

New Models for Learning Disability Day Support Collaborative

Design Persona: Miss F

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Improvement Hub
Enabling health and
social care improvement

Introduction

Miss F is a 12 year old girl who lives at home with her mum and elder sister. She also has older adult siblings who live away from home and while her dad does not live with her, he is her personal assistant and a key part of her care team.

Miss F was exposed to [Group B Strep Infection](#) during birth and then suffered a [Hypoxic Brain Injury](#) at around 2 year old while in hospital with an acute respiratory infection, neither event was managed appropriately, resulting in much trauma for the family and a difficult relationship with the NHS. Miss F also has cerebral palsy, epilepsy, sensory impairment, breathing difficulties, undiagnosed neurodevelopmental disorders, scoliosis and is completely immobile. Her care needs are intense as her health status fluctuates throughout the day and night. Unfortunately this impacts on her windows of opportunity to be included in life outside her home and constant intensive medical care.

She requires 2:1 support from a team of NHS complex care staff along with SDS staff who her mum employs. She attends an ASN school about a 10mins drive from her home for which she needs trained escorts to take her to school due to her complex health and disabilities.

Miss F lives in a big old house at the top of a hill with her own bedroom and bathroom. There is a big garden although she is only able to access a small part of it. There is a sensory room in the garden and Miss F uses a wheelchair assisted vehicle.

She is fed via a gastrostomy tube several times a day/night. I have nutrini energy liquid food (liquid diet) , water bolus and medication via my button. Miss F also has oxygen therapy all of the time. Her saturation levels and heart rate is monitored constantly which helps carers provide proactive airway support. Her temperature and respiratory rate is monitored 24/7 and suction to help clear her airway is necessary.

Miss F has a lot of routine medication that needs to be taken at different times of the day. She has a breathing management plan which keeps her safe at home or school and most often in times of airway difficulties out of hospital. She also has a seizure management plan which holds information about the types of seizure's how to manage them. Miss F has pseudomonas (a type of infection) in her lungs and is given nebuliser therapy twice in 24 hours to help minimise the disease. She also has regular saline nebulisers after routine chest physiotherapy.

Miss F is doubly incontinent and needs help with every aspect of her life. She is unable to move voluntarily and often has involuntary movement. She is unable to see the world around her but may be able to see light at times. She can hear and I am able to recognise the voices of people I know.

I am a very happy most of the time. I only feel sad when I feel unwell.

Introduction continued

A very intense 24 hour programme of Postural Care is in place along with a carefully adapted wheelchair to suit Miss F's body shape. She has a comfortable chair with lateral support to provide the postural support that she needs whilst relaxing. A sleep system for her bed keeps her as symmetrical and comfortable as possible when in bed.

Miss F has a standing frame at school to help stretch and experience the standing position. At home she has a bath chair to keep her comfortable and safe in the bath. An [Acheeva](#) bed allows Miss F to get around her home and garden where able to lay flat, which helps with compromised airway support. She has leg splints, leg gaiters and hand splints. This equipment helps to keep her hands and legs in a comfortable position. Her favourite position is when laying flat in bed, feels safe and can breathe more easily. She is not happy to be in her wheelchair for any length of time. Her airway can become blocked in the upright position and she can start to feel scared that she is unable to breathe.

Miss F is entirely dependent on the adults around her to manage her airway, pain levels, and temperature. Her hearing and vision are assumed low and communication is very difficult to read if someone does not know her very well, which means she can appear very passive and with limited engagement. Miss F needs to be closely observed at all times and often her medical needs to be managed by two trained carers/nurses. Miss F enjoys listening to others chatting away.

My communication

Miss F loves to be part of everything that's going on and enjoys all types of interaction. She will smile and giggle when really contented, and enjoys interaction back from adults and peers.

She loves to 'chat' at home and at school where everyone knows her communication well. When relaxed she can give some eye contact and recognises familiar voices and sounds. She has a naughty sense of humour and enjoy raucous sounds and voices around me.

Miss F can access switch communication tools and benefits from adult support to utilise some intentional arm and wrist flexes. I enjoy using [Big Mack Communicators](#) to relay messages to others and also to participate in turn taking games and fun with friends, e.g. 'Turn the page please!' 'My turn!'. She enjoys making use of wireless switch adapted cause and effect level activities with sound on the interactive whiteboard.

My communication

The best way for people to understand Miss F is to be around her for long periods of time, learning from facial expressions and likes and dislikes. All the people around Miss F are able to understand her without her being able to verbally communicate with them. This continuity and familiarity of staff has given her the best chance of being looked after well and proactively keeping her safe and comfortable.

