

# **Diabetes SA - Transition and Type 1 Diabetes Workshop**

#### Background

- Research suggests that many adolescents and young adults with diabetes struggle to engage with health professionals across the transition years, potentially increasing their risk of suboptimal diabetes care and devastating consequences.
- Transition in the context of diabetes means a physical change from paediatric to adult healthcare and becoming more independent with self-management, however adolescents and young adults go through many transitions including education, work, social roles and relationships.
- Diabetes SA aimed to develop a workshop that supports the transition process from paediatric to adult diabetes services, and addresses common concerns around transitioning to adult care and adult life.



## Diabetes SA - Transition and Type 1 Diabetes Workshop

- The 'Transition and Type 1 Diabetes Bridging the Gap' workshop was a collaborative project between Diabetes SA and the Women's and Children's Health Network in South Australia with support from local adult diabetes services in South Australia.
- This was an interactive workshop for teenagers with type 1 diabetes aged 12-18 years and their families with a focus on the transition to adult diabetes care and adult life.
- The workshop involved personal stories from young people with diabetes, information from health professionals (paediatric and adult endocrinologists and Credentialled Diabetes Educators), written material and peer led discussion groups.
- Funding for this workshop was provided by the National Diabetes Services Scheme (NDSS)

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# Program Development

- The development of this workshop included identifying topics of interest and the appropriate delivery of education, based on results from:
  - the 2012 NDSS Youth and Transition Survey,
  - the 2007 National review of transitional care,
  - the 2006 NDSS/Diabetes Australia 'Young Adults with Diabetes Needs Analysis,'
  - interviews with SA based paediatric and adult Credentialled Diabetes Educators and
  - discussions with young adults living with diabetes.



## Aims of the Workshop

- To encourage and support discussions about transition to adult healthcare between teenagers with diabetes, their family and the diabetes care team.
- To provide the opportunity of peer support for young people with type 1 diabetes.
- To provide the opportunity of peer support for parents/guardians of young people with type 1 diabetes.
- To increase the participant's awareness of the transition process and factors to consider.
- To increase the participant's knowledge about adult diabetes services in metro and rural South Australia.
- To identify common topics of interest and concern among teenagers with type 1 diabetes and provide opportunity for them to discuss these topics in a peer led environment.



# Outline of the Workshop - 3 main sessions

- A joint session (parents/guardians and teenagers) focusing on 'moving on to adult care' including information from health professionals and personal stories from young adults with diabetes focusing on preparing for transition, the differences between public and private services, what to expect from adult care, finding a diabetes team, adult diabetes services (including specialist) available in SA, transitioning to university and the workplace.
- <u>Teens only discussion group</u> led by young adults living with diabetes based on main concerns about transitions to life as an adult with diabetes.
- <u>Parents/guardians only discussion group</u> led by a paediatric mental health nurse, paediatric endocrinologist and Credentialled Diabetes Educators with a focus on the parents role in transition and their main concerns.



# **Evaluation**

- Two separate evaluation forms were developed for the parents and teenagers.
- Closed questions targeted process evaluation.
- Open questions were used to asses impact evaluation.
- Open questions were asked to assess the need for future topics and allow for any general feedback.
- The tools used were not validated evaluation tools.
- The peer led discussion group was set up to provide the opportunity to determine the most common concerns among the teenage participants and the parent/guardian group.



## Results – teenage group

- 26 teens aged 12-18 years attended with 18 completing the evaluation.
- 27% rated the overall workshop as 'very good,' 66% as 'good' and 5% as 'poor.'
- 22% rated the joint session as 'excellent,' 61% as 'helpful' and 5% as 'somewhat helpful.'
- 52% rated the teenage discussion group as 'excellent,' 41% as 'helpful' and 5% as somewhat helpful.
- A common trend in the qualitative results suggest that the teenagers valued the time to talk to other teenagers with diabetes about common concerns.
- "I learnt that many people go through the same kinds of difficulties that I do, as well as some helpful information about rights in the workplace."
- "I think this was a great experience to engage in and I would like to come here again."



- The peer led discussion group revealed four main topics of interest/concerns for the teenagers attending (ranked from most to least common):
  - 1. Does managing diabetes get any easier as you become an adult.
  - 2. How to manage alcohol and diabetes.
  - 3. Dealing with diabetes in the workplace.
  - 4. Managing exercise.
- There were other comments and discussions about being worried about complications, being worried about meeting a new diabetes team and wanting parents to give them more independence.
- Topics were consistent across age groups, although the younger ages (12-13 years) felt that they were not ready to talk about transition.



#### Results – parent/guardian group

- 43 parents/guardians attended with 25 completing the evaluation.
- 64% rated the overall workshop as 'very good,' 32% as 'good' and 4% as 'fair.'
- 12% rated the joint session as 'excellent,' 70% as 'helpful' and 16% as 'somewhat helpful.'
- 37% rated the parent/guardian discussion group as 'excellent,' 50% as 'helpful' and 12% as somewhat helpful.
- A common trend in the qualitative results and discussions suggest that:
  - 1. Families recognised that there are common issues, which was reassuring.
  - 2. Families felt that many of their issues are related to 'general teenager' issues, which would be valuable to address in another workshop.
- Overall parents/guardians wanted more time for open discussion and felt that more information on drugs and alcohol for the parents was required.



Conclusion/recommendations

- Qualitative results echo the importance of peer support for teenagers living with diabetes and also suggest the importance of peer support opportunities for parents/guardians.
- Comments from some of the12-13 year olds (and their parents/guardians) suggest that they were not ready to discuss the details of transition.
- Future workshops should provide more time for peer support and open discussion.
- Future parent/guardian workshops should provide more information on troubleshooting for certain teenage behaviours.
- Camps and social activities for teenagers and adolescents with diabetes should continue in order to encourage peer support opportunities.
- This program could be adapted and piloted in young adults (aged 18-25 years) with diabetes to assist with the transition process.