

Kate



Kate is 12 years old chronic disease. Kate is very mature and takes her responsibilities in life seriously. She never complains, despite the many challenges she faces. Her courage is admirable; she a hard worker and loves her Mum very much. Kate has a wonderful sense of humour and is very self assured. She loves spending time with her friends.

Kate and has Cystic Fibrosis, an inherited disease that affects the lungs and digestive system. She likes to stay as healthy as she can. Kate enjoys swimming, walking and cycling, which fit in around school and treatments. She also goes to Guides one evening a week with her school friend Louise who is always there for her. Kate is sociable and makes friends easily. Her mother is an alcoholic and has poor health. Her parents are divorced and Kate lives with her mother but rarely sees her father. He has never come to terms with Kate's diagnosis and has given no support as a Dad, or with regards to managing her illness. Kate is the main carer for her Mum and she is an only child.

Kate has an implanted Intra Venous Port for delivery of antibiotics which needs regular flushing to keep the line open. She requests to have her regular intravenous antibiotic therapy treatment (which is given for a two week period about six times a year) at home or in school so that she does not have to leave her mother alone at home. Kate wants to manage her own port and give herself the medication.

Kate has support from the local (CF) team, a Barnardos' social worker and the school. The school have been very supportive and the school nurse has agreed to help Kate with her antibiotics at school when she needs to take them, as she already has some other medication which she has to take with her school meals and physiotherapy at school.

What I want and do not want in the future - hopes and fears



To keep as well as I can for as long as I can.

To keep out of hospital.

To stay at school until I am 18 and then go to university.

To keep going to Guides.

Spend time with my friends at school.

To go away on holiday somewhere hot and dry with my Mum (this helps my chest feel better).



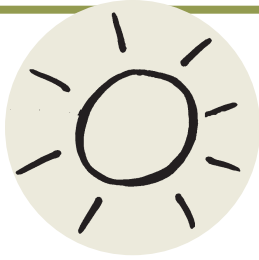
Being ill.

Having to be admitted to hospital.

Missing too much school and not seeing my friends and teachers.

Something happening to my Mum - I do not want to be alone.

What does a good day and a bad day look like for me?



I get up early enough to do my physiotherapy and I remember to take my medicine. I have my breakfast without any rush.

I make sure Mum is awake and she gets up and helps me get ready to leave for school.

Mum seems settled and not too upset.

I meet my friend, Louise and catch the school bus and get to school in good time.

I feel well and have a really good day.

I have art - my favourite lesson.

Mum is waiting for me when I get home. She is cheerful.

We have tea together - spaghetti bolognese and garlic bread.

I watch Eastenders on TV.

Big hot bath and bed.



I get up and find Mum in tears. She has been drinking. I have to sit with her and I am late doing my own care and have to rush around.

I do not feel great and feel as if I may be getting a chest infection.

I am worried about Mum when I leave for school and think about her all day. I cannot concentrate on school and would prefer to be with her.

I get home. Mum is still in her nightclothes. I have to sit with her all evening. I make myself a quick snack tea - piece of toast or something.

It takes ages to try to persuade Mum to go to bed.

I go to bed late and feel exhausted.

My decisions and actions

My decisions	Any action needed for my decision to happen	
<p>I want to be responsible for managing all my own care at home, including my Portacath. I want to learn how to look after and flush my own port at home. I want to be able to have my antibiotics through the port at home and at school I do not want to spend my whole life going in and out of hospital.</p> <p>This will allow me to be there for my Mum, she is always upset when I get admitted to hospital and that makes her poorly. I worry about her at home on her own.</p> <p>I believe I can do my own IVs. I already do my own physiotherapy and take my tablets without anyone helping me.</p>	<p>I need to be taught by the nurses at the hospital how to flush my Portacath and how to mix up and give my own intravenous antibiotics.</p> <p>I would like a nurse to watch me give my antibiotics a few times until I am happy to do it without anyone there. I would like my school nurse to learn with me so she can help me at school if I need her to.</p>	
Who	Will do what	By when