

Working with IBD A Guide for Employers

Supporting employees living with
Crohn's disease or ulcerative colitis



Did you know?

- 2.2 million Australians of working age have a disability.
- A disability is any condition that restricts a person's mental, sensory or mobility functions. It could be caused by accident, trauma, genetics or disease.
- A disability may be temporary or permanent, total or partial, lifelong or acquired, visible or invisible.
- 88 percent of disabilities are invisible.
- The *Disability Discrimination Act 1992* requires employers to provide adjustments whenever it is necessary, possible and reasonable to do so. These adjustments could be any administrative, physical, or procedural accommodations made in a workplace to enable a person with a disability to work effectively, such as an enlarged computer screen or flexible hours.
- Australian research indicates that 86 percent of all such adjustments cost less than \$500 and most can be implemented quickly. Government financial assistance may be available to employers in some cases.
- The burden of disability for people living with IBD is comparable to that for people living with rheumatoid arthritis, severe asthma or amputation of an arm.
- Disability due to IBD is more severe than living with Type 1 diabetes or epilepsy.
- The economic cost of IBD in Australia is \$2.7 billion annually.
- Loss of productivity accounts for more than half the \$500 million financial cost of IBD.
- Productivity costs include absenteeism, workplace separation, early retirement and premature death.

Source: Access Economics Report 2007
“*The Economic Costs of Crohn’s Disease and Colitis in Australia*”

www.crohnsandcolitis.com.au

What you need to know

In addition to your obligation to recognise the rights of employees under the *Disability Discrimination Act 1992*, understanding and acting upon issues affecting your employees with IBD can greatly impact your bottom line.

This booklet has been produced as a guide to help you understand the important issues you should consider if you employ any individuals living with IBD.

Source: Diversity@work

www.diversityatwork.com.au

The Cost of IBD

- Inflammatory Bowel Disease (IBD) is more prevalent than epilepsy, multiple sclerosis, rheumatoid arthritis, eczema and schizophrenia.

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Introduction

Introduction

In Australia, there are approximately 61,000 (1 in 350) people with inflammatory bowel disease (IBD). Although IBD can occur at any age, it is most commonly diagnosed for the first time in people between 15 and 35 years of age. This coincides with a time when people are likely to be concerned about their job and employment prospects.

This employer guide has been developed to help employers and managers better understand what it means to have IBD, and how it is possible, often with only minimal adjustments to the work environment, to support employees with IBD and enable them to fulfil their potential. It also considers the legislation relevant to managing people with chronic conditions such as IBD.

The content in this guide applies to many chronic medical conditions but is intended primarily to assist employers support their employees with IBD.

In Australia, there are approximately 61,000 (1 in 350) people with inflammatory bowel disease (IBD).

What is inflammatory bowel disease?

Inflammatory bowel disease (IBD) is a medical term that describes a group of conditions in which the intestines become inflamed (red and swollen) and ulcerated (open sores that may bleed). Two major types of IBD are Crohn's disease and ulcerative colitis. These conditions are similar but different. For example, ulcerative colitis affects only the large intestine (colon and/or rectum) whereas Crohn's disease can occur in any part of the gastrointestinal tract, from the mouth to the anus.

The exact cause of IBD is not yet known, but it is considered to be an auto-immune disorder. In people with a genetic susceptibility to IBD, the immune system mounts a superactive response to environmental "triggers" (possibly proteins, bacteria and/or viruses). This causes inflammation in the intestines (gastrointestinal tract) and leads to the symptoms of IBD.

The most common symptoms of IBD are:

- abdominal cramps and pain
- frequent diarrhoea (may be bloody) or sometimes constipation
- severe urgency to have a bowel movement

- fever during active stages of disease
- loss of appetite and severe weight loss
- tiredness and fatigue.

A percentage of people with IBD may also experience problems outside the gastrointestinal tract such as:

- joint pain
- skin conditions
- eye inflammation
- liver disorders (rare)
- thinning of the bones (osteoporosis).

