

## **TRANSCRIPT: Hospice and respite care – Matthew**

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Matthew is my second child of three and he's got complex medical needs and is profoundly disabled. Matthew's care really is a 24-hour, seven days a week job. Because it is such a time commitment and it doesn't stop when you're at home or when you're at hospital or at school, with Matthew respite is absolutely crucial to us as a family, to do all the things that normal families can do.

Respite provision varies across the country a huge amount. We consider ourselves lucky in that we get one night a week at a local respite centre for children with complex health needs and we also get 16 nights a year at a children's hospice that delivers palliative care, end of life care for children and it's also there for children that are not expected to reach young adulthood.

The hospice is about 45 minutes away from us and we have to really weigh up whether Matthew's well enough to do that length of journey. They do have a 'Hospice at Home' care team that, for example, if Matthew's discharged from hospital but is still too unwell to go to school and needs full-time care at home, they have a team that will come out and give us four hours respite at home.

Wherever Matthew goes he has his own set of care plans that look after all of his health needs and he also has an emergency pack which has everything vitally important if he needed to go to hospital. So, that ensures that there's consistency of care whether he's at home or receiving respite.

Having everything in place like that makes handover a lot smoother and you are reassured that there's no gaps in his care, that everyone follows the same routine that we follow at home, and that consistency's really important to us and it's important to Matthew as well. If he starts deteriorating health-wise, they know what the cut off point is for him to go to hospital. It does make us very reassured and we're relaxed because we know that if we don't have a 'phone call, everything's going well and Matthew's being looked after.

The hospice have family accommodation, so you can choose whether you want to leave your child there and go away on a holiday or you can stay with your children and your partner at the hospice. My two other children absolutely love staying. They call it a holiday home because it has all the facilities there that they could dream of. There's a hydrotherapy pool. There's a sensory room, a music room, art and crafts, and all the staff there really involve the family and encourage everyone to be together as much as you want to be, or you can leave the caring part to the staff and you're there to play and be a mum and dad again.

In an ideal world, you would love more respite time that's more flexible and suited to your needs. I struggle in the mornings and when Matthew comes home from school because I have to get three children ready for school and then, again, when they all

come home from school it's absolutely manic. That side of flexibility would be great and it would also be really fantastic if you could have more nights when you needed it, if your child deteriorated and you needed some more care because you needed a break because of that.

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