



Scleroderma and the Workplace

A guide for employers
and employees



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As a person with scleroderma, this guide may assist with conversations with your employer or provide knowledge, confidence and understanding of workplace adjustments, and your rights under the Disability Discrimination Act 1992.

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What is scleroderma?

Understanding scleroderma

It is important to highlight that no two people with scleroderma are the same. The information provided is only a guide and it is best to learn from each individual what aspects of scleroderma affect them.

Scleroderma, or systemic sclerosis, is a chronic connective tissue condition generally classified as one of the autoimmune rheumatic diseases. One of the common symptoms is the thickening or hardening of the skin. It comes from the Greek: **sclero = hard, derma = skin**.

You can find out more in our Understanding & Managing Scleroderma resource available on our website.

Why is work important?

Employers, managers and workplace leaders may be concerned about the possible impact a long-term condition like scleroderma will have on an employee's performance and reliability at work.

However, there are simple and inexpensive things that can be done to minimise the effects of scleroderma on a person's work life. Support that will not only benefit the employee, but also the organisation.

It's good to bear in mind as an employer, leader, or HR professional that work is often extremely important to people with a medical condition. This is because:

- After diagnosis, a job can provide a sense of normality, routine and stability;
- Work can help an employee retain self-confidence and give them a sense of purpose;
- Financial security can be critical for employees to pay for their usual bills and medical expenses;
- A job may be important to a person's sense of worth and make them feel like they're contributing to society;
- Work may offer a person social contact that's good for their mental health.

The benefits of being a supportive employer

Supporting an employee diagnosed with scleroderma will help them cope with what may be a difficult time in their life, but it can also lead to clear benefits for your organisation too.



Retain knowledge and skills – By helping a person overcome physical and emotional barriers, organisations can keep hold of vital knowledge, skills and experience that has a positive impact on productivity and outcomes.



Save time and money – Retaining an employee avoids the cost and time of recruiting, inducting and training new employees.



Increase loyalty – By supporting a person with scleroderma, organisations benefit from greater loyalty from them and their colleagues and increase overall employee engagement.



Boost employer image – Effectively supporting people with medical conditions or diseases such as scleroderma may have a positive impact on how a range of audiences see your organisation, including customers and job applicants.



Reduce team pressure – If an employee isn't supported and has to leave their role, their colleagues may have to take on extra work while new employees are being recruited and trained. This can have cultural consequences on your organisation if employees see that their employers and leadership will not support them if they experience ill health due to factors beyond their control. This can lead to poor morale and reduced productivity.



Fulfil legal obligations – By law, employers or prospective employers cannot discriminate against an employee based on disability. This is defined broadly under disability discrimination laws to include:

- A temporary or permanent disability;
- Physical, intellectual, psychiatric, sensory, neurological, learning and psychosocial disabilities, diseases or illnesses; and
- Physical disfigurement and medical conditions.

Employers, managers, leadership and others in the workplace who unlawfully discriminate against an employee may be subject to legal proceedings and have to pay damages to the employee and incur legal costs. Additionally, legal proceedings are public and there is the risk of reputational damage to the employer, manager, and leader or individual involved in the contravention, if the disability discrimination claim proceeds to Court.

The importance of managers

Managers and leaders are an important source of support for a person diagnosed with scleroderma.

With the permission of the employee, it's important to speak to a HR manager, an internal work health and safety (WHS) professional or JobAccess. They can provide helpful resources and support to employers and employees, including advice on workplace adjustments, or details about a return-to-work plan.

You must not, under any circumstances, disclose confidential information that an employee wants kept private.

Why a well-informed and supportive manager is important

Managers are:

- Usually the person an employee contacts first when they're feeling ill at work or cannot go to work;
- Likely to play a key role in implementing workplace adjustments for an employee;
- Responsible for the workload of an employee and their team, and understands how much pressure or demand is placed on them; and
- Responsible for supporting an employee, so they don't feel isolated and anxious about returning to work after time off.