IBD is a chronic or life-long illness, but the ways in which it affects each person with the condition is highly individual.

It depends on:

- where the disease is located within the gastrointestinal tract
- whether or not inflammation is present at a given time
- how severe the inflammation is within the affected area.

When inflammation is present, symptoms appear and the disease is considered to be in an active stage. When inflammation is less or absent, symptoms may disappear altogether and the disease is considered to be in remission. For most people with IBD, the usual course of disease involves periods of remission interspersed with occasional flare-up of symptoms.

IBD cannot be cured as yet but it can be managed effectively, especially with the use of medications to control the inflammation. Most people with IBD may also require surgery at some point during the course of their disease.

IBD is not the same as Irritable Bowel Syndrome (IBS) and it is not contagious.



Employer rights

Do we have a right to know if an employee has IBD?

As an employer you may encounter three possible scenarios:

- a person with IBD has applied for a position within your organisation
- an existing employee is newly diagnosed with IBD
- an existing employee has a flare-up of disease after a period of remission.

There is no obligation for people with chronic illnesses such as IBD to disclose their condition during the recruitment or selection process unless they are asked directly about any known health condition that might impact on their job performance. Even then, they're under no legal requirement to disclose their condition, but some may choose to do so in order to prevent the risk of repercussions (e.g. dismissal) if knowledge of their condition eventually comes to light or to suggest workplace adjustments that might enable them to perform their work effectively.

Likewise, there is no legal requirement for a current employee to disclose a new or existing medical condition unless it is stipulated in their contract of employment.

An important first step towards encouraging someone with IBD to discuss their condition is to implement a fair employment policy

that covers all illnesses, including chronic conditions.

The reasons why someone with IBD may be reluctant to disclose their condition will vary with each individual. They may include fear of discrimination, possible job loss, desire for personal privacy, or even embarrassment. This is understandable as people in general don't tend to discuss their bowel habits with others. But the symptoms of IBD during disease flare-ups, in particular the frequent and often urgent need to go to the toilet, mean that the issue will most likely need to be addressed at some point.

Your understanding may give them the opportunity to open up...

If you suspect that an employee has a medical condition and it is impacting on job performance and workplace relations, it may be appropriate to draw the person aside and enquire in the strictest confidence and in a non-threatening manner if there is anything they'd like to discuss or if there's any way in which you can offer support. Your understanding may give them the opportunity to open up and disclose their condition. The decision about whether or not to tell others in the workplace about their condition must be left to the employee.

Likewise, if you know about an employee's IBD at the time of hiring, you must adhere strictly to their wishes regarding letting others in the workplace know about their condition. Often only a few key people need to know.

For more information regarding disclosure of disability, contact the JobAccess Advisers on **1800 464 800** or visit **www.jobaccess.gov.au**.



Does IBD affect a person's ability to do their job?

People with IBD can and do lead full and satisfying lives, complete with family, career and leisure-time activities. It's not uncommon for people with IBD to place a high priority on work performance as they are motivated to not let their condition impact too greatly on their everyday lives. Moreover, many people with IBD have long periods of remission when their symptoms are absent for months or even years at a time. If a person with IBD has the necessary skills and qualifications to do a particular job, they should be considered in the same light as other candidates for a position, or for a promotion.

At times of disease flare-up, people with IBD may have certain requirements such as:

- easy access to adequate toilet facilities
- greater flexibility in working arrangements
- a knowledgeable and supportive work environment.

Supporting your employee

It should be noted that these requirements are not specific to people with IBD, but are good management practices that can and should be applied to all employees. The application of these requirements in people with IBD is discussed in more detail in the section, “How can we support an employee with IBD in the workplace?”

Perhaps the most noticeable impact of IBD in the workplace is the amount of sick leave an employee may need at certain times throughout their condition. Again, this is discussed in more detail in the section, “How do we manage sick leave?”

Generally speaking, with good understanding of the nature of IBD and some minimal workplace adjustments, you can support and enable an employee with IBD to work productively and add value to your organisation.

Greater flexibility in working arrangements can help accommodate these needs...

