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Patient survey: The lived experience with Charcot-Marie-Tooth in Austria: therapies actually used and medical care

B. Chaloupek (1), K. Mannsberger (2)

(1) Chair Woman CMT-Austria, Eichgraben, Austria

(2) Secretary CMT-Austria, Wolfsberg, Austria

The aim was to comprehensively analyse the reality of life for people with Charcot-Marie-Tooth neuropathy (CMT) in Austria and to record the therapy plans actually used.

Therapies

Non-pharmacological therapies are the cornerstone of CMT management. Physiotherapy is considered indispensable by almost all respondents, followed by therapeutic massage and electrotherapy. (utilisation 30 % upwards). Exercise therapy is relatively new in Austria, so the utilisation rate of 16% is very high. It is also interesting to take a look at other therapies mentioned by the respondents themselves, such as energy work, music therapy, psychotherapy and speech therapy. They show that the disease is debilitating overall and that there is a need for systemic therapy.

60% of respondents stated that they had invested a block of time (minimum 4 weeks) in an inpatient rehabilitation stay in the last 5 years, 38% of them several times. There is great demand for these interprofessionally organised therapy weeks, as they include a gait analysis and enable individual atrophied muscles to be specifically addressed and developed.

Orthopaedic shoes are widely used (71%). Only 24% use orthoses.

Medical management

Risk in diagnostic pathway: The data highlights the significant diagnostic delay of a median of 7 years. This is time lost for therapy.

Risk in consultations: CMT requires continuous medical care from a variety of specialities. On average, the participants consulted 6 different specialists. CMT was not mentioned in 35% of the visits. This means that patients themselves must ensure that no contraindicated medication (e.g. neurotoxic substances) is prescribed and that the various treatments are coordinated.

Other topics covered in the survey: regional differences in care, fears at the moment of diagnosis and assistance from the wealth of experience of self-help in response to this, specific demands on the healthcare system.

Report (16 pages) see <https://qrco.de/bgC7Sk>