What are your legal obligations?

Employees with disability have no legal obligation to tell their employer about their disability.

However, in some situations it may be beneficial for them and their workplace to discuss their disability. For example, if they need changes made to the workplace to help them work safely and productively. Employees may be required to tell their employer about their disability if it directly relates to their ability to perform the inherent requirements of their role.

Many people with scleroderma will not consider themselves to be a person with disability, but an employee with scleroderma can meet the definition of a person with disability as outlined by the *Disability Discrimination Act 1992* (Cth) (DDA).

Fair Work Act 2009 (Cth)

Under the Fair Work Act 2009 (Cth), employees are subject to further protections under the general protection provisions. These include:

- It is unlawful for an employer to take adverse action against an employee because of their physical or mental disability. Adverse action can include dismissing an employee, taking disciplinary action, or discriminating against them. However, the adverse action may not be lawful under the Fair Work Act if it is not unlawful discrimination;
- An employer cannot take adverse action against an employee because they have taken annual leave or personal leave; and
- It is unlawful to terminate an employee's employment because they have been temporarily absent from work due to illness or injury if the employee has provided a medical certificate (or statutory declaration) about that illness or injury in accordance with the Fair Work Regulations 2009 (Cth). However, once an employee has used all their paid personal leave and then, been absent from work on unpaid leave for more than three months, this protection no longer applies. This does not mean an employer can automatically dismiss an employee. The default position under the DDA and general protection provisions of the Fair Work Act, that it remains unlawful to dismiss an employee because of their illness or injury.

Disability Discrimination Act 1992 (Cth)

Under the Disability Discrimination Act 1992 (DDA), **disability**, in relation to a person, means:

- (a) total or partial loss of the person's bodily or mental functions; or
- (b) total or partial loss of a part of the body; or
- (c) the presence in the body of organisms causing disease or illness; or
- (d) the presence in the body of organisms capable of causing disease or illness; or
- (e) the malfunction, malformation or disfigurement of a part of the person's body; or
- (f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
- (g) a disorder, illness or disease that affects a person's thought processes, perception of reality, emotions or judgment or that results in disturbed behaviour.

The DDA aims:

- (a) to eliminate, as far as possible, discrimination against persons on the ground of disability in the areas of:
 - (i) work, accommodation, education, access to premises, clubs and sport; and
 - (ii) the provision of goods, facilities, services and land; and
 - (iii) existing laws; and
 - (iv) the administration of Commonwealth laws and programs; and
- (b) to ensure, as far as practicable, that persons with disabilities have the same rights to equality before the law as the rest of the community; and
- (c) to promote recognition and acceptance within the community of the principle that persons with disabilities have the same fundamental rights as the rest of the community.

Under the DDA, a person with disability is not only protected against discrimination during their employment, but also when they're applying for a job. It is unlawful to dismiss someone because of their disability unless they are unable to perform the inherent requirements of their role after reasonable adjustments have been made. However, employers are not required by law to make adjustments that would pose an unjustifiable hardship on the organisation.

When determining whether an adjustment would pose an 'unjustifiable hardship', all relevant circumstances must be taken into account, including the following:

- (a) the nature of the benefit likely to be accrued or the detriment suffered;
- (b) the effect of the disability;
- (c) the financial circumstances and estimated expenditure required; and
- (d) the ability of financial and other assistance.

If an employer believes an adjustment would impose an unjustifiable hardship on them, it is up to them to prove this.

Flexible working arrangements

Flexible working arrangements include changes to the employee's hours of work, patterns of work and locations of work. Generally, an employee's request must be in writing and set out the details of the changes sought and the reason for the requested changes. Once employers receive a request, they have 21 days to provide a written response setting out whether they will grant or refuse it.

Importantly, an employer can only refuse a request if they have reasonable business grounds to do so. 'Reasonable business grounds' for refusing a request include:

- that the arrangement would be too costly for an employer;
- that there is no capacity, or it would be impractical, to change the arrangements of other employees or recruit new employees, in order to accommodate the requested arrangement;
- that the new arrangements would likely result in significant loss in efficiency or productivity;
- that the requested arrangement would have a significant negative impact on customer service.

