

## Promoting Evidence-Based Nursing Practice:

### *One person's story in context of the pilot study: Exploring transition of young people with type 1 diabetes from children's to adult diabetes health services*

The Royal District Nursing Service (SA Inc) has a workforce of 350 registered nurses and provides generic and specialists nursing services in both homes and clinics. The diabetes service is one of the specialties provided and two Clinical Nurse Consultants (CNCs) work exclusively with people who have been diagnosed with diabetes. As part of the CNC role, Diana Sonnack and Jenny Taylor work closely with the Women's and Children's Hospital (WCH) to provide support and education to children and adolescents who have been newly diagnosed with type 1 diabetes. CNCs receive referrals when young people leave children's services and have not made a successful transition to adult diabetes. Many young people have fallen through the gap between services and have missed routine medical and pathology review and revision of treatment concurrent to life style changes which manifest with growth and development into adulthood. Apart from missing out on review by the endocrinologist, referrals to the diabetes educator, dietitian, ophthalmologist have not been offered. By the time they are referred to RDNS CNCs, these young adults may already have serious long term complications of diabetes. This problem has led the CNCs to explore what health care professionals can do to facilitate a successful transition from children to adult diabetes services.

Type 1 diabetes is the most common metabolic disease that affects children (Christian, D'Auria and Fox 1999). In type 1 diabetes the pancreas is unable to produce insulin and treatment consists of at least twice daily insulin injections in order to prevent serious short and long term complications. In addition the management of diabetes involves frequent testing of blood glucose levels and constant attention to diet and exercise (Christian et al 1999). The importance of regular health care follow up for people with type 1 diabetes is well recognised and for children or adolescents the management is medically, educationally and psychologically complex (Frank 1992). Care is usually provided in a multidisciplinary paediatric clinic, which over the years becomes a safe and familiar environment to adolescents.

The motivation for this project was clinician driven because it is acknowledged that a significant number of young adults cease contact with adult diabetes services after being discharged from paediatric services. This places them in a position of vulnerability regarding their future health management. The transition from children's to adult diabetes health services occurs at a time when the primary responsibility for diabetes management shifts from the parent to the young adult. Children have access to a range of services focused on their developmental needs, both physiological and psychosocial, in the context of their diabetes. The support system available until they reached puberty provides them with opportunities to meet others in similar circumstances and promotes independence from their families. Young adults may experience a sense of isolation between childhood and adulthood in terms of diabetes services. Adult services provide for people with both type 1 and 2 diabetes, and this mixing of populations in the transition phase may amplify the difficulty young adults experience.

The primary aim of this pilot project was to explore the nature of transition from children's to adult diabetes services from the perspective of young adults who live with type 1 diabetes. This knowledge will be pivotal for the provision of comprehensive and sensitive health services for this group of consumers. Four participants were recruited to take part in the study. The methodology used for the project was participatory action research. Ethical permission was granted by the RDNS Ethics Committee. The participants met for six hours (two occasions) and the groups were facilitated by CNC, Diana Sonnack. Participants were encouraged to talk about themselves in response to some guiding questions: Can you tell us about yourself from the time you were diagnosed with diabetes to the present time? Can you give an example of how diabetes has changed your life? Which diabetes services have you utilised and what has been your experience with these services? As part of the report (see [www.rdns.net.au](http://www.rdns.net.au) in July 2003) we have told each of the participants story of being diagnosed with diabetes and their experience of being in transition from the children's to the adult diabetes service. Here is Clare's (a fictional name) story:

#### **Clare's Story**

At 19 years of age Clare projects herself as a confident and independent young woman. Clare is in the process of completing two year 12 subjects so that she can go on to further study in the area of children services. Two years ago she moved out of home but due to the high expenses she has since moved back in with her mother.

At the of age 12 Clare was diagnosed with type 1 diabetes. The diagnosis came suddenly after an acute episode of tonsillitis. Her mother and older brother were faced with a medical emergency when they found her in a coma. The doctor had been the day before and had treated her for tonsillitis and although she recalls feeling thirsty and passing more urine since the onset of tonsillitis she had otherwise been well. In hindsight though her mother recalls that she had lost weight although Clare had not noticed this herself. Clare was taken by ambulance to an acute care hospital for children and treated in intensive care until her blood glucose levels were stabilised.

