



# ACCEPTING THE DIAGNOSIS OF SCLERODERMA

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Accepting the diagnosis of scleroderma is a unique experience for each person. Some adapt quickly, while others require more time to assimilate the information. Certain people are upset by the news while others can feel a sense of relief, putting a name on their symptoms and reducing their feeling of uncertainty<sup>(1)</sup>.



## TOWARDS ACCEPTANCE

Someone who has difficulty accepting their diagnosis may need to grieve for their previous life before being able to adapt and accept their new reality. This process may include progressions and regressions. It is not necessarily linear<sup>(2)</sup> and it varies from one person to the other, depending on their interpretation of their situation and their ability to bounce back<sup>(1)</sup>. Regardless of the path taken, it is important to respect the person's pace.

### STATE OF SHOCK

Upon the confirmation of the diagnosis of scleroderma, the person may feel shocked<sup>(2)</sup>. Various physiological reactions may occur, such as an apparent insensitivity to the news, a ringing in the ears, blurred eyes, a cold sensation, a feeling of heaviness, uncontrollable laughter, a feeling of paralysis, etc.

### DENIAL

The person may experience denial towards the news, refusing the diagnosis, and adopting behaviours to protect themselves<sup>(2)(3)</sup>. For example, they may seek a second medical opinion, distract themselves with other activities, or suppress their emotions.

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### A WHIRLWIND OF EMOTIONS

The person may feel various emotions, which can change in nature or intensity, and may leave and resurface at times<sup>(2)</sup>. They may feel helpless towards the situation, not knowing how to proceed with the confirmation of scleroderma<sup>(3)</sup>. They may tend to have more negative interpretations of certain situations and may seek to isolate themselves.

By gradually accepting the situation, the person can experience their emotions with less intensity, better understand their situation, and continue their path toward acceptance.

### ACCEPTANCE AND ADAPTATION

Finally, acceptance occurs when the person accepts their current situation<sup>(3)</sup>, including the reality of scleroderma. They let go of elements beyond their control (like the presence of the illness) and focus on the things within their control (like decisions and actions).

### SUGGESTIONS

Here are concrete actions that a person can take during their process of acceptance of scleroderma.

#### INFORMATION

Because scleroderma is a little-known disease, a person is likely to have many questions and concerns when the diagnosis is confirmed. They can therefore develop their knowledge on this subject<sup>(1)</sup>. They can learn about scleroderma, its forms, symptoms, and causes. They can also learn more about the different treatments available. They can obtain information from their doctor, specialized professionals on this subject, or the *Scleroderma Quebec* website.

#### HEALTHY LIFESTYLE

Responding to basic physiological needs (e.g., eating, sleeping, etc.) is essential for the body to function optimally<sup>(4)</sup>. Therefore, a person should try to ensure that these primary needs are met. In doing so, they can facilitate their acceptance process by avoiding additional challenges, such as difficulty regulating stress<sup>(5)</sup>, fatigue, difficulty concentrating, etc



#### In practical terms, a person could:

- ▶ Eat at regular hours and have balanced meals. However, they must follow their doctor's medical recommendations.
- ▶ Sleep at regular hours and maintain a sleeping routine.
- ▶ Practice physical activity according to their interests and capabilities (e.g., walking, sitting outside, taking in the fresh air, etc.).
- ▶ Try to maintain a daily routine by continuing their regular activities<sup>(2)</sup>.

#### ENJOYABLE ACTIVITIES

To clear their mind, a person can focus on activities they enjoy<sup>(2)(5)</sup>. These may include current or new activities, which can be done individually or with others. The choice of activities varies from one person to another depending on their interests, abilities, schedule, etc. Examples include music, art, social activities, cooking, exercising, etc.

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### SOCIALIZATION

When a person receives confirmation of the diagnosis, they may feel isolated. To help them get through this period, they can talk about it with others and seek support. For example, they can speak with their family and friends, contact helplines, speak with a professional, and/or participate in a support group. These suggestions could help break their isolation, help them feel more supported, and lower their level of stress<sup>(6)(7)</sup>.

### EMOTIONAL RECOGNITION AND ACCEPTANCE

Each person follows a unique path to accepting their diagnosis and may experience various emotions. By acknowledging and accepting these emotions they can then allow themselves to express rather than repress them and this can help to regulate emotions<sup>(2)</sup>. For example, a person becomes anxious while learning about their diagnosis. They allow themselves to express this emotion, which helps them to reduce its intensity. They are then more opened to address it by seeking help, and trying treatments recommended by professionals, etc.



### IN CONCLUSION

In summary, confirmation of the diagnosis of scleroderma may require a process of acceptance. We encourage the person to progress at their own pace, practice self-care, and seek support.

If a person has concerns during their acceptance process, they can seek professional help by calling the Health Link BC's 811 number, request professional follow-up or participate in a SABC support group. SABC support group info: [sclerodermabc.ca](http://sclerodermabc.ca).



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