The social model of disability

In Australia, most businesses and government entities are moving towards the social model of disability, outlined under the United Nations Convention on the Rights of Persons with Disabilities.

The social model of disability, as opposed to the medical model of disability outlined in the DDA, recognizes that it is society that creates the barriers for people with disability and this makes it harder for people with disability to participate on an equal basis.



By removing these social barriers we create a fair and equal opportunity for people with disability to experience greater independence, choice, and control.

The social model of disability definition is outlined in the United Nations Convention on the Rights of Persons with Disabilities and defines disability as:

“ a long-term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder a person’s full and effective participation in society on an equal basis with others. ”

First steps

If an employee is diagnosed with scleroderma, they may or may not decide to tell you about their condition. This is likely to depend on the type of scleroderma they have, how severe it is and their treatment plan.

If an employee does share their diagnosis, it is a good idea to organise an initial meeting or meetings with one or more of the following people:

- Their manager.
- Their HR manager.
- JobAccess.

However, it should be the employee that decides who attends the meeting or meetings. For example, they may not feel comfortable speaking about their condition with their manager. They may want other people to be present, such as a colleague, family member, friend or trade union representative.

Topics you may wish to cover in an initial meeting with a person with scleroderma

- Your organisation's policies on work health and safety, taking time off work, workplace adjustments and coming back to work after time off.
- What workplace adjustments would immediately help the employee, for example, time off work for medical appointments, which may be paid or unpaid; different or reduced working hours or any workplace adjustments.
- Would they like a formal workplace assessment, including assessment of ergonomics.
- If and how information should be shared with their colleagues.
- The person's legal rights with regards to discrimination.

At the end of this initial meeting, it's reassuring to let your employee know they can speak to you, or a designated key contact, if they ever need any help.

Establishing good two-way communication is critical to positive outcomes being achieved for a person with disability or medical condition and the organisation employing them.

Telling colleagues

It usually helps to talk to an employee early on about who could be informed of their disability information and what information should be passed on.

Colleagues may be more understanding about time off and changes to how they work if they know what's happening. However, if the person decides they want to keep their situation confidential, you must respect their decision and cannot, under any circumstances, share their disability information.

If your employee agrees they would like to inform others about their disability or condition and its impact, it's important to clearly establish with them:

- What information they want to share and what should remain confidential.

- Who should be informed – colleagues from their team or department, all managers, your whole organisation.
- How the information should be passed on – by the person themselves; by their manager, with or without them present; by another colleague.
- How colleagues should be told – by telling one person at a time; in a meeting; via email.

With the employee's permission, you may also want to provide advice to the person's colleagues about how they can support and be a good friend to someone with scleroderma. This may involve you directing them to sclerodermaaustralia.com.au so they can find out more about the condition.

Learning what your employee needs

With the right support and adjustments, a person with scleroderma can usually continue employment. However, it's important to regularly speak to them about any issues they're facing and possible solutions to maintaining their work capacity.

This is something you may wish to do by using the checklist below. Your organisation and the employee may benefit from the help of an external body such as JobAccess.

Checklist for identifying needs and potential solutions.

- ✓ Discuss with your employee the parts of their role they can complete without any barriers.

- ✓ Establish what could be done differently to help them perform their role to the best of their ability. For example, would certain technology help them perform their role better, such as speech recognition software.

- ✓ Examine their working environment – Is it easy for them to move around it? Are there any accessibility issues? Are they too close to airconditioning vents?

- ✓ Discuss with your employee if they feel they can continue in their current role. Would a different role in your organisation be a better option for them? Look at potential retraining and professional development options.

- ✓ After discussing their needs and potential solutions, clearly outline what actions will be taken, when they'll be taken and who will be responsible for them.

