**Standing in the Wings Plenary Report**

**Lindsey Mitchell**

As an occupational therapist working in wheelchair services for the last 18 months, I was thrilled to hear that I had been awarded a bursary place to attend PMG Conference 2019. As part of this I chose to submit a short report based on a plenary entitled Standing in the Wings, presented by Anne Duffy; who gave a heartfelt description of her experience as a parent of a son with Duchenne’s muscular dystrophy.

Anne’s son, Andy, who is now aged 27, was diagnosed with Duchenne’s muscular dystrophy at the age of 4. Ann chronicled a timeline of Andy’s life, punctuated by photos and videos, (many of which included his elder brother Peter); highlighting the initial symptoms of Duchenne’s she noticed in Andy, the anxiety caused by waiting times when accessing a diagnosis, her fight to ensure that Andy went to mainstream school and the bureaucracy involved in accessing appropriate equipment and adaptations.

It reinforced for me the impact that health, social and educational professionals have on a person’s life, with Ann remembering interactions which were particularly positive or negative. It was clear that her sense of humour and patience had been tested on many occasions.

As a wheelchair occupational therapist, I was very interested when Ann began to discuss the various wheelchairs her son had used. Ann described that initially her son was not entitled to a powered wheelchair because her home had not been adapted. A number of years later when Andrew started secondary school he was issued with an NHS wheelchair which did give him some independence but unfortunately it sounded like a milk float and required him to lean forwards in the seat to use the controller.

This was replaced with a Golf chair via Kate Fox (physiotherapist) who started a neuromuscular charity in Winsford, Anne highlighted that this was an improvement on the previous chair and improved Andrew’s quality of life. But the best powered wheelchair by far was funded by Caudwell Children and was fitted with a riser function; this enabled Andrew to reach the tables in the science labs and take part in social activities such as watching his beloved Stockport County, allowing him to rise up with the crowd when his team scored a goal. It was great to hear what a difference that right piece of equipment makes to a person’s life.

I work within an NHS wheelchair service and there are limits to the types of equipment we can provide. Ann highlighted that the best powered wheelchair her son used was funded by Caudwell Children which is an amazing charity that I often signpost families to. Signposting patients, families and carers on to other services which may be able to assist them is a vital part of the role of a wheelchair clinician; my colleagues and I endeavour to keep up to date with information relating to potential funding providers, either general or condition specific, to whom patients can apply to access suitable equipment.

Anne pointed out that some of the most valuable assistance had been offered by the family care officer from the Muscular Dystrophy Campaign, regarding information and support when Anne encountered what seemed like never ending battles against bureaucracy, from accessing home adaptations to the more recent issues around care charges and maintenance costs for home equipment; this emphasized the importance of signposting or referring on to condition specific organisations.

As clinicians we need to remember that although an appointment at wheelchair services is about the patient, the patient and their family or carers are a team, so it is essential that what we take the needs of the team into consideration and check that carers are receiving the support that they require. This may include referring siblings to young carers groups or hospice sibling groups and providing contact details for support groups to parents. Anne identified that both she and her sons would have benefited from mental health support during transition from child to adult services, but this was not available.

The plenary concluded with Ann performing a monologue she had written. It was based on a trio of answer phone messages left by a character called Lily Drake for a therapist who had had a positive impact on her son Steven’s life. Thanking the therapist for the small gestures which had been invaluable to her son’s progression and to share that her son had settled down, recently become a father, and had a baby Drake (like Sir Francis or the duck) of his own. This powerful performance was a beautiful reminder of the privileged position we occupy as therapists and what a difference we can make.