How can we support an employee with IBD in the workplace?

Each individual with IBD is unique and their needs may differ from others with the condition or at various times during the course of their illness. As a general guide, the particular needs of a person with IBD are likely to include the following:

Easy access to adequate toilet facilities

People with IBD often have a frequent and urgent need to get to a toilet to avoid having an accident. In addition, the smells and sounds of diarrhoea can cause them considerable distress. Not only are they embarrassing, they may unwittingly disclose their condition to others.

Providing immediate access to private and adequately-ventilated toilet facilities in the workplace is essential for employees with IBD. Offering use of a disabled toilet where available or, if possible, providing a customised cubicle with floor to ceiling walls and extractor fan in shared toilet facilities are some solutions to consider.

Where possible, locate the employee’s workstation closest to the toilet facilities. This can help minimise workplace disruption and allow for greater privacy and discretion.

Cover for urgent toilet breaks

People with IBD who work in positions with fixed breaks (e.g. schools, shops, factories) may need support from their managers or co-workers to cover them for short periods in the event of an urgent need to go to the toilet. The same need may apply in office situations (e.g. during meetings) or out in the field (e.g. tradespeople).

Flexible working arrangements

People with IBD generally need to attend regular medical appointments and may require regular tests or ongoing hospital treatment. These often need to be scheduled within standard weekday working hours of 9 am to 5 pm. During disease flare-ups, people with IBD often experience extreme tiredness and fatigue, which tends to be worse in the morning and may impact on their ability to arrive at work on time or to concentrate early in the day.

Greater flexibility in working arrangements can help accommodate these needs.

In particular, time off for medical appointments, later starts and shorter or more flexible working hours during times of active disease, and working from home wherever possible, are all useful means of helping an employee with IBD through difficult times still remain productive.

Other methods may include job sharing and team working as appropriate.

Flexi-time can also allow the employee to make up for any significant time lapses at work and maintain a fair workplace.

Understanding of specific treatment requirements

People with IBD generally require medications to manage their condition and may need to take these at specific times throughout the day (e.g. 1 hour before food or 2-3 hours after food). Certain types of medications (e.g. corticosteroids) can cause unpleasant side effects, especially when high dosages are required over long periods of time. Some people with IBD may have particular food requirements, such as liquid nutrition only, or may need to eat several small meals regularly throughout the day in order to lessen the symptoms of abdominal pain and diarrhoea.

Supporting your employee

Understanding your employee's specific treatment requirements and the possible implications in the workplace can help you work in with them with minimal effort and fuss. Good communication and forward thinking are key strategies to making this happen. A few examples are provided below but the possibilities are endless.

- If a meeting is planned, be sure that your employee is aware in advance of the date, time and expected duration. Understand if he/she needs to slip away for a few minutes to take medication, have a small meal or visit the bathroom. Ensure that the location and layout of the meeting room allows for easy and discrete access to toilet facilities.
- If you're having lunch during an in-house meeting or with a client at a restaurant or café, consider in advance whether the menu has suitable choices for a person with IBD. Many eating establishments provide their menu on the internet.
- If possible, install a refrigerator and microwave on premises to accommodate your employee's food requirements

Allowances for travel


Travel is often a key issue for people with IBD. Because of a frequent and urgent need to access a toilet, many find it difficult to use public transport and would prefer to drive to work or outside meetings.

Allowance for car travel and/or provision of a parking space close to the workplace would be helpful in these cases. Although many workplaces provide disabled parking spaces, most people with IBD do not meet current criteria for a Disabled Person's Parking Permit and are not entitled to use these spaces. Alternative solutions should be provided as appropriate.

Social support

Many people with IBD experience feelings of isolation which stem from a perception that others won't understand their disease. Many are reluctant to tell others about their condition because they're embarrassed by the nature of the symptoms or for fear of being treated as "special" or "different". Attempts to hide or deny their condition often add to their overall stress and can contribute to depression.