Time off work

A person with scleroderma is likely to need time off for treatment, check-ups and tests, especially following their initial diagnosis. How much time off they need will depend on the type of scleroderma they have, how severe it is and their treatment plan.

An employee may be able to arrange their medical appointments outside of work hours. But if this isn't possible, they may request time off from work to attend them.

It's a good idea to discuss your organisation's policy on medical appointments shortly after your employee's diagnosis and what time off they may need.

It's also important to note that your employee may be classed as a person with disability by law. As a result, you may be discriminating against them if you don't let them have time off for a medical appointment.

If an employee (other than a casual employee) cannot work because of their illness, they are entitled to take paid personal leave. If an employee has used all their paid personal leave, they are entitled to take unpaid personal leave. Alternatively, an employee may elect to take paid annual leave if they have run out of personal leave or require time off to attend medical appointments. An employer cannot unreasonably refuse an employee's request for annual leave.

Further, the general protections provisions of the Fair Work Act protect employees from being subject to adverse action for taking

leave or being absent from work due to their illness or to terminate an employee due to a temporary absence from work due to illness or injury as explained in the paragraph above titled *'What are your legal obligations'*.

Workplace adjustments for an employee

Under the DDA, an employer must make reasonable adjustments to any elements of a job which places a person with disability at a disadvantage compared to a person without disability (commonly known as workplace adjustments). The only exception to this requirement is if the adjustment would cause the employer unjustifiable hardship.

There is no fixed description of what a reasonable adjustment should be. As explained above, under *'What are your legal obligations'*, whether an adjustment is reasonable will depend on:

- The effect of the disability;
- How much the adjustment will help the person;
- How practical it is to make the adjustment;
- The cost of making the adjustment (including availability of financial or other assistance);
- How the adjustment will affect the company or organisation; and
- The size of the company or organisation employing the person with disability and the resources it has.

There is a simple question to ask yourself, ***"Are they necessary, possible and reasonable?"***

If an employee has scleroderma, it's important to talk to them about what would help them in their role before making any adjustments.

It's also worth noting that workplace adjustments are often easy to implement and usually don't cause disruption to a workplace (*See the examples under 'potential adjustments for people with scleroderma'*).

Many adjustments are free or inexpensive. An individual or organisation can apply to JobAccess to assist with the cost of adjustments through the Employee Assistance Fund.

Potential adjustments for people with scleroderma

Workplace adjustments can generally be broken down into four categories.

Work methods, work arrangements, work-related communications, and equipment & facilities.

1. Work methods

This could include:

- A reduction in workload;
- Altering tasks;
- Providing additional time or support to complete tasks; or
- Access to a quiet room if they're affected by fatigue or pain.

Make it easy for them to notify you if they're affected by pain or fatigue while at work and need to go home. Try to do this in a way that doesn't draw attention to them.



2. Work arrangements

This could include:

- Time off for regular medical appointments;
- Flexible start and finish times;
- Changing your employee's job description to remove tasks that create barriers;
- Working from home permanently or a number of days per week if they are immunocompromised or experience fatigue or chronic pain;
- If the person does start to work from home permanently, helping them to stay in touch with colleagues so they don't become isolated;
- Allowing for regular breaks to stretch and move about, as sitting still for a long time can lead to pain and stiffness.

Ensure there is clear understanding of any policies that relate to leave and how this might work for medical appointments.



3. Workplace communications



This could include:

- Live captioning or transcripts of meetings to assist with note taking and memory;
- Providing documents in accessible formats; and
- Speech to text software.

