

Ben



Ben is 14 years old. He is a very positive, outgoing and friendly young man. He has a wicked sense of humour and loves to be the centre of attention, he will always entertain and make people laugh. He is a talented sportsman and has loved playing and watching football and rugby. He supports Leicester City and Leicester Tigers. He was diagnosed with leukaemia a year ago. Leukaemia is a cancer of blood-forming cells. Active treatment has failed and Ben has been discharged from hospital and is now receiving palliative/end of life care at home. His Mum died of cancer two years ago and Dad is his main carer. His elder brother Simon and has left home and works. His sister, Mary is married and has a baby.

Ben and his father both want to have as much care as possible delivered at home. Dad is exhausted. He has support from the GP, children's community nurses and children's Macmillan nurse. The school and Ben's school friends have also been giving lots of support, although Ben has not been attending school for some time.

The family have been given the opportunity to access the local children's hospice for additional support with symptom control, palliative respite support and End of Life care/bereavement support, but they are both very unsure about this. Ben has things he wants to do before he dies. It is late autumn and he is looking forward to Christmas which his favourite time of year.

My decision making agreement (Ben's perspective)

Decisions to be made	How I must be involved	How the decision is made and who makes the final decision
<p>Can I be looked after at home when I am very ill?</p>	<p>I would like my family, the nurses and doctor to listen to me and my wishes. I want to have as much of my care as I can from my Dad. He is good at remembering what medicine I need and when I should take it. I would like the doctors and nurses to give me information and talk to me directly, not over my head to my Dad. Then I can understand what the choices are for my care and can help make decisions.</p>	<p>The final decision is really down to my Dad. We need to find a place where Dad can manage to look after me and where he can get the help he needs. At the end of the day I will probably be happy where ever I am as long I am with my Dad all the time .</p>
<p>Should my Dad and I accept some support from the hospice?</p>	<p>I would like to visit the hospice with my Dad to look around and see what we think about it.</p>	<p>Dad needs to make the final decision as he has to look after me. I want it to be as easy as possible for him and my family.</p>

How would I like to be remembered?

Well and healthy.

As a brother, son and uncle.

Happy and laughing.

Fun loving.

A good friend.

Mad about Christmas.

Good sense of humour.

Sporty - especially good at playing football.

Leicester City and Tigers fan.

Good at telling jokes.