

Glossary dedicated to CDG Symptom Prioritization Questionnaire – (CDGSPQ)

WHO DEVELOPED THIS PROJECT?

This project is developed under the scope of **CDG & Allies – Professionals and Patient Associations International Network (CDG & Allies – PPAIN)** and led by Dr. Vanessa Ferreira, Prof. Dr. Paula Videira and Prof. Luísa Barros. We had the support of experts like Pf. Dr. Jaak Jaeken, Pf. Eva Morava, Dr. Mercedes Serrano, Andrea Miller (CDG Care), Merell Liddle (CDG Australia), Claudia Vazquez (CDG USA) and CDG & Allies - PPAIN colleagues. CDG & Allies-PPAIN is a unique international patient-led network focused on increasing CDG knowledge and ultimately, contributing to future therapies and better management of CDG.

HELP CONTACT:

If you need help, please do not hesitate to contact us asking for help related to this survey at <https://worldcdg.org/contact>. We will be available to schedule a SKYPE, WhatsApp CALL, or Zoom meeting.

Management/ rehabilitation therapies

Acupuncture is a key component of traditional Chinese medicine which inserts thin needles into strategic points of the body. It is commonly used to treat/ relieve pain. More information [HERE](#).

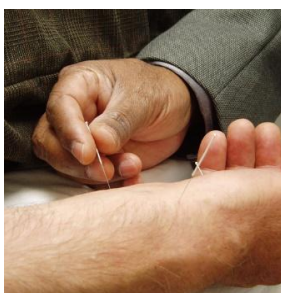


Figure source [HERE](#).

Anti-gastroesophageal reflux measures including thickening of feeds, keep of an upright position after eating.

Apitherapy is a branch of alternative medicine that uses honey bee products (including honey, pollen, propolis, royal jelly and bee venom) to treat. More information [HERE](#).



Figure source [HERE](#).

Aquatic therapy comprehends treatments and exercises performed in water for relaxation, fitness, physical rehabilitation, and other therapeutic benefits. More information [HERE](#)

Art therapy can help to improve cognitive and sensory-motor function, self-esteem, self-awareness, emotional resilience. It can also help in resolving conflicts and reduce distress. More information [HERE](#).



Figure source [HERE](#).

Avoiding triggers of the signs and symptoms (e.g. seizures; stroke-like episodes)

Braces to correct vertebral column disorders.



Figure source [HERE](#).

Equine-assisted therapy comprehends treatments that involve activities with horses and other equines to promote human physical and mental health. More information [HERE](#).



Figure source [HERE](#).

Fecal/ stool transplant is the transferring fecal bacteria and other microbes from a healthy individual into another individual, to restore of the colonic microflora. This process can be done through the infusion of stool via colonoscopy, enema, orogastric tube, or by mouth in the form of a capsule containing feces. Among others, it is an effective treatment for *Clostridioides difficile* infection (CDI). More information [HERE](#).

A **feeding tube** is a device used to provide nutrition to people who cannot obtain nutrition by mouth, are unable to swallow safely, or need nutritional supplementation. Feeding assistance can be by nasogastric tube or gastrostomy tube. More information [HERE](#).

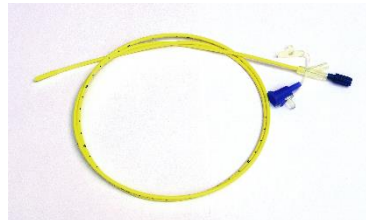


Figure source [HERE](#).

Glasses to preserve or correct the vision (e.g. in case of strabismus treatment or myopia).

Music therapy is the use of music to address the physical, emotional, cognitive, and social needs of an individual. It involves listening to melodies, playing an instrument, writing songs, and guided imagery. More information [HERE](#)



Figure source [HERE](#).

Occupational therapy provides assessment and intervention to develop, recover, or maintain the meaningful activities, or occupations, of individuals. It increases people's independence and satisfaction in all aspects of life. More information [HERE](#).



Figure source [HERE](#).

Osteopathy is an alternative medicine that emphasizes physical manipulation of the body's muscle tissue and bones. More information [HERE](#).



Figure source [HERE](#).

Physiotherapy or **Physical therapy** helps restore movement and function when someone is affected by injury, illness or disability, through movement and exercise, manual therapy,

education and advice. More information [HERE](#)



Figure source [HERE](#).

Psychotherapy treats mental health problems by talking with a psychiatrist, psychologist or other mental health providers.

During therapy, the patient learns about his/ her condition and your moods, feelings, thoughts and behaviors. It helps the patient to learn how to take control of his/her life and respond to challenging situations with healthy coping skills. More information [HERE](#).

Speech and language therapy evaluates, diagnoses, and treats communication disorders (speech disorders and language disorders), cognitive-communication disorders, voice disorders and swallowing disorders. More information [HERE](#).



Figure source: By Catarina Domingues, Speech and language therapist, Portuguese School of Mozambique.

Vision therapy involves eye exercises and training to improve some eyes disorders. More information [HERE](#).