

"Patients in other regions seem to have a really good local service. It felt as though we were unlucky enough to have a child born with leukaemia but we were doubly unlucky to have a MK42 postcode."



Patient Profile:

James (son), Hannah (mother)

- James was born with acute lymphoblastic leukaemia.
- James received treatment at Addenbrookes Hospital for first 10-11 months of his life.
- James has been an outpatient for 14 months and will continue to receive chemotherapy until November

Acute Lymphoblastic Leukaemia

- Overproduction of immature lymphoid cells (lymphoblasts) which fill the bone marrow preventing production of healthy blood cells
- Symptoms include increased risk of infection, bruising and anaemia
- Treatment is long and gruelling and principally involves chemotherapy and steroids

"The nurses are extremely capable and highly skilled. A couple of the nurses had been oncology nurses on wards before. Having their support eases the pressure at such a difficult time."

After leaving Addenbrooke's to live at home on a more permanent basis, support from a local oncology nurse from Bedford Hospital was provided for James (when the nurse was available).



After two months, the local oncology nurse left and was not replaced. We were left with the prospect of a 3-4 hour round trip to Addenbrooke's in order for James to get all the care he needed as Bedford Hospital NHS Trust does not officially treat children's oncology patients.

"This was a difficult time. It seemed as if the two Trusts [Bedford and Addenbrooke's] were blaming each other – neither seemed to be able to explain the reason for this."



Fortunately it was arranged for James to go to Children's Assessment Unit once a week at Bedford Hospital.

"We were grateful for this offer because we were trying to live a more normal life."

However, if the nurse was unavailable, James had to be taken to Addenbrooke's.



In March 2020, Covid-19 meant that changes were made to the service offer as a consequence of business continuity measures. It was arranged that Children's Community Nurse's would visit weekly to provide the care and support James and his family needed.

"The nurses are outstanding. We hope that this care can continue post-Covid. If we'd had this sort of care available early on, very stressful moments in James' treatment could have been avoided."

PATIENT STORIES