



An employer's guide to managing endometriosis at work

Myths and misunderstanding

One in ten women suffer from endometriosis. This makes it as common as diabetes. Comparative prevalence rates relate to women with diabetes, not the whole population. Yet many people have not heard of the condition. This is partly because menstrual problems are still difficult for many people to discuss and partly because the average time from symptoms to diagnosis in the UK is a shocking 7 years.

There is a real difference between a healthy menstrual cycle and endometriosis.

Your employee may be experiencing a range of symptoms and health difficulties.

The purpose of this guide is to give you an overview on the legal situation when it comes to managing a woman with endometriosis at work.

Whatever you and your employee decide to do, there are consequences. You will both be starting a juggling act where you have to balance your employee's:

- physical health
- psychological health
- financial situation

AND your obligations to:

- work in a way that does not damage her
- get the work done
- be fair to other workers
- continue to be able to afford the sick person

Having 'imaginary rights' or 'imaginary obligations' creates a lot of resentment in the workplace. So many people are confused about this. It can be more useful to focus on mutual problem-solving in a way that takes both parties' needs (and their rights and obligations) into account.

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Sick pay

We talk about 'sick pay', but in reality there are two types of sick pay.

Statutory sick pay

This is not paid at the employee's normal rate of pay but at the statutory sick pay (SSP) rate - currently £88.45 per week. Use this link to check entitlement:

<https://www.gov.uk/statutory-sick-pay>.

SSP is not paid for the first three days of sickness and it runs out after 28 weeks. Self-employed workers are not entitled to this, nor are employees who do not earn enough to pay National Insurance.

Employees must provide the necessary self-certification form, or GP 'fit note' (used to be called a 'sick note') if the absence is 7 days or more. Self-certification forms are often available in the GP surgery but can also be downloaded from:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/412139/SC2_12_14.pdf

- o Intermittent sickness

Anyone with intermittent short term conditions can do badly out of this, since the initial three-day waiting period will be repeated for each absence unless the condition recurs within 28 days of the last absence. For some women with menstrual related problems such as endometriosis, the cycle of repetition can mean the sick leave is linked. For other sufferers of repeating conditions that are more erratic or on a longer cycle of repeats, the repeating three day 'nil payment' periods can be a real problem.

- o Long term sickness

Longer term sickness can result in the statutory sick pay period of 28 weeks expiring. After this you are no longer obliged to pay SSP and your employee will receive the appropriate benefit directly from the government. There is no carry forward or SSP entitlement so unused entitlement in one year cannot be added to another.

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- o Who bears the cost?

When SSP was first introduced, the employer paid the money through payroll but reclaimed it from the Government. Since 2014, SSP is paid and funded by the employer.

- o Zero hours contracts

There are complications around zero hours contracts since the 3-day waiting period for SSP is calculated against 'qualifying days', which are normally the days your employee is contracted to work. You may need to take advice on this from your payroll processor, or your accountant. But this does not mean people on zero hours are never entitled to SSP.

Employer's sick pay

Many organisations contract to pay sick pay beyond SSP. There is no general legal requirement to do so, but once you have issued a contract saying you will pay more, then you should honour your own contract.

Data protection and confidentiality

Information about your employee's health, or medical conditions is categorised as 'sensitive data' under the Data Protection Act.

Information about health means more than just medical reports and medical certificates - it also includes information held by you, which might be in emails between you and your employee or their manager or an occupational health advisor, as well as formal documents, computer records and physical file records.

Privacy

Your employee is entitled to refuse to disclose information about her health. You cannot force her to agree to disclose her medical history or information.

However, if she needs special arrangements at work then she would be unwise to refuse to support her claim with some medical evidence if asked.

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Many women are concerned about data privacy in general, and the sharing of health information in particular. These concerns are often the reason for an initial refusal – particularly as endometriosis is a very personal and feminine condition. Many women refuse because they do not want their colleagues to know the details of their medical condition. You should not be permitting the unauthorised sharing of personal data in any event.

Sensitive data is more tightly restricted than ordinary personal data and despite the fact that many organisations do not really know much about this, it is possible to arrive at something that respects your employee's rights to privacy, but gives the necessary information to those individuals who **need** to know.

