days
- Persistent low mood, loss of interest in things you used to enjoy, or crying frequently
- Anxiety that feels unmanageable or interferes with daily life
- Withdrawing from friends, family, or activities
- Sleep problems beyond those caused by nocturia
- Thoughts of self-harm or feeling life isn't worth living

If you recognise any of these, please reach out for support. This might mean speaking to your GP about a referral to a counsellor or psychologist, joining a chronic pain support group, or contacting a mental health helpline.

Therapeutic Approaches That Can Help

- **Cognitive Behavioural Therapy (CBT):** Helps you identify and change unhelpful thought patterns and develop coping strategies
- **Acceptance and Commitment Therapy (ACT):** Focuses on accepting difficult feelings whilst committing to valued actions
- **Mindfulness-Based Stress Reduction:** Teaches present-moment awareness to reduce stress reactivity
- **Pain psychology:** Specialist support for people living with chronic pain

You don't have to struggle alone. Seeking mental health support is a sign of strength, not weakness.

Notes, Ideas, and Questions

Use this space for anything that doesn't fit neatly into the sections we've covered. This page is yours to fill however you like.

You might want to note:

- Patterns you've noticed that don't fit the questionnaire structure
- Ideas for things you'd like to try or explore
- Questions that have come up as you worked through this workbook
- Observations about what makes your symptoms better or worse
- Anything else that feels important to remember or share

Your Notes:

[illegible]

You've Completed Your IC Phenotype Workbook

Congratulations on completing this workbook. Taking the time to reflect deeply on your symptoms, patterns, and experiences is no small task. You should feel proud of the work you've done here.

This workbook is now a valuable tool—a snapshot of your IC/BPS experience that you can share with your clinician, refer back to over time, and use to track how your symptoms and phenotypes might change as you try different treatments.

Remember these key points as you move forward:

You Are Not Alone

Millions of people worldwide live with IC/BPS. There is a growing community of support, research, and understanding.

Your Experience Is Valid

IC/BPS is real. Your pain is real. You deserve to be believed, supported, and treated with compassion.

There Is Hope


With the right phenotype-guided treatment approach, many people find significant improvement in their symptoms and quality of life.

You Are More Than Your Condition

IC/BPS is something you live with, but it doesn't define who you are. You deserve joy, connection, and a meaningful life.

At IC Ally, we believe in you. We believe in your strength, your resilience, and your right to comprehensive, compassionate care. Take this workbook to your next appointment. Advocate for yourself. Ask questions. And know that you're taking important steps towards better understanding and managing your IC/BPS.

We're with you on this journey.

 **Final Disclaimer:** This IC Phenotype Workbook is an educational self-reflection tool. It does not diagnose IC/BPS or any phenotype, and it is not a substitute for personalised medical advice. Please discuss your answers with a qualified healthcare professional. New, severe, or concerning symptoms require prompt medical review.

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