Social support from friends, family and co-workers helps people with IBD cope better with their condition and interact successfully at all levels including work. It might be helpful to discuss with your employee about whether and how best to tell colleagues about their condition. This employer guide may be a useful first step in that regard. Others may wish for someone else to speak on their behalf; for example, a friend, colleague, occupational health worker, trade union representative



or disability employment advisor. Once co-workers are made aware of the condition and its implications, they're much more likely to engage and provide the necessary support and social interaction.

Empathy, not sympathy!

People with IBD have only one point of difference from those without the condition – their gastrointestinal tract doesn't work quite as well. In all other respects they're the same as anyone else and deserve to be treated in the same manner as others in the workplace. This can be as formal or informal as is appropriate for the work situation.

Social support from friends, family and co-workers helps people with IBD...

Always assume that a person with IBD is of normal intelligence. Less than one-third of people with disability have an intellectual disability and IBD in no way affects a person's intellectual capacity.

In the workplace (or during the interview process), some people with IBD may be offended or feel uncomfortable when:

- an interviewer or manager assumes unusual sensitivity and avoids asking essential questions
- they're openly and constantly admired for their courage
- sympathy is constantly offered (this is a fine line)
- they're stared at or people avoid eye contact with them
- they're assumed to need help
- they're constantly reminded of their disability rather than their abilities.

Supportive and flexible management approaches will enable most people with IBD to work productively. And most are highly motivated to do so. However, it is also important to be aware of the legal considerations that may apply to people living with IBD or other long-term health conditions.

Workplace discrimination

Is IBD considered to be a disability?

Although many people with IBD don't consider their condition to be a disability as such, they may qualify for protection against discrimination.

The federal *Disability Discrimination Act 1992* (DDA) provides several definitions of disability. Those that apply most to IBD include:

- total or partial loss of a part of the body
- malfunction, malformation or disfigurement of a part of the person's body.

Some states use slightly different definitions of disability according to their own disability discrimination laws but they are substantially the same.

The fact that IBD may go into remission or that symptoms can be controlled by medication does not prevent it from being covered by the DDA.

The definition of disability includes future disability and "imputed" disability, which is something that someone believes another person has, even if they do not.

The DDA recognises two types of unlawful discrimination:

- direct discrimination
- indirect discrimination

Direct discrimination occurs when someone is treated less favourably, or is proposed to be treated less favourably, than someone else in similar circumstances who does not have a disability. Less favourable treatment may include being ridiculed or denied something to which the person was entitled.

People with IBD have only one point of difference from those without the condition...

Indirect discrimination occurs when someone is expected to meet some sort of criteria that they are unable to meet because of their disability, and these criteria are probably able to be met by someone else without a similar disability. For indirect discrimination to be unlawful, the expectation or criteria placed on the person with a disability must be something that is "unreasonable in the circumstances".

How does the *Disability Discrimination Act 1992 (DDA)* apply in the workplace?

Disability discrimination is unlawful only in certain areas. In the employment environment, it means that an employer cannot discriminate in their terms and conditions of employment during the application process or in promotion or dismissal.

According to the DDA, it is unlawful to:

- directly discriminate against an employee because of their disability
- indirectly discriminate against an employee because of their disability
- harass an employee because of their disability
- require an employee with a disability to provide information that might be used to discriminate against them
- victimise an employee because they have made a disability discrimination complaint.

Employees who make a complaint about disability discrimination in relation to employment must be able to show that their disability does not stop them from doing what the job is essentially about. This does not mean having to meet all the requirements of the job, only the essential ones. In the federal Act, this is called

meeting the “inherent requirements of the job”. During the recruitment process, employers have a responsibility to inform prospective employees about the essential requirements of the job.

In order for an employee to meet their job requirements, employers may need to make some adjustments to the workplace. Some examples of adjustments are provided on the following page. Employers are not allowed to discriminate against employees because of their need for adjustments.



Workplace adjustments

What adjustments may need to be made for employees with IBD?

