

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.

Diets

Breastfeeding/breast milk is when you feed your baby breast milk, usually directly from your breast. It's also called nursing. More information [HERE](#).

The **formula** is a safe complementary manufactured food and a suitable breast milk substitute, usually prepared for bottle-feeding or cup-feeding from powder (mixed with water) or liquid (with or without additional water). More information [HERE](#).

Omnivorous diet (regular diet) includes both plant and animal foods.

Vegetarianism is the abstaining from the consumption of meat (red meat, poultry, seafood, and the flesh of any other animal), and may include abstention from by-products of animal slaughter. Vegetarian diets include:

- **Lacto vegetarianism** which includes dairy products but not eggs.

- **Ovo vegetarianism** which includes eggs but not dairy products.
- **Ovo-Lacto vegetarianism** which includes animal products such as eggs, milk, and honey.
- **Vegan diet** which excludes all animal products (e.g. dairy products, eggs, honey).

More information [HERE](#).

Semi-vegetarian diets (also called a **flexitarian** diet) consist largely of vegetarian foods but may include fish or poultry, or sometimes other meats, on an infrequent basis. Semi-vegetarian diets include:

- **Macrobiotic diet** consisting mostly of whole grains and beans, but may sometimes include fish;
- **Pescetarianism**, which includes fish and possibly other forms of seafood;
- **Pollotarianism**, which includes chicken and possibly other poultry;
- **Pollo-pescetarianism**, which includes poultry and fish, or "white meat" only.

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

Ketogenic diet/ keto diet is a high-fat, adequate-protein, low-carbohydrate (sugar) diet. This diet or fasting forces the body to burn fats into fatty acids and ketone bodies, rather than carbohydrates into glucose (a sugar). An elevated level of ketone bodies in the blood (a state called ketosis) is a treatment for **seizures/ epilepsy** and is also effective in treating **type 2 diabetes**. The ketone bodies passing into the brain and replacing glucose as an energy source. Side effects can include constipation, high cholesterol, growth slowing, acidosis, and kidney stones. More information [HERE](#).

Medium-chain triglycerides (MCTs) diet includes a supplement called MCT (present in palm kernel oil and coconut oil) that produce more ketone bodies per unit of energy than classic **Ketogenic diet** (which are mostly long-chain triglycerides), allowing to eat more protein and carbohydrate, and still be in a state of ketosis. This diet can also be used to treat seizures/ epilepsy, as well as lymphangiectasia. More information [HERE](#) and [HERE](#).

Intermittent fasting, also known as **intermittent energy restriction**, refers to various meal timing schedules that cycle between voluntary fasting (or reduced calorie intake) and non-fasting periods. It may help with obesity, insulin resistance, dyslipidemia (an abnormal amount of fat, such as triglycerides, cholesterol and/or fat phospholipids, in the blood), hypertension and inflammation. More information [HERE](#), [HERE](#) and [HERE](#).

A **sugar-free diet** to us means a diet free of refined sugar – things like processed foods and white flours, rice and bread.

A **gluten-free diet** is a diet that strictly excludes gluten, which is a mixture of proteins found in wheat, spelt, Kamut, triticale, barley and rye. Although oat usually does not have gluten can occur cross-contamination of oat, with other gluten-containing cereals. More information [HERE](#).

A **lactose free diet** means eating foods that have no lactose, a sugar that is a normal part of dairy products. More information [HERE](#).

Fermentable Oligosaccharides, Disaccharides, Monosaccharides And Polyols (FODMAPs) are a group of sugars poorly digested/ absorbed in the small intestine, prone to absorb water and ferment in the colon (by gut bacteria), producing gas. The extra gas and water cause the intestinal wall to stretch and expand.

FODMAPs occurs naturally and can help prevent digestive discomfort for some people because they promote beneficial alterations in the gut flora.

However, in people with gastrointestinal disorders (e.g. irritable bowel syndrome (IBS)), with a highly sensitive gut to ‘stretching’ the intestinal wall, **low-FODMAP diet** can help to improve digestive symptoms (pain and discomfort).

FODMAPs include short-chain oligosaccharide polymers of fructose (fructans) and galactooligosaccharides (GOS, stachyose, raffinose), disaccharides (lactose), monosaccharides (fructose), and sugar alcohols (polyols), such as sorbitol, mannitol, xylitol, and maltitol. More information [HERE](#).

A **low-fat diet** restricts fat and often saturated fat and cholesterol as well. It helps to reduce the occurrence of conditions such as heart disease and obesity. More information [HERE](#).

A **low-protein diet** involves a decrease in protein intake. It is a therapy for inherited metabolic disorders (e.g. phenylketonuria and homocystinuria) and kidney or liver disease. It also seems to reduce the risk of bone breakage. More information [HERE](#).

A **low-sodium diet** (salt intake of fewer than 5 grams per day for adults) is commonly prescribed to reduce blood pressure and risk of cardiovascular disease, stroke and coronary heart attack, as well as kidney disease. More information [HERE](#) and [HERE](#).

Diet for management of hypoglycemia with continuous tube feeding, iv glucose infusion at

a rate of 8 to 10 mg/kg/min and inclusion of complex carbohydrates, with a low glycemic index (e.g. uncooked cornstarch), in the diet standard treatments for **hyperinsulinemic hypoglycemia**. More information [HERE](#) and [HERE](#).

Diet rich in fish or other seafood: Fish and shellfish are good sources of many vitamins and minerals. Oily fish, such as salmon and sardines, has high in long-chain omega-3 fatty acids, which can help to keep your heart healthy. Thus, a healthy, balanced diet should contain at least two portions of fish a week, being one of them one of oily fish. More information [HERE](#).

An **anti-inflammatory diet** comprehends foods with protective compounds that reduce inflammation (e.g. antioxidants and polyphenols). Examples of anti-inflammatory foods are tomatoes; olive oil; green leafy vegetables (e.g. spinach, kale, and collards) nuts (e.g. almonds and walnuts), fatty fish (e.g. salmon, mackerel, tuna, and sardines) and fruits (e.g. strawberries, blueberries, cherries, and oranges). More information [HERE](#).

Avoid food that triggers signs and symptoms (e.g. food allergens, food undigested)