Psychological Impact of Ramsey Hunt Syndrome

Dr Corah Lewis, Clinical Psychologist, Oxford University Hospitals

Being diagnosed with Ramsay Hunt Syndrome (RHS) can be a very difficult experience. In addition to physical symptoms discussed elsewhere on this webpage, many people experience a profound psychological and social impact. These effects are not always visible to others, but they are very real, and they can be just as challenging as the physical symptoms.

It is completely normal to feel overwhelmed in the early stages. Many people report feeling anxious, low in mood, or uncertain about what the future will hold. For some, the emotional impact may improve as physical symptoms begin to resolve, but for others, they can persist. Everyone is different and will feel different in themselves after being diagnosed with RHS. Below, we have summarised what we know from the research and clinical experience about the psychological impact of RHS. Some of the areas discussed may be relevant to you, some may not. We have also included information about how you can go on to seek psychological support.

Self-Esteem

One of the things we hear the most is the impact that RHS can have on someone's self-esteem and confidence. Our faces are central to how we express ourselves and how we are seen by others. Often, people can say this is something they took for granted before a change in their appearance. People can experience a sense of loss and change in their identity when this is different. This can be particularly difficult in things like photographs or video calls. People often find themselves comparing their appearance to that of others or to themselves prior to the onset of their RHS. We know that it can therefore be tempting to avoid situations where we feel self-conscious. In the short term this can help people to feel less anxious, but in the longer term this can lead to them feeling isolated.

Anxiety and Depression

It is not uncommon to experience anxiety, depression, or both, particularly if the physical impacts of RHS persist. The unpredictability of recovery can lead to a heightened sense of anxiety. We know that RHS can often be initially misdiagnosed which can add to people's frustration or concerns about recovery.

Importantly, the level of anxiety or depression experienced does not necessarily relate to the degree of facial weakness. Some people with relatively mild symptoms experience significant emotional distress, while others with more visible or severe palsy may experience less distress. This highlights the importance of recognising the psychological impact of RHS as a separate but equally important aspect of care.

Social Interactions

Smiling plays a vital role in communication and relationship-building, serving as a greeting understood by people everywhere, regardless of their language or background. Many people with RHS report feeling that it is significantly harder to express themselves and their emotions. Smiling, laughing, or showing empathy can become physically difficult or painful. If people are self-conscious of their facial palsy, they may change the way they socialise. This could be through trying to hide their smile, reduce eye contact or limiting all facial expressions to maintain resting symmetry. Additionally, if a person is also experiencing hearing loss or tinnitus, this can add further challenges to socialising. Over time, many people with facial paralysis adapt to communicate in alternative ways, such as through direct eye contact, speech, the use of gestures and body language.

Unfortunately, people with facial paralysis may experience stigma or feel judged based on their appearance. They may notice others staring, asking intrusive questions or even making unkind remarks. Some people find it helpful to develop a short few sentences explaining their RHS as a way of responding to questions or staring. This gives people the chance to think through how much detail they want to share ahead of time.

Intimate Relationships

Kissing can be challenging for people with facial palsy. This can be especially difficult when starting a new relationship or dating for the first time. Being open and honest about what feels comfortable, what helps, and what may cause discomfort can foster better understanding and ease between partners. Couples can also explore other forms of intimacy, such as physical touch or shared activities that foster closeness. Reconnecting through meaningful time together, shared experiences, and moments of fun can help strengthen intimacy and emotional connection.

Self Help

The Clinical Psychology team at the Oxford Facial Palsy Unit have developed some self-help guides informed by Cognitive Behavioural Therapy to help people with Facial Palsy. Booklets on the following areas are available:

- Managing Anxiety - Facial Palsy: Managing anxiety

- Managing Your Mood - Facial Palsy: Managing your mood
- Building Your Self-Esteem - Facial Palsy: Building self-esteem
- Communicating with Confidence - Facial Palsy: Communicating with confidence
- Coping with Comments, Questions and Staring - Facial Palsy: Coping with comments, questions and staring
- Advice for Carers, Friends, Family and Partners - Facial Palsy: Advice for carers, friends, family and partners

Peer Support

Living with RHS can be an isolating experience, especially if you feel that those around don't fully understand what you're going through. Many people report feeling as though they have to explain their RHS repeatedly, or that their concerns about appearance, pain, fatigue or emotional wellbeing are not taken seriously. In this context, connecting with others who have had similar experiences can be incredibly valuable. It can also offer practical benefits, for example tips on coping strategies, rehabilitation resources, or simply reassurance that your feelings are valid. Whether through one-to-one conversations, group meetings, or online forums, hearing others' stories can reduce feelings of shame or isolation. It can also foster a sense of community and hope, especially in the early stages when more is unfamiliar.

Some support groups are for people with all types of facial palsy, while others are focused on RHS itself. If in-person groups are not available in your area, online communities can provide a similar sense of connection and support.

Psychological Therapy

We know from research in the area that psychological therapy can be a helpful step to improving people's mental health and quality of life when living with RHS. Psychological therapy offers a safe space to explore what you're experiencing, understand the emotional impact of your RHS, and develop coping strategies that are meaningful to you. In particular, Cognitive Behavioural Therapy (CBT) and Acceptance and Commitment Therapy (ACT) have been shown to improve mood in people with Facial Palsy. Many people find it particularly beneficial to speak with someone who has experience working with individuals affected by facial palsy or wider visible difference. These therapists are more likely to understand the nuanced challenges that come with altered facial expression, appearance-related distress, and the impact on social interactions and identity. How to go about seeking support will vary developing on a person's location. I

Summary

Developing RHS can have a significant impact on someone's mental health, self-esteem and identity. These psychological effects can vary greatly from person to person and are not always linked to the severity of physical symptoms. Communication, intimacy, and social interactions may become more difficult, and stigma around visible difference can contribute to this. Support through therapy, self-help resources, and peer communities can play a crucial role in helping people live a fulfilled life alongside their RHS.