You may find it helpful to read the relevant employment code ([Quick guide to employment practices code](https://ico.org.uk/media/for-organisations/documents/1128/quick_guide_to_the_employment_practices_code.pdf)). [It can be found at https://ico.org.uk/media/for-organisations/documents/1128/quick_guide_to_the_employment_practices_code.pdf]

Make some notes about:

- who needs to know the full extent of the medical condition?
 - how and where will this information be held
 - do some people simply need to know your employee has a medical condition? (not what it is)
 - who are they?
 - who doesn't need to know anything at all?
- Communication plan

It can be helpful to work with your employee to create a 'communication plan' that avoids rumour and speculation. This is particularly useful if you are agreeing to flexibility or working arrangements that co-workers need to support.

It should contain:

- A medical fact file (securely held) for those who need the full facts. Most people have very limited knowledge of how specific medical conditions affect other people. Unless we have been unfortunate enough to have that condition, or have a close friend or relative with that condition, we tend to vastly underestimate what is needed to cope with it.

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- A simple overview of your employee's specific condition and a list of people (if any) who need to know about that, along with an agreed statement of what they will be told including:
 - A statement this is not to be shared beyond them
 - A reminder of their obligations on confidentiality
 - Who to contact if they have problems or need to know more
- A brief statement about the fact your employee has a medical problem that means their working arrangements will not always be identical to others.

You need to agree with your employee who needs the first category of information (complete), who needs the second (overview) and who needs just to know there is an arrangement.

Whilst you cannot do much to affect how naturally empathetic your team are, you can do something to provide those that need to know with information that will allow them to avoid tactless and hurtful remarks such as 'are you really that ill?'.

The 'you don't look ill to me' problem is a common one for anyone suffering from diseases that cannot be clearly seen. These are known as invisible illnesses and it causes particular trauma to people with conditions that are not visible to ordinary people to constantly be challenged on whether they are faking it. You should avoid putting your employee in a position where she feels she has to justify her arrangements or disclose her medical data in order to 'prove' she is not malingering.

Endometriosis and employment law

Equality and Disability

- Disability

A person has a disability if she has a physical or mental impairment which has a substantial and long-term adverse effect on her ability to carry out normal day-to-day activities.

If that condition prevents her from carrying out day-to-day tasks (even if this is not every day but a repeat cycle), then she may be entitled to the protection of the Equality Act.

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'Substantial' is an important word. It is entirely possible that two women with endometriosis will fall on either side of that definition because of the extent of the effect the condition causes.

- o Reasonable adjustments

Your employee is entitled to put in a request for adjustments that would enable her to continue working or would reduce the disadvantage suffered as a result of her disability.

Sometimes it can feel to you as if a request for a disability adjustment really means:

- I am very ill
- give me what I need
- you should pay
- I will then do what I want when I feel able to

If you are feeling this way, then it probably means that you and your employee have work to do before you can arrive at a decision on what needs to be done.

Disability rights (including adjustments) are quite clearly set out by the Equality and Human Rights Commission on their web site ([EHRC](#)).

You may find it helpful to start with:

- Finding out more about the condition and its *typical* effects on someone at work
- Finding out whether your employee is at the worse or better end of this spectrum
- Looking at their absence level compared to colleagues
- Looking at the effect this has had on the business in terms of what steps you can take to cover this, cost incurred, effect on deadlines, cover, etc.
- Where the pressure points really are
- What could be changed
 - o Give it to someone else
 - o Change duties
 - o Reduce/change hours
 - o Home working
 - o Special equipment
 - o Something else?
- Would this make a difference?

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- What would it cost?

You may want to compare the cost of any adjustments to the cost of recruiting and training a replacement. Adjustments are not necessarily bad value compared to the alternatives.

You are obliged to grant a request for a reasonable adjustment. If you are thinking of refusing or suggesting an alternative, please take advice before you arrive at a decision.

- Occupational Health

If you have concerns about your employee's health and safety at work, or need a formal assessment of whether there is a disability that affects her ability to carry out day to day tasks, you will need an occupational health report.

A GP can certify that your employee suffers from endometriosis but they have limited ability to help with what adjustments might be useful. Neither they nor a consultant specialising in gynaecology can advise on what would help and avoid health and safety problems in the workplace.

Not all occupational health consultants are fully familiar with endometriosis and it is often necessary for the various medical practitioners to work together, with your employee's consent, to collect the appropriate data and make recommendations.

- o Sex discrimination

Certain medical conditions are more prevalent in one gender than another. If for example you are a woman with a recurring gynaecological condition, you would be expected to be treated similarly to a man with a recurring heart condition that required the same amount of time off work or working from home.

