

## GUIDELINES

# Diagnosis and clinical management of alcohol related physical complications: summary of NICE guidance

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This is one of a series of *BMJ* summaries of new guidelines based on the best available evidence; they highlight important recommendations for clinical practice, especially where uncertainty or controversy exists. The supporting evidence statements, the members of the Guideline Development Group, and further information about the guidance are in the full version on [bmj.com](http://bmj.com).

Continued hazardous and harmful drinking can result in dependence and tolerance, with risk of alcohol withdrawal syndrome on abrupt reduction or cessation; it may also result in damage to almost any organ or system in the body. Hazardous and harmful drinkers are commonly encountered among hospital patients, with 863 300 alcohol related admissions to hospital in 2007-8, an increase of 69% since 2002-3.<sup>1</sup> The cost to the NHS of treating acute and chronic drinking is estimated to be as much as £2.7bn a year.<sup>2</sup>

This article summarises recommendations made in the recent guidance from the National Institute for Health and Clinical Excellence (NICE) for the diagnosis and clinical management of alcohol related physical complications in adults and children (aged over 10 years).<sup>3</sup> That guideline should be read in conjunction with the NICE public health guidance on the prevention and early identification of alcohol use disorders in adults and young people<sup>4</sup> and the forthcoming NICE clinical guideline on the management of alcohol dependence and harmful alcohol use.<sup>5</sup>

### Recommendations

NICE recommendations are based on systematic reviews of best available evidence and explicit consideration of cost effectiveness. When minimal evidence is available, recommendations are based on the Guideline Development Group's experience and opinion of what constitutes good practice. Evidence levels for the recommendations are in the full version of this article on [bmj.com](http://bmj.com).

### Acute alcohol withdrawal

#### Admission to hospital

- For people in acute alcohol withdrawal with alcohol withdrawal seizures or delirium tremens, or for those at high risk (for example, those who have a history of alcohol withdrawal seizures or delirium tremens) of developing either condition, offer admission to hospital for medically assisted alcohol withdrawal.

- For young people aged under 16 years who are in acute alcohol withdrawal, offer admission to hospital for physical and psychosocial assessment, in addition to medically assisted alcohol withdrawal.
- For people who are alcohol dependent but not admitted to hospital, offer advice to avoid a sudden reduction in alcohol intake (as this may result in severe withdrawal) and information about how to contact local alcohol support services.

#### Assessment and monitoring

- People in acute alcohol withdrawal should be assessed immediately on admission to hospital by a healthcare professional skilled in the management of alcohol withdrawal.

#### Treatment for acute alcohol withdrawal

- Offer pharmacotherapy for the symptoms of acute alcohol withdrawal as follows:
  - Consider offering a benzodiazepine or carbamazepine
  - Consider offering clomethiazole as an alternative to a benzodiazepine or carbamazepine. However, use this with caution and in inpatient settings only.
- Follow a symptom triggered regimen (box) for drug treatment for people in acute alcohol withdrawal who are either in hospital or in other settings where 24 hour assessment and monitoring is available.

#### Management of delirium tremens

- In people with delirium tremens, offer oral lorazepam as first line treatment. If symptoms persist or oral medication is declined, give parenteral lorazepam, haloperidol, or olanzapine.

#### Management of alcohol withdrawal seizures

- In people who are having or who have had an alcohol withdrawal seizure, consider offering an immediate dose of quick acting benzodiazepine (such as lorazepam) to reduce the likelihood of further seizures.

#### Wernicke's encephalopathy

- Be highly alert to the possibility of Wernicke's encephalopathy (clinical features include global

### Symptom triggered regimen

A symptom triggered regimen involves tailoring treatment to the person's individual needs, which are determined by the severity of withdrawal signs and symptoms. The patient is regularly assessed and monitored, either using clinical experience and questioning alone or with the help of a designated questionnaire such as the revised clinical institute withdrawal assessment for alcohol scale (CIWA-Ar).<sup>6</sup> Drug treatment is provided if the patient needs it, and treatment is withheld if no withdrawal symptoms are present.

## bmj.com archive Previous articles in this series

- Diagnosis and management of idiopathic childhood constipation (*BMJ* 2010;340:c2585)
- Management of lower urinary tract symptoms in men (*BMJ* 2010;340:c2354)
- Neonatal jaundice (*BMJ* 2010;340:c2409)
- Pharmacological management of neuropathic pain in non-specialist settings (*BMJ* 2010;340:c1079)
- Assessment of recent onset chest pain or discomfort of suspected cardiac origin (*BMJ* 2010;340:c1118)

confusion, eye muscle weakness, and ataxia), particularly if the person is intoxicated.

