

- Try to choose a time to be intimate when your partner's symptoms are mild and take things slowly. Further information and advice is available in the leaflet entitled 'Sex, Cystitis & Overactive Bladder' available from Bladder Health UK
- Expect that plans to go out or socialise may have to be cancelled sometimes at the last minute. Make sure that your friend or relative knows you understand and that this hasn't spoiled your day. Try to make alternative arrangements perhaps to do something quietly together at home.
- Many BPS sufferers can feel isolated and alone. Encourage your partner to go along to one of the BHUK support groups to connect with other sufferers. Where this is not possible, encourage them to join Facebook and connect with others via the closed pages there. They could also join the BHUK Facebook page at the following link: <https://www.facebook.com/BladderHealthUK/>

BHUK also have website forums where sufferers can chat anonymously and in confidence to other sufferers. These are available at:

**[www.bladderhealthuk.org](http://www.bladderhealthuk.org)**

Our Advice Line is a constant source of confidential support to sufferers and their partners. It is open daily between 9.30am and 2.00pm

 **0121 702 0820**

Bladder Health UK does not engage in the practice of medicine. It is not a medical authority nor does it claim to have medical knowledge. In all cases Bladder Health UK recommends that you consult your own doctor or urologist regarding any course of treatment or medication. Any products mentioned in this publication are not necessarily recommended or endorsed by Bladder Health UK.



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Supporting a  
Friend or Relative  
with Bladder Pain  
Syndrome



**Bladder  
Health UK**

# Supporting a Friend or Relative with Bladder Pain Syndrome



This leaflet has been provided for you by Bladder Health UK to help you to support a friend or loved one with Bladder Pain Syndrome/Interstitial Cystitis.

Being diagnosed with BPS/IC is often frightening and can make a sufferer feel anxious about the future and isolated. They can wonder if confiding in others and asking them for support might make them appear needy and dependent or make others turn away from them. Your support at such a difficult time in their lives can make all the difference in the period of adjustment which inevitably follows a diagnosis of Bladder Pain Syndrome.

## What is BPS/IC

BPS/IC is a debilitating and chronic bladder disorder. Typical symptoms include extreme pain as the bladder fills and the need to pass urine frequently and urgently.

While there is no cure for the disease, there are a variety of treatments a sufferer can have to alleviate the symptoms and also measures a sufferer can take to improve their symptoms themselves.

Further information on BPS/IC can be found in the BHUK BPS/IC Handbook.

## What Are Some of The Issues Faced by the Sufferer?

If you have a partner or a friend who is diagnosed with BPS/IC you may want to support them but may be unsure of how to do this.

It is important first to be aware of some of the issues the sufferer may be facing and to be flexible and well-informed about the condition itself.

- It is common for sufferers to struggle emotionally along the path to a receiving a diagnosis or after diagnosis. Being diagnosed with any chronic illness can raise a lot of questions about the future and how to cope.
- BPS/IC sufferers can wonder whether confiding in others about the pain might prompt them to turn away and can fear that they will be judged as constantly complaining when they talk about the illness and how they feel.
- Sufferers also fear that others will not believe them when they share their struggles and symptoms. Many people with BPS/IC fear that others will think they are faking or exaggerating their illness.
- BPS/IC can mean that sufferers need to make some major adjustments to their lives to accommodate the illness and learning to implement these changes can prove tricky at first.

- Sex can be painful and this can sometimes cause tensions within a relationship which can be hard to cope with.
- Dietary changes need to be made which can make socialising difficult.
- IC/BPS can affect sleep patterns and can lead sufferers to feel exhausted at times.

## How Can A Friend or Relative Help?

Learning to cope with a chronic bladder illness like Bladder Pain Syndrome/Interstitial Cystitis can be challenging and your support and care along the journey can make all the difference.

- Listen - sufferers often feel anxious and positive reassurance that a sufferer can learn to cope with the challenges the condition will bring can make all the difference. If you feel that your partner would benefit from further emotional support, encourage them to seek help from a counsellor or therapist specialising in treating chronic illness.
- Do not judge the sufferer listen when they talk about their illness and how it makes them feel.
- Believe them - The most powerful words you can say to someone with BPS/IC are 'I believe you'. Sadly many sufferers are told by friends, family and even healthcare practitioners that they are exaggerating their illness.
- Support your friend/partner with the changes they will need to make to live positively with the disease.

Read the BHUK Diet Booklet and plan meals using the Recipe Book together. Both these resources are available from Bladder Health UK Support the sufferer when you are out together when explaining to others why they are not able to drink or eat spicy food.

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