

PSYCHOLOGICAL IMPACTS OF MARFAN SYNDROME ON FAMILIES

This resource is intended for healthcare professionals to better understand the impact Marfan syndrome can have on the whole family and not just the patients. This resource helps signpost the main challenges they may experience, how you can help them, and what wider help is available.

WHAT IS MARFAN SYNDROME

Marfan syndrome is a genetic disorder that affects the connective tissue in the body, it is caused by a mutation in the FBN1 gene. It can be a spontaneous mutation or hereditary. It is an autosomal dominant condition. It can affect the musculoskeletal system, the heart and eyes. Each patient may express the disease differently.

PSYCHOSOCIAL IMPACTS

DEALING WITH THE DIAGNOSIS

Parents will experience a cascade of emotions. Each family unit will react differently; some may feel relief, some will be grappling with guilt. It is important to reassure parents and be empathetic.

UNCERTAINTY

Parents may experience uncertainty about the future as Marfan Syndrome is complex. This can take an emotional toll on the whole family. It is important to inform parents about their condition appropriately.

PHYSICAL CHALLENGES

Due to musculoskeletal problems and subluxation of joints, patients may experience physical challenges during day-to-day activities. Parents should carry out risk assessments and allow them to safely do activities that are age appropriate.

BODY IMAGE

Patients with Marfan syndrome may experience self-esteem issues as they look different from their peers. It is important to explore this with the patient and signpost them to emotional support such as therapy.

SOCIAL ISOLATION

Families may experience social isolation as people in their community may not understand what Marfan syndrome is, so they may not be very sociable - exploring this and suggesting support groups is helpful.

SCHOOL

Schools may not fully understand how to support students with Marfan Syndrome. It is important to teach parents about how they can advocate for their child and who to get in contact with. [Marfan trust Guide for Schools?](#)

SIBLINGS

Siblings may feel jealous of the extra attention the Marfan-affected child may receive from their parents. It is important to recommend parents to family therapy or make simple conversation with siblings if present at appointments

STRESS

Being a parent is stressful, introducing multiple appointments, risk assessments and uncertainty for the future can cause increased tension within the family unit which can have a negative impact on the child and parents

EXPANDING THE FAMILY

Parents can be worried about having future children with the same condition. Healthcare providers should advise genetic counselling. Language should be empathetic and supportive as this can be a difficult situation

SUPPORT YOU CAN PROVIDE

EDUCATION

Empower families by allowing them to understand what the condition is. This can be done by you or signposting patients to educational material.

COMMUNICATION

Ensuring the language is clear and understandable, helps reduce parents stress as they are fully informed. Being empathetic is important as parents may feel stressed or anxious

LONG-TERM PLANNING

This can help parents understand what the future for their child entails, helping them prepare better for the future. By planning, anxiety about the future may be defused.

EVIDENCE

As a healthcare provider, you can look at statistics and keep up to date with current research to inform patients about the best possible treatments available.

HOLISTIC APPROACH

Working with other healthcare providers can help manage a complex condition such as Marfan Syndrome. It is important to update notes and include all information for cohesive care

ADVOCACY

Assisting parents in navigating healthcare systems, accessing support services, and advocating for their child's needs can alleviate practical burdens.

OTHER RESOURCES AVAILABLE

MARFAN TRUST
GENETIC COUNSELLING SERVICES
MEDICAL JOURNALS AND PUBLICATIONS

For more info:
Scan QR Code



References

- 1.Nielsen, C. et al. (2019) 'A review of psychosocial factors of Marfan Syndrome: Adolescents, adults, families, and providers', *Journal of Pediatric Genetics*, 102(03), pp. 109–122. doi:10.1055/s-0039-1693663.
- 2.van Andel, M.M. et al. (2022) 'A cross-sectional study on fatigue, anxiety, and symptoms of depression and their relation with medical status in adult patients with <scp>m</scp>-<scp>arfan syndrome</scp>. psychological consequences in <scp>m</scp>-<scp>arfan syndrome', *Clinical Genetics*, 102(5), pp. 404–413. doi:10.1111/cge.14211.
- 3.Child, A. (2016) 'Chapter 26: Psychosocial Aspects of Marfan Syndrome', in *Diagnosis and management of Marfan syndrome*. New York, NY: Springer