- Offer thiamine to people at risk of developing Wernicke's encephalopathy (those with harmful or hazardous drinking, malnutrition, or decompensated liver disease). Thiamine should be given in doses towards the upper end of the range recommended in the *British National Formulary*<sup>7</sup> and given orally or parenterally as described in the full guideline.
- Offer parenteral thiamine to people with suspected Wernicke's encephalopathy for a minimum of five days, unless Wernicke's encephalopathy is excluded. Follow parenteral treatment with oral thiamine.

### Alcohol related liver disease

#### Assessment and diagnosis

- Refer people to a specialist experienced in the management of alcohol related liver disease to confirm a clinical diagnosis of such disease.
- In people with suspected acute alcohol related hepatitis whose suspected hepatitis is severe enough to require corticosteroid treatment, consider a liver biopsy to confirm the diagnosis.

#### Referral for consideration of liver transplantation

- Refer patients with decompensated liver disease (jaundice, ascites, or encephalopathy) for assessment for liver transplantation if they still have decompensated liver disease after best management and three months' abstinence from alcohol and are otherwise suitable candidates for liver transplantation according to guidelines.<sup>8</sup>

#### Corticosteroid treatment for alcohol related hepatitis

- Offer corticosteroid treatment to people with severe acute alcohol related hepatitis and a poor prognosis as determined by Maddrey's discriminant function of  $\geq 32$ . This is calculated as  $4.6 \times (\text{prothrombin time} - \text{control prothrombin time (seconds)}) + \text{either (bilirubin in mg/dl) or (bilirubin in } \mu\text{mol/l divided by 17)}$ .<sup>9</sup>

#### Nutritional support for alcohol related hepatitis

- Assess the nutritional requirements of people with acute alcohol related hepatitis. Offer nutritional support if needed, and consider using nasogastric tube feeding.

#### Pancreatic surgery versus endoscopic therapy for chronic alcohol related pancreatitis

- Refer people with pain from chronic alcohol related pancreatitis to a specialist centre for multidisciplinary assessment.
- Offer surgery rather than endoscopic therapy to people with pain from large duct (obstructive) chronic alcohol related pancreatitis.

#### Enzyme supplementation for chronic alcohol related pancreatitis

- Offer pancreatic enzyme supplements to people with chronic alcohol related pancreatitis who have symptoms of steatorrhoea or poor nutritional status as a result of exocrine pancreatic insufficiency.

- Do not prescribe pancreatic enzyme supplements to people with chronic alcohol related pancreatitis if pain is their only symptom.

### Overcoming barriers

Implementing symptom triggered dosing regimens for acute alcohol withdrawal (where 24 hour assessment and monitoring is available) may require additional training and staff time. However, importantly, the clinical evidence review and economic analysis suggest that symptom triggered regimens are associated with positive outcomes such as lower doses of medication and a reduced length of hospital stay. The impact of the recommendation on referral for liver transplantation is difficult to assess, but referral rates may increase if patients are currently being asked to abstain for longer than three months before referral. The recommendations to refer patients with alcohol related liver disease and with pain associated with chronic pancreatitis may lead to a small but noticeable increase in the number of referrals.

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## EASILY MISSED Endometriosis

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This is a series of occasional articles highlighting conditions that may be commoner than many doctors realise or may be missed at first presentation. The series advisers are Anthony Harnden, university lecturer in general practice, Department of Primary Health Care, University of Oxford, and Richard Lehman, general practitioner, Banbury. If you would like to suggest a topic for this series please email us (easilymissed.bmj@bmjgroup.com).

Endometriosis is the presence of functional endometrial glands and stroma at various extrauterine sites in women, predominantly those of reproductive age, from all ethnic and social groups. It is a common, benign, oestrogen dependent, chronic gynaecological disorder and a common cause of chronic pelvic pain in women presenting in primary care. Other symptoms include dysmenorrhoea, deep dyspareunia, and infertility, all of which can have an impact on the physical, mental, and social wellbeing of these women.

### How common is it?

Endometriosis is estimated to affect 5-10% of women in the reproductive age group.<sup>1</sup> Prevalence is difficult to determine due to difficulties in diagnosis caused by the diversity of symptoms and their severity and because endometriosis may be asymptomatic.

