

Expectations and Responsibilities of child orthopaedic patients and their families (Revised June 2014)

This is written for parents and carers, for young people who are orthopaedic patients, and for expectant parents. We hope that the points made will be helpful to your unique, and sometimes age-specific, needs – whether your experience is minor and temporary, or a complex life-long condition.

In treating children with orthopaedic conditions, the British Orthopaedic Association is committed to ensuring a high quality of care for children, young people and their families.

1. Shared responsibilities

Some orthopaedic patients have chronic conditions requiring long-term care involving several teams of hospital specialists, and input from local health and social services teams. Parents and carers should be aware that the surgeon's and the clinical team's responsibilities are to the patient. Patients and parents can expect to play a part in communicating between the various services. The orthopaedic team members will also make direct contact with their counterparts in other service teams.

2. What you can reasonably expect of the hospital and the treatment team

Overall, the team should provide high quality services, based on assessed needs.

- provide timely and accurate diagnosis by people trained in dealing with children and adolescents
- ensure all members of the multi-disciplinary team have the appropriate qualifications (e.g. where it is necessary for the patient to have a cast it should be put on either by or under the direct supervision of a member of staff who holds a British Casting Certificate)
- communicate clearly both to patients (in an age-appropriate way) and to parents/carers, about the condition, the risks involved in proposed treatments, and the planned outcomes of all treatments (surgical and non-surgical) being proposed, by appropriate use of written, verbal, and diagrammatic information, and demonstration
- provide clear information for patients and parents about any medicines prescribed, their effects and possible side effects
- make shared decisions, involving the patient and the family, on how the condition will be treated, and including (if appropriate) an opportunity for the patient to sign a consent form in addition to the mandatory parental/guardians signature for those under 16 years old.
- provide effective pain management, responsive to the individual needs of the patient
- ensure appropriate provision and continuity of treatment in managing the transition between paediatric (under 16) and adult (over 16) care services and teams

The team should provide services co-ordinated around their individual and family needs.

- communicate clearly and promptly about appointments
- provide adequate on-site parking (especially for blue badge holders), and clear information about public transport services to the hospital
- explain the range of specialists and specialist services involved in the proposed treatment (the "care pathway")
- ensure that the hospital provides an adequate supply of the right equipment (such as wheel chairs and equipment to support and promote physiotherapy activity) to cover demand
- involve patients and family in decisions about medicines, and indicate sources of specialist support where medicine management is complex

- offer advice about what input might be sought from the patient's physiotherapist, GP, local community nurses, pharmacists and other health professionals, to support recovery and management of the condition

The team should provide services which promote social inclusion, where possible enabling you and your families to live ordinary lives.

- show commitment to the support of patients and their families living with life-long conditions, involving paediatric, play specialist and mental health care input as appropriate
- ensure appropriate liaison with the patient's school, and provision for in-hospital education

3. Your responsibilities as parents/carers and as older child patients

The child patient's treatment team needs family co-operation, and this is how parents and carers can help:

- attend clinic and hospital appointments on time
- give as much notice as possible of cancellations of appointments
- ensure that a parent or carer who is able to understand and give consent to treatment attends appointments where patients are under 16 years old
- if the parent or carer needs professional interpretation, make your team aware as soon as possible so that this can be organised
- read literature and ask questions to ensure you and the patient (if of an appropriate age) understand what you are being told
- bring a note of the patient's symptoms, the medicines currently being taken, and any side effects noticed to appointments
- follow the advice given by your team. If you think there will be difficulty doing this, discuss the problem with the appropriate member of the team
- comply with hospital expectations on hygiene and cleanliness
- be considerate of other patients and their families in the outpatient area and on wards
- use hospital equipment (e.g. wheelchairs, crutches) responsibly, and return them when no longer needed
- keep the family GP practice and other health professionals informed about any concerns you have about the care/ treatment plan and scheduled hospital treatment – this is in addition to letters which will be sent from the hospital on the matter
- keep the school and (where necessary) social services involved and up to date with aspects of care which affect the patient's education and support
- tell the team if anyone else needs to be informed about the treatment (e.g. estranged parent)
- if needed, discuss and plan the transition between paediatric and adult care with the team, taking into consideration the impact of the transition on key elements of the patient's life e.g. public examinations