Many adjustments required by employees with IBD are inexpensive or may not cost anything at all, and/or cause little disruption to the workplace. Some examples include:

- allowing time off for medical appointments or treatment
- offering shorter, different or flexible working hours
- providing unlimited toilet breaks
- locating the workstation close to a toilet
- providing a car-parking space close to the workplace entrance
- re-allocating certain duties among other staff members
- considering job-share opportunities
- offering another place of work or the option of working from home
- adjusting performance targets to account for the effect of sick leave or fatigue.

Under the federal Act, employers do not have to make adjustments if it would be an “unjustifiable hardship” for them to do so. Factors that need to be taken into account in this regard are:

- the benefits the adjustment will have for other employees who may be affected by the adjustment

- the disadvantages the adjustment will have on other employees who may be affected by the adjustment
- the effect of the disability on the employee, and what this means in terms of the adjustments they require
- the costs of making the adjustment.

Where adjustments are more expensive, such as installing separate toilet facilities, it may be possible to apply for financial assistance through the Workplace Modifications Scheme.





What is the Workplace Modifications Scheme?

The Workplace Modifications Scheme pays for the costs involved in modifying the workplace or purchasing special or adaptive equipment for eligible employees with a disability. There is no restriction to the types of modifications that can be approved under the Scheme provided that each application meets the eligibility criteria.

In order to qualify for assistance employers must employ a person with disability for at least eight hours a week in a job that is expected to last for at least three months. In addition, the employee will:

- have an ongoing disability that has lasted, or is likely to last, for two years or more
- have a disability that results in a limitation, restriction or impairment affecting their everyday activities that requires a work-related adjustment
- be an Australian citizen or permanent resident
- be employed under a legal industrial arrangement that complies with the minimum standards established by federal, state or territory law.

For more information, contact the JobAccess Advisers on **1800 464 800** or visit **www.jobaccess.gov.au**.

What can we do if an employee feels discriminated against?

An employee might feel discriminated against if they have received an unfavourable performance review or have been overlooked for promotion because, for example, they've been unable to meet their targets because of sick leave or tiredness caused by their IBD. There may also be disagreement about "reasonable" adjustments to the workplace to accommodate their needs or they may feel victimised by harassment or bullying from co-workers.

Most employees would prefer not to take formal action. Making a formal complaint through the internal grievance procedures of an organisation or through the Human Rights and Equal Opportunity Commission (or equivalent state body) can be a lengthy and stressful experience.

Personal leave

Often the opportunity to talk things through resolves any issues. At minimum, all employees should be made aware of your organisation's internal grievance procedures. Ideally, they should feel comfortable about discussing any problems with a line manager, HR/personnel department or union representative as applicable. Alternatively, they may wish to appoint a friend or relative to liaise in the event of disagreements. In all such cases, it is good practice to keep detailed records of meetings.

How do we manage sick leave?

All employees (except casual employees) are eligible for sick leave in the event that they suffer a personal illness or injury. However, there may be times when people with IBD need to be away from work for longer periods of time, possibly due to a severe flare-up of symptoms or they require surgery for their IBD. Taking out Salary Continuance Insurance (also called income protection insurance) is an option you may wish to discuss with your employee. Some organisations provide this type of insurance as a benefit for all their employees.

It is recommended that any absences from work because of your employee's IBD are recorded separately from other sickness absences, such as having a cold or flu.

This is to prevent the possibility of discrimination if decisions about promotion or bonuses, for example, take into account illness-related absences.

It is common for people to lose confidence about being able to return to work, even after a relatively short time away on sick leave. Keeping in touch with your employee can help ease this process. It may be helpful to set up a standard procedure outlining how your employee can maintain contact with work when absent for longer periods. At times it may be appropriate that a family member is the first point of contact. The employee may prefer contact with a co-worker, close colleague, union representative or occupational health worker rather than their line manager. This may help them feel supported as opposed to being "checked up on". It's also a good idea to establish what type of contact they'd prefer, either by telephone, email, letter or in person. And it's important to not pressure an employee into returning to work too soon before they're ready.

For more information about sick leave entitlements, contact the Workplace Authority on **1300 363 264** or visit **www.workplaceauthority.gov.au**.