If a man and a woman are both disabled you would still expect them to be treated in the same way when it comes to sick leave, etc.

Organisations can sometimes have unconscious biases when it comes to illnesses – giving months off to an injured rugby-playing man because the boss happens to be a rugby fan, whilst dismissing women who are off sick 'too much'.

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Try to stand back and check carefully how colleagues are treated when it comes to sickness, exploring whether there may be conscious or unconscious patterns of tolerance or lack of tolerance.

Endometriosis may cause fertility problems in many women. Time off for treatment related to infertility can be directly related to pregnancy and if your employee is having time off for this purpose, she may have separate protection at some stages. If so, she must not be subject to a detriment for doing this. There is no need for a male comparator at this stage.

If you are not sure if your employee is having fertility related treatment and tests or general diagnostic tests or treatments, you should make sure you have up to date and appropriate medical information before taking **any** action about this.

Ordinary flexible working request

There is a real difference between an employee making a request for reasonable adjustments under the Equality Act, and making a flexible working request.

All employees have the right to make flexible working requests – but employers are not obliged to grant them, simply to consider them. This is less of an obligation than when she makes a disability adjustment request (see earlier).

If your employee is not disabled (or unwilling to disclose the fact or agree to an occupational health report) she can make a general flexible working request.

Although the statutory wording is “flexible working”, she cannot apply under the statute to work ‘flexibly’ as most of us would understand the word – i.e. variable hours that she chooses. She can apply under the statute to *change* work location or *change* work hours to some other specific place or work pattern. These are normally permanent rather than temporary changes.

- o Location or hours?

Many ‘flexible working requests’ are in fact requests to work at home. To the individual this may also mean a request to work only when they are well. To most bosses, this request is a request to work the **same** hours from another location.

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Be absolutely clear about what is being agreed to. This will avoid arguments and disappointments around availability at a later date.

- o Data security

If your employee does not have a place to work or store your data securely, then you and she may not be able to lawfully comply with the Data Protection Act. This applies to personal data. You can often create secure workspaces 'in the cloud'. This is not as expensive or difficult as it was even a few years ago.

- o Annual hours

This is where an employee contracts to work a total number of hours in the year. This can be more flexible for you both, and can be a useful solution.

- o Duties

Changing duties may be appropriate to prevent injury, or to allow someone who can't attend reliably to get out of highly deadline driven tasks and into more routine ones.

- o Measures of success

Many bosses are nervous about having employees work from home or flexibly. This is particularly true if you don't have ways of measuring whether the job is being done properly. If you can think of some simple measures of success – or adapt some that already exist in your workplace – this can radically improve how this works out.

- o Regular communication cycles

Home based and 'flexible hours' employees are often suspected of not doing enough work – simply because they can't be seen. Make sure you pre-book regular communication slots with your employee – by phone, skype or office visits – where you review their work and update her on what is going on. Never assume she knows what is going on.

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- o Cost

If you are agreeing to a reduction in hours then deal specifically with how this will impact pay. If you are agreeing to a change in duties, deal expressly with whether this will change the hourly or pay rate.

- o Supporters

If your employee needs the support of key individuals to provide cover or alter their work to support her request, ask her permission to talk to them about this and work out how this might work.

Sickness and holidays

If your employee falls sick during annual leave she is entitled to request having her holiday back to you in exchange for sick leave. That would mean pay for the period would be at the appropriate sick pay rate.

You need to make sure she takes her full statutory annual leave entitlement (currently 28 days for a five day a week worker) during your holiday year.

Annual leave is viewed as part of health and safety compliance. Do not allow your employee to fail to take their basic entitlement – often loyal but sick individuals will offer this, but in the long run it is not only unlawful but it will damage their health and put them at risk of injury, and you are risk of litigation if things go wrong.

There are limited provisions to carry holiday forward and many organisations will not permit it. Disabled or long term sick employees have more flexibility to require this.

Benefits and credits

Benefits, tax credits and allowances are changing very rapidly and it is a good idea to encourage your employee to check each year what she is entitled to and how to apply. Sometimes varying the hours contracted for (with consent) can make a radical difference to how much she earns without costing you a great deal.

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Demystified?

It is always going to be a bit more difficult managing an employee with a health condition that affects her ability to attend work reliably.

If you can accommodate her, you will have the benefit of:

- Someone who is not keen to leave you
- Retaining an employee
- Systems and ways of working that can be used again in the future
- Knowing you have helped someone be productive for you.

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