### Why is it missed?

Endometriosis is often labelled “the missed disease”<sup>2</sup>; in the United Kingdom the average time between onset of symptoms and a definitive diagnosis is 7-8 years.<sup>3</sup> This delay is usually due to failure to recognise the nature of the symptoms of endometriosis. Diagnosing the condition on the basis of symptoms alone can be difficult as they are so variable (table)<sup>4-7</sup> and overlap considerably with those of other conditions, such as irritable bowel syndrome and pelvic inflammatory disease, even though it is rare to isolate a microbe causing pelvic inflammatory disease from the genital tracts of women undergoing investigation of symptoms.

Diagnosis is problematic in primary care for several reasons. Patients initially present to the general practitioner not with endometriosis but with symptoms that are difficult to differentiate from other conditions. Often, women (not uncommonly soon after menarche) who present with symptoms associated with menstruation, however severe, are told that it is part of being a woman or it is just painful periods, and that they will have to bear it.<sup>8</sup> Many women with endometriosis are therefore mislabelled as having idiopathic dysmenorrhoea or as having pelvic inflammatory disease even when there may be no preceding episode of acute pelvic inflammatory disease. Thus the

### CASE SCENARIO

A 26 year old presents with several years of severe dysmenorrhoea (with little relief from non-steroidal anti-inflammatory drugs) and dyspareunia which is increasingly affecting her relationship with her partner. Her general practitioner suspects endometriosis, as endocervical swabs show no evidence of infection and her symptoms improve slightly after he advises her to take the pill continuously. He refers her to a gynaecologist with interest in endometriosis for more definitive management of her symptoms. Laparoscopy confirms the diagnosis and she is successfully managed with a gonadotrophin releasing hormone agonist pill for six months.

non-specific nature of symptoms may make diagnosis problematic in primary care.

### Why does this matter?

Endometriosis causes chronic pelvic pain, menstrual disorders, and infertility. A survey in 2005 showed that in the European Union, endometriosis cost member states more than €30bn a year in lost working days, and of the 7025 women with endometriosis who completed the survey, 82% reported that the condition had caused them to take time off work in the past five years.<sup>9</sup> About 30-40% of women with infertility have endometriosis. It is a major contributor to depression from chronic pelvic pain syndrome and to sexual dysfunction and its consequences, including relationship disharmony, bowel and bladder symptoms, and depression (from chronic pelvic pain).<sup>10</sup> Consequently it is not unusual for women with these symptoms to be passed from one specialist to another.

### How is it diagnosed?

#### Clinical features

The clinical presentation of women with endometriosis varies considerably, with a significant proportion of those with the condition being asymptomatic and diagnosed

#### Symptoms of endometriosis

Symptom	% of women with endometriosis presenting with symptom*
Dysmenorrhoea <sup>4,5</sup>	40-87
Bloating <sup>4</sup>	42
Lethargy <sup>4</sup>	40
Chronic pelvic pain <sup>4,6</sup>	20-80
Constipation <sup>4</sup>	29
Low back pain <sup>4,5</sup>	29
Deep dyspareunia <sup>4,5</sup>	19-42
Dyschezia <sup>4,6</sup>	13-30
Infertility <sup>5</sup>	9
Cyclical rectal bleeding <sup>5</sup>	9
Menorrhagia <sup>4</sup>	7
Diarrhoea <sup>4</sup>	8
Haematuria <sup>5</sup>	3

\*Studies comprised 50 participants,<sup>4</sup> 101 participants,<sup>5</sup> and 141 participants<sup>6</sup>; see also the epidemiological review.<sup>7</sup>

### KEY POINTS

Consider a diagnosis of endometriosis in every woman of reproductive age presenting with menstrual or chronic pelvic pain, especially pain associated with dyspareunia

All adolescents with chronic pelvic pain (especially cyclical pain) that is unresponsive to conventional treatment should be investigated for endometriosis

The combination of pelvic tenderness, retroversion of the uterus, and induration in the posterior fornix indicates a high likelihood of endometriosis

Where there is a strong clinical suspicion of the diagnosis in primary care, a three month trial of gonadotrophin releasing hormone agonist or the combined pill may be used to help diagnosis

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► A patient's journey:  
Endometriosis  
(*BMJ* 2010;340:c2661)

incidentally at laparoscopy. Symptoms typically develop as early as adolescence and persist after menopause in some women.<sup>11,12</sup> Endometriosis should be considered in adolescents with chronic pelvic pain that is not responding to conventional treatment; up to 69% have endometriosis at laparoscopy.<sup>11</sup>

