

Pain, Physical and Social Functioning, and Quality of Life

Pain is one of the most frequently reported symptoms in MHE. In a national cohort study from the Netherlands, over 80% of adults and 63% of children with MHE reported recent pain, mostly in the lower extremities and especially during activities such as walking. Pain, limitations in joint motion, skeletal deformities, and limb-length discrepancies can make participation in sports, work, and school difficult for people with MHE.

- Almost half of the children surveyed experienced difficulties in school, with many requiring adjustments or support.
- 46% of adults stopped participating in sports due to MHE-related symptoms.
- Adults with MHE scored lower in six out of eight domains on the RAND-36 quality-of-life scale, with notable deficits in physical functioning, social functioning, and general health.

Despite these challenges, most people with MHE adapt well, balancing their physical limitations with available resources and support.

Strategies for managing pain include:

- Rest: Many people with MHE find comfort in resting during periods of increased pain, particularly after physical activities like walking or climbing stairs (which are frequently identified as sources of discomfort).
- Heat: About a third of adults in the study report the effectiveness of heat in easing musculoskeletal pain and reducing stiffness in impacted areas.
- Medications About a third of adults in the study used over the counter medication (like advil or tylenol) to manage symptoms, particularly during periods of acute pain.

Strategies for living well with MHE (beyond pain management) include:

- Support systems play a crucial role in improving outcomes. Engaging with advocacy organizations and support groups can provide emotional support, practical advice, and resources to navigate school and work environments.
- In schools, accommodations such as modified physical education programs or ergonomic tools can improve students' experiences and ability to learn.
- Advocating for workplace accommodations and proactive health management can empower individuals with MHE to maintain a higher quality of life.

MHE is a chronic condition, with symptoms that persist into adulthood. Routine monitoring and surgical interventions may be necessary to manage pain, correct deformities, and to address complications like nerve compression or malignant transformation.

Goud, A.L., de Lange, J., Scholtes, V.A.B., Bulstra, S.K., & Ham, S.J. (2012). Pain, Physical and Social Functioning, and Quality of Life in Individuals with Multiple Hereditary Exostoses in the Netherlands: A National Cohort Study. *The Journal of Bone and Joint Surgery*, 94(11), 1013-1020. <https://doi.org/10.2106/JBJS.K.00406>
The best clinical decisions are made with a trusted physician. This is not intended to replace a discussion with your clinical team.