

Caring for the child with MLD

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- The first reported case of MLD was 1933
- Therapies for all are still many years away
- MLD is considered a rare disease in UK
- There is poorly co-ordinated care in UK, which is a major issue for patients and families
- A Multi-Disciplinary Team (MDT) needs to be well co-ordinated as disease evolves
- Team around the child and family is extensive
- Nutritional support:

Sufferers are often poorly nourished and, therefore, cannot combat illness

Gastro-Intestinal (GI) symptoms include reflux, vomiting (can be treated using Ranatidine) and Constipation – need to use diet, fluids and medication

- Pain is an issue and can be treated by medication
- Dystonia can be treated by medication

Meds

- Hip Subluxation/dislocation is common
- Bone density becomes an issue
- Chest infections and aspiration are problems

Drooling/suction/hyocin/botox

- Prevention of problems by using

Flu Vaccinations

Nebulisers

Suction

Prophylactic Anti Bodies

Hand washing

Physiotherapy

Always avoid with anyone who is unwell

- Mobility becomes progressively worse, and scoliosis is a problem

Treat using Aids, OT, Physiotherapy and home adaptations

- Sleep is affected

CEREBRA and other Web sites offer advice

- Seizures – treated by medication
- Communication is a big issue – child loses the ability to speak and adults cannot hold a rational conversation. Learning to “think” for the child/adult important.
- Visual damage

All children need an EHCP (Education and Health Care Plan)

Respite and palliative care - this no longer means helping children to die well. It means helping children and families to live well and then when the time is certain to help them die gently.