



CASE STUDY – HOW WE HELP FAMILIES

A single parent of twin adolescents with a life limiting health condition was recently (early 2015) introduced by the social work department to our ASCS Area Officer in Tayside. At the time of the introduction the school holidays were about to commence and the family were in the process of moving to a new purpose build home provided by their local authority to meet their needs and accommodate their wheelchairs. It was a busy and exciting time for the family, but also a stressful time. In addition to this the daughter was to be admitted to a dedicated children's hospital in another city, where it was anticipated she would stay for a week. In order for the parent to be able to stay in hospital and support her daughter, who also has autistic spectrum disorder, arrangements had been made for the other teenager to be cared for at the children's hospice Rachel House.

The parent explained she was feeling extremely anxious about the forthcoming hospitalisation of her daughter, given previous experience of admissions to this particular hospital when difficulties had arisen around access to necessary equipment and facilities and stated "hospital bed spaces and toilet /shower facilities do not accommodate or meet the needs of people with physical disabilities and wheelchairs users very well." Added to the parent's anxieties was the fact her daughter was unhappy about going to hospital and was reluctant to discuss the matter. The planned procedure was to have a bi-pap machine fitted, which requires a great deal of commitment from the patient during the hospital stay and thereafter at home, as well as support from parents and carers. The parent also explained some other worries including not being able to see her other child, whom she would drop off at Rachel House before going to the hospital, driving in an unfamiliar city and finding a disabled parking space when she arrived at the hospital.

With permission from the parent the ASCS Area Officer was able to make contact with the Charge Nurse on the ward and discuss this young person's admission. Discussions took place regarding practical arrangements and around the specific medical equipment required, such as the type of hoist and compatible slings required, appropriate mattress, commode and disabled toileting facilities. This discussion became a sharing of ideas and information and included the impact of autistic spectrum disorder for the young person, such as routine and consistency of carers. Discussions took place around facilities for the parent and it was agreed a room would be provided. The opportunity to have a day pass to leave the hospital as most procedures would be carried out in evening was discussed as a possibility and access to offsite family support and provision was arranged by the ASCS Area Officer.

The Area Officer made contact with the local Paediatric Complex Needs/Palliative Care Nurse to obtain additional information about the young person and her needs and to share information about arrangements being put in place. The Charge Nurse from the dedicated children's hospital agreed to make arrangements for a local disability nurse to visit the family on the ward to offer support.

The Area Officer kept in contact with the family, mainly through text messaging and email, to ensure they were fully aware of any discussions taking place and arrangements being put in place and updated the Social Worker and Community nurse as appropriate. In essence the Area Officer took on a co-ordinating type of role in order to ensure this young person's health rights were met.

Following the discharge of the young person from hospital the ASCS Area Officer and the parent met to discuss how things had gone and what if anything had been different from previous admissions to this hospital. The parent said "From the minute we arrived at the hospital we felt welcomed and all the necessary equipment was ready." She also felt "A smaller, more consistent number of staff cared for my daughter and this was helpful as she was able to get used to them...because she was so comfortable I even managed to sleep in my own room, with the exception of the first night. Getting some sleep meant I coped better and I was more supportive to my daughter when she needed me." On

a couple of occasions they were able to arrange a day pass, as had previously been discussed and mum explained “We had shopping trips to town and it actually felt a wee bit like a holiday!” She also explained that things went very well in hospital, with her daughter fully committing to the procedure and she continues to do so at home, which she believes is because “...everything was put in place for us before we arrived at the hospital and the experience was so different to the previous one.” Finally the parent said “Now I know what can and should be provided for my daughter during a hospital stay, I would feel able to speak up to ensure her healthcare rights are met in future.”