The actual diagnosis of diabetes did not bother Clare too much and she thinks this may have related to the fact that her high blood glucose levels and other medical conditions had made her a bit 'delusional'. She remembers accepting the diagnosis and coping well whilst in hospital. However when she got home things were a little bit more difficult:

*I was about 12 I think when I first was diagnosed with a million things at once but yeah, when I first found out I don't think I was really bothered – I was in intensive care so I was like yeah, whatever – tell me later, I might have a reaction. And yeah, I pretty much was alright with that – until I got home. Cause I didn't have to see the needles and I had this really big phobia of needles before I got diabetes so yeah, I got home and I just*

*didn't want to do it so my Mum had to make me do it, by ringing the hospital and telling me that a nurse was going to come and attack me if I didn't. So I decided to do it myself.*

Despite this initial set back Clare has been able to accept and successfully incorporate diabetes into her life. She feels that it wasn't too much of a transition for her even though she had a bit of a sweet tooth. Being a fussy eater was initially difficult because after being diagnosed with diabetes she had to start eating a wider variety of food. Honey sandwiches and lollies were not a sufficient diet for her to continue with. The comment below demonstrates Clare's independence although clearly the period of transition required some adjustment:

*I haven't really had many really huge reactions to it but I think it has been a little bit harder since I've had to leave there [children services] like you get in your comfort zone, being 12 and then suddenly you're 18 and yeah, everything just changes.*

Having diabetes and becoming independent can be challenging. Starting to go out on your own with friends has to also be balanced with insulin injections, food and blood glucose monitoring. Clare recalls that this was sometimes difficult especially in the beginning. An example that Clare provided was when she was involved in theatre shows and the combination of late nights and long hours on stage was sometimes difficult. Clare felt that this was made a little easier by the fact that she only needed two insulin injections a day. Since moving to the adult sector she has been placed on an intensive insulin regime of four injections a day and she feels this can make situations such as this more difficult to manage.

At age 17 Clare was told by the paediatric services where she was attending appointments that she needed to move to the adult sector. At this appointment she was told that she would have one more appointment at the paediatric clinic and following this an adult Diabetes service was recommended and consequently arranged. Initially Clare had some problems because clerical staff never arranged follow-up after her first appointment at the new hospital:

*I got referred to the [adult hospital] and I had one appointment with the doctor there... and then I didn't hear anything for awhile [9 months]...I had no idea, I just thought they were a bit useless. And then you know I rung up Sally [diabetes nurse educator from the paediatric clinic] and I said to her look, I need a referral to somewhere, anywhere'll do, so long as they know what they're doing.*

Fortunately for Clare she was able to seek help from her previous health service and get the situation rectified. She was provided with advice and a new appointment was made with a different doctor within the same hospital. She is now happy with her new doctor and starting to feel more settled within the new system. To date Clare has not been referred to any other health professional such as the diabetes nurse educator or dietitian. She is however involved in a phone in insulin stabilisation service that assists her to adjust her insulin on a weekly basis.

For Clare transition has not been a major issue. She has only noticed minor differences between the adult and paediatric clinics. Clare recalls that she only ever saw the DNE informally whilst at the paediatric clinics and that her doctor changed during the time that she was at the paediatric clinic. This may explain why she has not noticed a huge change since moving on to the adult sector:

*They've always had that kind of oh okay, you're here now approach no matter where I was. I always felt like, okay, you're here to see me for this so I mean we'll fix you and you can go home. Like, it was never – it wasn't as much transition for me because it's sort of – I've always found it to be like that. ... At the [paediatric clinic] I had about 3 doctor changes, that kind of thing, so I've just sort of gone, oh okay, this is how it works, I'll just flow with it kind of thing.*

Clare also explained that she had initiated going to appointments at the paediatric clinic without her mother being present and this assisted to prepare her for the adult sector. What Clare's story highlights is the importance of gaining independence as a young adult so that transition to adults services becomes a natural extension into adulthood. One wonders whether the combination of Clare's independence and the fact that she hadn't established strong ties to the paediatric clinic is what contributed to making the transition process easier for her.

### **Conclusion**

We have selected a story that shows the way one independent young woman had initiated appointments, albeit after waiting nine months, but our data from this small project suggests that transition from the paediatric service to the adult service is ad hoc and largely unstructured. From the literature it is clear that this finding is consistent with other research studies. The way in which adolescents are prepared for transition appears to lay in the hands of the paediatrician who then arranges an endocrinologist in the adult sector. There did not appear to be any formalised preparation procedures in place within the paediatric clinics at the time that these young people made their transition. For young adults to be supported through this period of change there needs to be a structured and coordinated approach across the state. There needs to be systems in place to minimise the number of adolescents who end up falling through the gaps. The young adults in this project had not had a diabetes education update for some time and now that they are in the adult setting they didn't even have a contact person other than their endocrinologist. Education and support is ongoing particularly when there are many changes in the lives of young adults. Often when adolescents move into the adult sector changes are made to their insulin regimes as they move from two injections a day to a more intensive regime of four injections a day. This may provide a wonderful opportunity for the diabetes nurse educator to be introduced and become part of their support network.

### **References**

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