The clinical manifestation of endometriosis is diverse.<sup>13</sup> Case series and cohort studies show that some symptoms are more commonly reported than others (see table).<sup>4-7</sup> Bowel or bladder symptoms in some patients make the diagnosis difficult to distinguish from irritable bowel syndrome or interstitial cystitis.<sup>14</sup>

A pelvic examination may be entirely normal but classic findings include uterine and adnexal tenderness, a fixed retroverted uterus, nodularity of the uterosacral ligaments, and adnexal masses. The tenderness often makes eliciting the other classic features difficult. There is, however, evidence that performing the examination during menstruation helps to make the diagnosis, but many women will be reluctant to be examined at this time.<sup>14</sup>

### Investigations

The indicative diagnostic test is visualisation of the pelvis at laparoscopy by an experienced gynaecologist.<sup>3</sup> A positive result increases the likelihood of detecting the disease histologically to 31% (95% CI 21% to 46%) and a negative result decreases the likelihood of detecting endometriosis to 0.7% (0.1% to 5.0%).<sup>15</sup> However, attempts should be made to reach a diagnosis on the basis of history and a detailed clinical examination rather than delaying this until a laparoscopy is performed. A therapeutic trial with gonadotrophin releasing hormone agonist or the combined oral contraceptive pill (without the pill-free interval) for three months in suspected cases may also be used to help diagnosis. Ultrasound has been shown in a systematic review to be useful in diagnosing endometriomas and deep infiltrating rectovaginal disease, with a positive likelihood ratio of 7.6-29.8 and a negative likelihood ratio of 0.12-0.4.<sup>16</sup> Magnetic resonance imaging is of limited value in diagnosing any peritoneal disease.

### How is it treated?

Although there has been much clinical research on the nature of endometriosis and on treatment alternatives, the treatment options (medical or surgical) depend on the informed choice of the woman as well as her age, fertility plans, previous treatment, the nature and severity of symptoms, and the location and severity of disease.

Medical treatment may reduce symptoms in 80-90% of patients, but none of the options has been shown to reduce recurrence of symptoms once treatment has stopped. Suppression of ovarian function for at least six months is the basis for most medical treatment, and the options include the combined oral contraceptive pill, medroxyprogesterone acetate, and gonadotrophin releasing hormone agonist.<sup>13</sup> More recently, the levonorgestrel intrauterine system (Mirena) has been shown to be effective even after three years of use.<sup>17</sup> In a small uncontrolled trial, the levonorgestrel intrauterine system (Mirena) seemed to control symptoms effectively in mild to moderate disease even after three years of use, although discontinuation rates were high.<sup>17</sup>

Recurrence (from soon to up to three years after stopping treatment) of symptoms varies from an estimated 37% for mild disease to 74% in severe disease.<sup>1</sup>

The success and the advisability of surgery depends on the severity of the disease, its location, and the extent of the symptoms. Surgical options include removing entire lesions that are severe and deeply infiltrating (which may reduce pain related to endometriosis); ovarian cystectomy in the case of endometriomas; adhesiolysis; and bilateral oophorectomy, often with a hysterectomy. Patients undergoing radical surgery should be counselled about the possibility of symptoms persisting after bilateral oophorectomy.<sup>2</sup>

Multidisciplinary treatment should include pain management services, clinical psychologists, gynaecologists in secondary care, and general practitioners in primary care. Although centres of excellence are being advocated, these should ideally be managing advanced disease.

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## A PATIENT'S JOURNEY

# Endometriosis

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This is one of a series of occasional articles by patients about their experiences that offer lessons to doctors. The *BMJ* welcomes contributions to the series. Please contact Peter Lapsley (plapsley@bmj.com) for guidance.

During the 15 years since endometriosis manifested itself, a large number of medical and surgical interventions, many of them unpleasant, have produced no sustainable benefit

Periods are an unwelcome fact of life to teenage girls; unfortunately pain, too, seems to be an accepted part of womanhood. I can't remember when my period pain started—it was just always there. I happily colluded with my general practitioner, female relatives, and friends in thinking that period pain is normal. I would try not to talk about it, reach for the painkillers and hot water bottle, and get on with things. I was put on the contraceptive pill aged 14 and regularly missed school and later university and work, but every time I mentioned the pain it was put down to growing up and I was given another prescription for mefenamic acid or a different brand of the pill. It makes me angry to think of the missed opportunities for referral to a specialist, diagnosis, and potential treatment before my endometriosis became so severe.