How best can we support a person returning to work after sick leave?

Employees should be involved in planning their return to work as this gives them the opportunity to voice any concerns they may have or to request workplace adjustments. If they've been away from work for some time, a phased return might be appropriate. This could involve working only a few hours a day at first and gradually increasing the number of hours as their health improves. Other useful strategies to consider in the early stages of a return to work are reducing workload, re-allocating certain duties among co-workers, or allowing the employee to work from home if possible. In the event that the employee has to remain away from work until reasonable adjustments are put in place to enable their return (e.g. relocating their workstation close to a toilet), this should not be recorded as sick leave.

Ongoing support and regular reviews

IBD is an unpredictable disease and your employee's condition and specific needs may change over time, for better or worse. The employee may wish to vary workplace adjustments to make it easier for them to continue working, or because they have fewer special requirements during remission

or after surgery for their IBD. It is helpful to have periodic reviews with your employee to ascertain their specific needs.

What happens if it's not working out?

In the work environment it goes without saying that the job must get done and that everyone needs to contribute their fair share. Most people with chronic conditions will have a good understanding of the impact of their illness on work performance and can suggest adjustments that will enable them to work effectively.

There may be rare occasions when, despite reasonable workplace adjustments, your employee's condition makes it difficult for them to continue in their current job or to accept an alternative job. In these circumstances you may have no other option than to consider termination. However, before taking this step, it's advised that you consult with the employee, obtain medical evidence as required (in consultation with the employee), consider whether alternative employment can be offered and inform the employee that you are considering terminating their employment.

General information

What's in it for me as an employer?

As an employer you're entitled to wonder if it's worth while employing someone with a chronic medical condition such as IBD. Given that some of the most expensive aspects of employment are recruitment and employee retention, the simple answer is "yes", if that person is right for the job. Remember also that people with IBD often experience long periods of remission where symptoms may be absent for months or even years at a time.

Research undertaken by the Australian Safety and Compensation Council has highlighted some important facts about employing people with disability. Some key points from their report include:

- **There is no conclusive evidence to support the suggestion that workers with a disability are more likely to be injured at work than other employees**
- **Many people with a disability have the qualifications and skills to match the demands of the workforce**
- **Minimal cost – maximum benefit**
- **The costs involved in making workplace adjustments tend to be minimal, with employers reporting that the benefits of employing workers with a disability outweigh any costs**

- The productivity of people with a disability is similar to that of employees without disability
- Workers with a disability have lower absenteeism and higher retention rates than employees without a disability, which reduces the costs associated with recruitment and training of new staff
- Inclusion of people with a disability in the labour force leads to economic and social benefits for people with a disability, employers and the community as a whole.
- Employers can address a skills shortage by employing capable, enthusiastic workers with relevant skills and qualifications
- By providing a safe working environment for all employees, employers can improve productivity, morals and save money.

A full copy of the Australian Safety and Compensation Council research report, *Are People with Disability at Risk at Work?* can be found at **www.ascc.gov.au**.

For more information, contact the JobAccess Advisers on **1800 464 800** or visit **www.jobaccess.gov.au**.



Information Sources

Are people with disability at risk at work?

Australian Safety and Compensation Council.

www.ascc.gov.au

Employment and IBD: a guide for employees.

National Association for Colitis and Crohn's Disease (NACC).

www.nacc.org.uk

The Economic Costs of Crohn's Disease and Colitis in Australia.

Access Economics Report 2007

www.crohnsandcolitis.com.au

The Inside Story: A Toolkit for Living Well with IBD.

Crohn's & Colitis Australia. © 2009

Using Disability Discrimination Law.

Victoria Legal Aid. August 2008

Work, Superannuation and Disabilities.

Maurice Blackburn Lawyers.

Miss Anita Singam BSW

Employment Specialist

Disability Discrimination Legal Service

www.communitylaw.org.au

Diversity@Work

www.diversityatwork.com.au

JobAccess

www.jobaccess.gov.au

Workplace Authority

www.workplaceauthority.gov.au



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