

UNDERSTANDING SCLERODERMA AND THE NDIS

This brochure provides information for people with scleroderma to help apply for NDIS so you can get access to the supports and services you may need.



scleroderma **australia**

What is the 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 and home modifications.

To be eligible for the NDIS a person must be aged under 65, satisfy residency requirements, and be able to demonstrate disability or impairment that has substantial impact on their daily life. The NDIA will make a decision about your eligibility. For more information, go to 'Am I eligible' on the NDIS website. (If you are over 65, see the My Aged Care website.)

Applying for the NDIS

There are a number of steps involved in applying for the NDIS. The information on the NDIS website is very helpful. Becoming a 'participant' of NDIS can make a significant difference to the lives of people with scleroderma. The first step is to make a successful 'access request' application. Once 'access' has been approved there is assistance available within the NDIS to help with next steps such as support planning.

Firstly, you will need to complete an Access Request Form where you will provide information about yourself, including:

- details and evidence about your disability and how it impacts your day to day activities
- supporting information including current and/or relevant reports from medical specialists and allied health professionals.

Functional impacts of Scleroderma

Each person with scleroderma is different, and so is the impact scleroderma has on the things you need and like to do every day.

It is important to detail in your application how scleroderma limits or restricts your function. To 'meet access' you need to describe specifically how scleroderma impacts your mobility, communication, social interaction, learning, self-care and/or your ability to self-manage, describing that you now need additional support or equipment. For example, to cook a meal you may need assistance to carry the shopping, cut up vegetables or open the oven.

Scleroderma may impact:

Sclerodactyly and joint contractures

Tightening and hardening of the skin and tissues surrounding the joints results in decreased movement of the wrists, elbows, and other joints. Describe how this impacts your ability to, for example, clean your house, dress or garden.

Pain and stiffness of the joints

Symptoms of pain, stiffness, swelling, warmth or tenderness may accompany the arthritis-like joint inflammation. Describe how this can affect, for example, driving, working or hobbies.

Emotional aspects of Scleroderma

There is the impact of the diagnosis and ongoing changes the disease causes which may contribute to feeling alone or uncertain about where to turn for help and other emotional reactions such as fear, anger, guilt, and sadness. Describe how this may have, for example, impacted your well-being and other relationships.

Oral, facial, and dental problems

General tightening of skin over the face and the opening of the mouth may be decreased in size (microstomia) which can make lip and mouth movements as well as oral hygiene difficult. Describe how you need assistance with, for example, chopping up food or brushing and flossing teeth.

Digestive system and Gastrointestinal tract

Damage to muscle/tissues from the mouth to the anal canal can cause issues with swallowing (dysphagia), delayed gastric emptying (gastroparesis), weight loss and bowel motility. Describe if you require, for example, assistance with eating/drinking, nutritional support or continence products.



The NDIS is an individualised package supporting Australians living with a disability, their families and carers.

Getting an NDIS plan

Once you are assessed as 'eligible' for NDIS, that is become a 'participant', the second step in the process is developing a 'plan' which will list the supports and services you need. You will be contacted by the NDIA to attend a 'planning meeting'.

The NDIA has engaged Local Area Coordination (LAC) partners employed to help people understand and access the NDIS. They also work with NDIS participants to develop and use their NDIS plan. A LAC will help you to understand and access the NDIS, create and implement a plan and link you to information and support in your community.

It is a good idea to speak with your LAC to help you prepare for your planning meeting. You can contact the NDIA to find the location and contact details of your local LAC.

To ensure your NDIS plan meets your needs, it's important that you think about your goals and how scleroderma impacts on your everyday activities and different areas of your life. There are planning tools available on the NDIS website to help you consider what goals you want to set for the future. It's also good to talk to family, friends and other people you know who live with scleroderma.

For example, it is useful to ask 'what does a typical week look like' and to think about supports and services you currently receive or need.

Goals Your plan will be developed in response to your identified goals and the supports or services you need to achieve them. Examples of goals include finding and keeping a job, maintaining or improving your health, joining community groups, or becoming more independent.

Functional impacts Consider how scleroderma impacts your ability to complete everyday tasks and activities, for example, getting out of bed, getting dressed, or preparing a meal.

Supports What people and services currently help you? Some examples are someone who takes you to medical appointments, helps you cope or participate in social activities.

Examples of supports that you use or need may include:

- equipment (for showering, toileting, moving or playing sports)
- small aids (consumables)
- home modifications (ramps, grab-rails etc)
- continence equipment
- transport
- care (assistance in-home or in the community)
- therapy
- leisure therapy

More information

Along with your Access Request Form and Medical Professional Reports, you can download the following resources from the Scleroderma Australia website:

- Understanding and Managing Scleroderma
- ASIG Fact Sheet



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