It didn't help that, like many young people, I moved a lot. I had six GPs within as many years. The one constant was heavy, prolonged, debilitating periods.

By my early 20s I was working as a teacher, taking the mini pill, and using mefenamic acid, paracetamol, and ibuprofen. My visits to the GP were becoming more frequent, but neither I nor the GP connected the diverse, developing symptoms: nausea, spotting and prolonged bleeding, diarrhoea, and constant tiredness. In the summer of 2005 everything came to a head with some particularly bad period pain that became chronic. My mother wasn't to be fobbed off, and I was eventually hospitalised for several days and given a prospective

diagnosis of endometriosis. It was the first time I'd heard of the condition, and it took me a while even to learn how to pronounce it.

Over time, I have become better at communicating with medical practitioners and have educated myself about my illness and what I can do to help.

When the possibility of endometriosis was raised I couldn't understand why they wouldn't undertake a laparoscopy immediately. I'd been suffering for 12 years and was now unable to work; my whole life was on hold and yet I was being told to wait another three months. In desperation I went for a private appointment. After an initial examination the consultant scheduled me for an emergency laparoscopy the following week.

I thought this would be the answer to all my problems; my surgeon told me the risks and quoted a 70% success rate at his clinic. I needed a second operation as the endometriosis was too severe to treat initially. I had extensive excision of endometriosis and adhesions, but at the time it was presented to me as "only keyhole surgery; you should be back at work in a couple of weeks." I now know that I had a major operation and that not all laparoscopies are equal in terms of recovery. When my symptoms persisted, I felt that I was doing something wrong, complaining too much, or that my body wasn't reacting as it should.

Several months later, after abortive attempts to go back to teaching had ended in being hospitalised and I'd started on a course of gosarelin, I decided to give up my job. It was the right decision, as I wasn't well enough to work and needed the support of my family, who didn't live close by, but it took me a long time to adjust. I suddenly found myself moving back from Southampton to Belfast, living with family, unemployed, broke, ill, and still in as much pain as ever.

### A DOCTOR'S PERSPECTIVE

Julie's case provides a good example of some of the problems encountered in managing someone with chronic pain, especially when that person is young and unable initially to articulate their difficulties.

By the time I first met Julie in 2006 she had already consulted with several doctors and had been given several opinions as to the cause of her pain, so it felt very much as if I was "coming late to the party." Our first consultation ran over time, and it was clear that her frustration with the advice she had been given before our meeting was making it difficult to establish a rapport.

I admit that I was initially sceptical. Why was this bright, apparently healthy girl coming to me with a list of complaints and requests for several strong and potentially addictive drugs; was this somebody just trying it on with the next available doctor?

It didn't take long to realise, though, that Julie was in fact very genuine and able to state her case forcibly. Indeed, to all intents and purposes Julie is an "expert patient." This was both helpful and challenging—helpful in that she was able to

understand in detail the rationale behind treatment, allowing an informed decision to be made; challenging in that she often knew more about the subject than I did.

Over the past few years we have shared many ups and downs when treatment that initially seemed to be beneficial lost its effect, and it has been challenging to respond to these changes. Her treatment has often involved polypharmacy, occasionally with rarely used drugs, and it has sometimes been difficult to decide whether Julie's symptoms were a result of her illness or had an iatrogenic origin. To this end I have been fortunate to have the help of several excellent colleagues.

Those who are privileged to provide continuity of care (still, I feel, the bedrock of general practice, despite modern working practices) will appreciate the difficulty in motivating a patient during difficult times.

As in many such cases, I have felt a degree of hopelessness at my lack of ability to change Julie's management for the better, but you can still provide support by simply being a listening ear.

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My new GP was sympathetic, and with some further trips to hospital for emergency pain relief we established a regimen to follow at home. I switched to opiate patches, along with oral morphine for flare-ups. I am now thankfully able to manage my breakthrough pain at home. A TENS machine and basic meditation techniques have proved useful.

I have to take a lot of drugs just to function at a reasonable level. I have become used to the horrified looks from medical staff taking my history, and the implied criticisms of dependence and addiction. Endometriosis can cause pain and fatigue, fertility problems, sex and relationship issues, and it can sap all your strength, but it's an unseen disease. The incommunicable nature of pain combines with the social taboo of discussing "gynae" issues to make many sufferers feel very lonely.