4. Equipment and facilities



This could include:

- If they have mobility issues, giving them a parking space closer to the entrance of your premises;
- Changing where the person works in your premises, for example, a move to the ground floor may be preferable if they have difficulty going up and down stairs;
- Providing equipment or technology that will help them in the role, for example, a supportive chair or a keyboard and mouse that supports their wrists;
- If your employee struggles with gastrointestinal or mobility, ensuring that they can access a bathroom easily;
- If a person is affected by Raynaud's phenomenon, keeping their work area warm and ensuring that they're not working near a draft, near open windows or in a cold environment caused, for example, by airconditioning.
- Allowing your employee to dress warmly if they're affected by Raynaud's. This may mean they need to wear gloves, a hat or scarf at any time of the year.
- If digital ulcers occur, ensuring that tasks are modified or assistive technology is provided to perform the requirements of the role.
- Modifying workplace policies so that they don't put a person with disability at a disadvantage. The policies you look at might focus on sick leave, performance management or disciplinary procedures.

- Allowing your employee to have a phased return to work if they've had a long time off.

Please remember these are just suggestions. The support each individual needs will differ. Regularly speak with your employee about what adjustments will help them in their role.



How Scleroderma may affect physical health

Every person's experience of Scleroderma will be different. It depends on what type of Scleroderma they have and how their condition affects them.

In this section, we look at a range of symptoms and how they may affect a person's everyday life.

Skin changes

For most people, Scleroderma causes problems with the skin. This may mean a person diagnosed with Scleroderma experiences one or more of the following symptoms:

- Skin thickening
- Skin ulcerations
- Calcinosis
- Telangiectasia
- Dry skin
- Itchy skin

At work, this may lead to an employee feeling uncomfortable and self-conscious about their appearance.

Reduced movement

Tightening and hardening of the skin and of the tissues surrounding the joints can cause decreased movement of the wrists, elbows, and other joints, causing mobility impairment and disability.

As a result, they may struggle to do everyday tasks such as typing with a keyboard, lifting equipment, or walking long distances.

Tiredness (fatigue)

People describe fatigue as feeling tired, mentally exhausted, or physically overwhelmed day after day, no matter how much sleep they've had or what they've been doing, even if it's just everyday tasks.

Fatigue is a common challenge for people living with chronic conditions, including scleroderma. In fact, people with scleroderma in clinical studies listed fatigue as one of the top 3 symptoms that bother them.

Nausea and vomiting

The medications an individual takes to treat their Scleroderma may lead to a range of side effects, including nausea and vomiting. If they do experience these symptoms, their healthcare team will review their medications.

Weakened immune system

Common treatments for Scleroderma include medication to reduce the activity of the immune system.

In some cases, this means being more susceptible to infection.

Pain

Symptoms of pain, stiffness, swelling, warmth, or tenderness may accompany the arthritis-like joint inflammation that frequently occurs in Scleroderma. Muscle pain and weakness are other important symptoms, which can contribute to reduced mobility, physical function, and disability.

Chronic pain can be difficult to manage, but it can be treated. Early management of symptoms can dramatically improve quality of life and reduce the risk of a person developing depression.

With Scleroderma, pain can flare up quickly and at any time. This may mean an employee will suddenly not be able to complete a task or need time out.

Changes to the body

In some cases, Scleroderma can affect structures under the skin, such as fat, muscle, and bone. This may lead to a physical disability and an employee needing support to move around your workplace or carry out certain tasks.

Changes to the face

Scleroderma can affect the head and neck and cause a change in skin texture or a groove which runs vertically up the forehead into the hairline. It may also involve the cheek, chin, and the side of the neck.

Raynaud's Phenomenon

People with systemic sclerosis are also likely to be affected by a condition called Raynaud's. It is a condition that causes reduced blood flow to the hands and feet that can cause pain, and impact hand function and restrict mobility. A person may experience what is called a Raynaud's attack if they are exposed to the cold or become stressed. This may lead to numbness, tingling or pain in their fingers and toes, which can make everyday tasks extremely difficult.

Digital ulcers

Systemic sclerosis may lead to an individual developing painful sores on their fingers and toes (called digital ulcers). These must be treated straight away to protect the affected tissue and prevent an infection.

If an employee develops digital ulcers, it may be difficult for them to complete certain tasks that involve them using their hands or feet. They may need to visit their GP or hospital regularly and a period of planned sick leave may be required until the ulcers have been treated effectively.

