



Brittle Bone Society Patient Charter

Achieving better quality of life, care and treatments for those living with Osteogenesis Imperfecta.

The Brittle Bone Society Charter is a statement of the respect, care and support that people living with Osteogenesis Imperfecta (OI) deserve and should expect.



1: 15,000

are thought to have OI.



20%

of patients receive a wrong diagnosis.

55%

of adults with OI do not currently see an OI specialist.



62%



of adults with OI receive practical help on a regular basis from unpaid carers.

Our Charter

People living with Osteogenesis Imperfecta (OI) have the right to

- **1. Diagnosis**
Timely and accurate diagnosis of OI with appropriate referral to a centre of Expertise/Rare Bone specialists.
- **2. Care and Treatments**
Access to effective treatment, multi-disciplinary care and regular review by an appropriate healthcare professional.
- **3. Quality of Life**
Care and support from society and healthcare providers, to ensure active and independent living.
- **4. Informed Choice**
Involvement and choice in long term healthcare plan.

Help raise awareness of OI

Individuals (with OI)



Speak to your healthcare professional to explain your condition, there are over 8000 rare diseases. Do not expect your healthcare professional to have knowledge about OI.

Healthcare Professionals



Ensure appropriate assessment and treatments are provided and where relevant refer to an expert in the field of Metabolic Bone conditions.

Policy Makers/ Government



Support the establishment of coordinated models of care to ensure those 5000 individuals living with OI have access to consistent quality of care, reducing the impact on daily life and their level of independence.

Support the cause today- sign the charter!