Miss F's mother understands her the most. Miss F understands conversations that she hears and will giggle when hearing something funny or her favourite movie is on her iPad. She will giggle when there is a loud noise or cry if she is in pain or feels her airway is starting to block off.

Before COVID Miss F was doing really well with her switching skills at school however after 16 months of not being at school she is having to start all over again.

My motivations

Miss F loves to be part of everything, being with family and friends, listening in to conversations and especially happy when she is included and engaged. She loves loud and raucous music and activity and love to wear fashionable outfits and have her hair done in modern and cute hairstyles. She has a great sense of humour and love to 'chat' at home and at school where everyone knows her communication well.

She enjoys the garden when the sun is shining and sensory activities. She likes to use her [Big Mack Communicators](#) switches and particularly enjoys the wireless switch adapted cause and effect level activities with sound on the interactive whiteboard. She enjoys going to Rachel House children's hospice (usually cared for 2:1 by Trained Staff Nurses when there).

My frustrations

Miss F can feel frustrated when she is tired and unable to clear her airway. She also feels frustrated when out and about and people around her don't understand that she needs lots of support to be comfortable and breathe – then they make her feel that I should be in a hospital bed or at home.

Lack of understanding and accessible community facilities frustrates the whole family and means they are all isolated.

My short-term ambitions

Miss F would like to keep well and get stronger, with more windows of opportunity to learn and be well enough to be part of society.

She would like to have more places that to safely visit with changing place toilets and an area that her acute health care can be managed with privacy.

Miss F would love to have more support to access a life outside my home and to access groups with other young people, e.g. clubs and groups.

Miss F's mother thinks she should be a member of the Scottish Youth Parliament and be a voice for children living with severe complex health and disabilities.

My long-term ambitions

Miss F would like to enjoy her years at high school, learning and mixing with all of the children at my school, attend a drama group and enjoy being part of a performance.

Miss F would like to attend life long learning within the local college or university with her own carer. She would like to help teach students in all disciplines about how I live and the support I need to live a meaningful life e.g. nurses, physiotherapists, psychology students, teachers, musicians and they could teach her too. Miss F would like to have her lunch with other students at college and help people in our society understand her better.

She would like to have a CSP (**Carer Support Plan???**) in adulthood like she had in early years education. This ensured she had all the professional people and support to get the best chance at school. Miss F's mother has said that an adult version of [GIRFEC](#) is important to ensure Miss F gets all the support she needs as an adult living with severe complex health and disabilities.

Miss F needs a lot of nursing support all day and night. When she becomes an Adult she would like her own house next door to her mother's. It would mean her Mum could have the privacy she deserves after all of these years of sharing her life and house with NHS staff. Miss F wants to be like her big brother's and sister and have her own independence along with her own space away from living with her mother. She could visit me regularly and make sure I am being looked after well. If there was an emergency she wouldn't be too far away too and Miss F could visit her too. It would mean her mother wouldn't need to be her nurse anymore, she would love to be her Mum.

My experience of how I spend my day

Miss F has many days when she needs a lot of help to cough. These days are very tiring for her and the carers that are looking after her. On these days she can't really engage in the outside world and most importantly she is supported by her breathing plan and kept comfortable and safe. At school she has my own room with a bed to lay on throughout the day if she am having a bad airway day.

During a window of opportunity outside of complex healthcare Miss F is able to participate in what is going on around her. Her favourite activities are listening to music, being outside on a fresh air day, listening to stories, sensory play, gym, switching, the sensory room, pamper bath, finger painting and listening to other children around me.

Miss F doesn't go out very often because there are not many places with changing place toilets or an area for me to have my emergency airway support that would allow me privacy, dignity and respect. The general public do not like to see her having airway support and suction in front of them and may find it distressing. Miss F and her carers are just used to it.

Miss F is fully reliant on her family and those around me to meet her needs and care for her. She would be very isolated without the social interaction of peers and staff who know and care for her in Education. She is very limited in life as to where she can access life outside my home where she can be safely cared for due to the highly intense medical needs.

Her learning is centred around ensuring that she is pain free, she has a safe airway and she is able to be included safely. Health supports, communication and knowledge of her medical needs are key to my wellbeing.

Miss F's significant health care needs means she requires to be supported by familiar people with the necessary training and skills to meet her needs and keep her as well as possible. Staff must know her well so that they can quickly spot any problems and act proactively accordingly as she can become very ill, very quickly.