The gastrointestinal (GI) tract

Systemic sclerosis can affect any area of the GI tract, including the mouth, oesophagus (gullet), stomach, small and large intestines, and the rectum.

This means that an individual may be affected by a wide range of digestive issues, including acid reflux, swallowing difficulties, nausea and vomiting, pain, bloating, weight loss, diarrhoea, constipation, and incontinence.

Lung involvement

Systemic sclerosis can affect the lungs. This may mean that a person experiences a range of symptoms, including shortness of breath, cough, chest pain and dizziness. They may be particularly affected by these symptoms when they exert themselves, such as walking up a flight of stairs or lifting heavy objects.

High blood pressure

If systemic sclerosis does affect internal organs such as the heart, kidneys, and lungs, this can lead to an increase in blood pressure. This may lead to a person experiencing dizziness, headaches, and blurred vision.

How Scleroderma may affect mental health

The impact that Scleroderma and its treatment has on the mood and mental health of a person can vary greatly.

Some people cope well and don't require further emotional support, while others can be affected considerably and might need support on an ongoing basis.

As an employer, line manager or HR professional, one of the most important ways you can support a person with Scleroderma is to regularly check in with them and ensure they have the supports they need to perform their role at their best.

Feelings after a diagnosis

A person newly diagnosed with Scleroderma may feel isolated, fearful, and uncertain about where to turn for help. They may experience feelings and emotional reactions from time to time, including initial shock or disbelief, fear, anger, denial, self-blame, or guilt, grief, sadness, or depression. Family members may have similar feelings.

Work health and safety

In addition to the obligation to provide reasonable adjustments to employees with disability, employers also have an obligation to ensure the physical and mental health and safety of their employees. This includes taking all reasonably practicable steps to ensure they can safely perform their duties. Your organisation and your employees with scleroderma may benefit from the support of an occupational health and safety professional. They can help you understand what you need to do to support your employees in relation to their employment and work health and safety laws.

A work health and safety professional can also help to:

Identify adjustments, such as changing how a job is performed, modifying the work environment, adapting equipment, providing assistive technology or other equipment as needed.

Offer remote or hybrid working options to ensure the health and safety of employees and decrease the risks of people with weakened immune systems.

Create a return-to-work plan that ensures a person returns to work in a way that helps them stay well and do their job to the best of their ability.

Carry out a risk assessment to make sure an employee is doing work that's right for them from a health and safety point of view.

Inclusive and supportive workplaces

Most organisations agree that an inclusive workplace is important. What being inclusive means and how it comes to life varies widely from one organisation to the next. The key to an inclusive work environment is making sure each employee feels included, that they can bring their whole self to work and that they have the support they need to perform their role at their best.

Further information

JobAccess

If you don't have access to an internal WHS professional, you can reach out to JobAccess for a formal assessment.

<https://www.jobaccess.gov.au/home>

<https://www.jobaccess.gov.au/employment-assistance-fund-eaf>

National Disability Insurance Scheme (NDIS)

The NDIS provides people with permanent and significant disability with funding for supports and services they need to achieve their goals. This is being delivered by the National Disability Insurance Agency (NDIA) across Australia. NDIS funding is for reasonable and necessary supports that can help with daily living, social and community participation, assistive technology, access to employment and home modifications.

You can find out more about the NDIS by visiting <https://ndis.gov.au/> or accessing our Understanding Scleroderma and the NDIS brochure on our website <https://www.sclerodermaaustralia.com.au/wp-content/uploads/2020/10/Scleroderma-Aus-Understanding-Scleroderma-and-the-NDIS-Brochure-web.pdf>.

Disclaimer

This Guide and summary of laws contained therein is for general information purposes only. Legal advice should be obtained on individual circumstances as they arise.

The information provided in this brochure is general in nature and is intended to keep you informed. We recommend you consult your doctor or health professional regarding any medications, treatments or adjustments.

Thank you to our reviewers

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