



# Psychology support in the Osteogenesis Imperfecta (OI) team at GOSH: information for families

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Osteogenesis Imperfecta (OI) is a genetic condition present from birth. Its primary feature is fractures usually caused by minimal impact. This information sheet from Great Ormond Street Hospital (GOSH) describes the support available from our clinical psychologists when your child is being assessed and treated by the OI service. If you have any questions or would like to be referred for psychology support, please talk to your child's Consultant or Clinical Nurse Specialist (CNS). You can also contact the psychologists directly on 020 7405 9200 extension 5166.

A Clinical Psychologist is trained to understand how people think, feel and behave. Within the OI team at GOSH, the Clinical Psychologist supports children, young people and families with an OI diagnosis.

Coping with medical conditions can be very challenging at times and every child, young person and family will have a different way of managing and coping. We can give you guidance about any emotional, behavioural, developmental or educational concerns you may have, and suggest ways to cope with some of the challenges that can come from having a health condition and/or its treatment.

We can help at any point during your child's time at GOSH – as part of an inpatient stay, at any outpatient appointment or over the telephone. We can also provide information about how to access psychology support closer to home or from other organisations.

## What do we do?

We support a wide range of difficulties related to a child or young person's diagnosis, including:

- Providing a safe space for children, young people and families to talk about a diagnosis and the effect it might have on everyone in the family
- Helping children and young people to understand their condition and ways of talking to others about it if they want to
- Helping families balance the demands of everyday family life with managing your child's condition
- Linking you up with local services to help them understand and support your child's educational and behavioural needs
- Helping to reduce any anxiety or worries about coming to hospital or surgery
- Providing one to one therapy sessions for children and young people who are worried, upset or angry about their condition or have concerns about difference, such as in appearance or access to activities

- Managing the impact of OI on everyday life, such as school, friendships and family relationships
- Helping parents to talk to their child about the condition and support them in a way that suits everyone involved

## **Confidentiality**

We work closely with your doctor and your OI specialist team and always let them know that we've seen you. We often think together as a team about the best way of supporting you. You can let us know if there are issues you would prefer not to be shared with the wider team.

However, if we are worried about a child or adult's health and safety, we are legally bound to

inform the relevant agencies. We would discuss that with you at the time if relevant.

## **Our commitment to you**

Working with you and your child, we will always try to create a plan that is helpful and relevant to their wellbeing, individual and cultural differences. We will arrange an interpreter if you or your child would find this helpful.

## **Monitoring our service**

We are always trying to improve the experience for those who use our services. It helps us to understand what you experience when you come to GOSH – seeing what we do through your eyes can show us things that we might miss as staff.

## **Further information and support**

At Great Ormond Street Hospital (GOSH), contact the OI Team via our Administration Coordinator on 020 7405 9200 ext 5293. If you have a clinical question, please contact our Clinical Nurse Specialist (CNS) for OI on 020 7405 9200 ext 5824. You can contact the OI psychologists on 020 7405 9200 extension 5166.

There are four national services commissioned by NHS England for children with OI. GOSH is one of these and the others are Birmingham Children's Hospital, Bristol Children's Hospital and Sheffield Children's Hospital.

The Brittle Bone Society offers support and advice to parents of children with all types of OI. Telephone them on 01382 204 446 or visit their website at [www.brittlebone.org](http://www.brittlebone.org)