One of the problems with treatment is that none of it is guaranteed to work, as the disease isn't fully understood. From my surgeons' point of view, each of my operations has been successful—but from my point of view, surgery hasn't worked. The medical treatments I've tried have been unpleasant and lacking in any sustainable benefit. Gonadotrophin releasing hormone analogues and the Mirena coil had horrible side effects. For several months now I've not been taking drugs that interfere with the hormonal cycle, and it's a great feeling to have regained my hormonal independence.

I've been seeing a gynaecologist who specialises in endometriosis for the past two years. If the surgery I had a year ago doesn't provide any reduction in pain then I've exhausted all the current gynaecology options. There's no point going through the stresses of surgery without a good chance of success. In a strange way this is helpful, as I can get on with coping rather than expending energy on a fruitless search for a cure.

Five years after diagnosis, I've just about come to terms with my illness. It still gets me down when I have to pull out of social plans, or when my latest attempt to go back to work in some part time, voluntary capacity fails. I am active and ambitious—staying home reading all day doesn't come naturally, but I have to pace myself as activity brings on pain and my energy levels are low. Recently, however, I have been on a condition management course via the local Job Centre, which has been very useful.

The nature of endometriosis is especially frustrating. The pain is random, and though I might have several better days in a row, the threat of severe pain is always there. I would love to be able to live independently, but I know that I am just not physically able to cope alone.

It's hard to manage financially, and the loss of employment combined with existing on benefits (state support) has had a negative impact on my self esteem, as has the never ending process of proving that I'm entitled to benefits. I feel an acute pressure to "fit in" and justify my circumstances. At the age of 30, I should be progressing in my career and setting up my own home. Endometriosis robs young women of their futures.

I have had amazing support from friends and family, especially my mother and my boyfriend of two years. One of the strange aspects of chronic pain is the desire to communicate the experience—to have a witness to your

#### USEFUL RESOURCES

*Counselling*—I paid for sessions, at a reduced rate, through a disability charity as the NHS waiting list is so long and I'm not in the most need in terms of psychiatric care

*Patient support*—the friendship and support from the Belfast Endometriosis (and Hysterectomy) Support Group has been invaluable, and I have learned a lot from the website Pelvic Pain Support Network ([www.pelvicpain.org.uk](http://www.pelvicpain.org.uk)). Talking over my experiences and listening to those of others has made me realise I'm not alone and things can improve. It's easy to lose hope for the future—but seeing the turnaround in other group members' lives after successful treatment gives me renewed hope

*Pain clinic*—I now see an NHS pain specialist and have started trying some of the clinic's treatments. I am currently undergoing a course of lignocaine infusions, but it's reassuring to know of other possible options

*Expert Patient Programme*—this NHS programme ([www.expertpatients.co.uk](http://www.expertpatients.co.uk)) is not run in Northern Ireland, but I have found help with the Condition Management Programme for benefits recipients, and I've researched pain and relaxation myself

*Aromatherapy*—in 2006-7 I had a course of "palliative" aromatherapy massage and reflexology at my local hospital. This service has since been cut

*Physiotherapy*—I suggested to my GP that I be referred for gynaecological physiotherapy after researching it online—this has been very helpful

*Acupuncture*—I get reduced price sessions through a local charity

*Citizens Advice Bureau*—has been invaluable in helping me to fight for the benefits I should be getting ([www.citizensadvice.org.uk](http://www.citizensadvice.org.uk))

suffering—and they have helped me most just by listening and holding my hand.

I was initially extremely nervous about dating and becoming emotionally or physically intimate, and blurted out to my boyfriend the whole history of my illness early on. I expected him to run away, but he has been patient and understanding. Sex can be especially painful, but by talking about it and making sure we remain close in other ways it doesn't cause problems in our relationship.

I have fears for the future. Pain has been my main symptom, but as I get older fertility is likely to become a bigger issue. A hysterectomy is a choice I may have to face in the next few years. Then there is the possibility that trying to conceive would not be easy, nor would caring for a young family while in pain.

I try to take each day and week as it comes, to enjoy the days when I am able to be active and accept those when I am sore. Being ill has shaped my interests; I am now a member of the BMA's Patient Liaison Group and would like to pursue a career in health policy, and to continue to raise awareness of endometriosis and chronic pain.

My pain is part of me and has changed and shaped my personality. I can put things into perspective and don't get anxious over the small things. Life doesn't always go your way; the trick is to adjust your expectations accordingly and make the best of it.

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