

TRANSCRIPT: Respite and the involvement of other professionals – Matthew

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To access respite, Matthew gets assessed by the Continuing Care Team Panel, which is made up of people from social services and healthcare professionals, and they will look at Matthew's care needs and you almost get points awarded for different disabilities and illnesses and then it's determined what level of care you get.

Respite is staffed by paediatric nurses and learning disability nurses and they also have qualified nursery nurses that are specialised in special needs children and those with complex health needs. The hospice is, again, staffed with paediatric nurses and care workers that are specialised in special needs children, and they also have a number of doctors that work there every single day.

Matthew is the centre of a huge team of individuals. There are over fifty professionals involved for caring for Matthew, whether that's through social services, education, health, voluntary sectors and myself, as mum, also ends up being Matthew's key worker to advocate his needs and his wishes to all of those professionals involved in his care.

All of those services can be very disjointed and it can be very frustrating actually to get them to work across boundaries. As a parent, I am the only person that oversees everything about Matthew and you really have to work hard to get all the agencies working together.