

Australian Diabetes Educator

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Diabetes Through the Lifespan

Feature article

Managing diabetes across the lifespan

Young Adults with type 1 diabetes –
The neglected group?

The Northern Territory Diabetes in Pregnancy Partnership:
Improving models of care in remote Australia

Original research

Knowledge gaps surrounding insulin use in adults with type 2 diabetes

Living with diabetes

The silent sufferers of diabetes



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From the Editor

Dr Kate Marsh, BSc, MNutrDiet, PhD, Grad Cert Diab Edn & Mgt
Advanced Accredited Practising Dietitian & Credentialed Diabetes Educator



We are excited to bring you the first online edition of the ADE. It's been a busy few months planning and designing the new platform to ensure it is user-friendly and a valuable resource for our members.

The online platform provides a number of benefits including the ability to print, share and comment on articles as well as being able to browse or search for past articles. You can also link directly to further reading and references within each article. We have chosen a fairly simple design and layout, making it easy to read on a variety of devices. But for those who don't always have access to the internet or who prefer to read offline, there will still be a PDF-version for each edition which can be downloaded from the ADEA website.

The theme for this edition is *Diabetes Through the Lifespan* and we have a great range of articles related to this topic.

Ashley Ng discusses the results of her research looking at the needs of young adults with type 1 diabetes (T1DM), including some useful tips for those of us working with this group. Ivan Chan presents his research findings on knowledge gaps surrounding insulin use in type 2 diabetes (T2DM), suggesting a need for more structured education around insulin use in this group. And Cherie Whitbread and colleagues from the Northern Territory (NT) Diabetes in Pregnancy (DIP) Partnership discuss the challenges of managing diabetes in pregnancy in the NT and how these challenges are being addressed by the NT DIP Partnership.

Trisha Dunning's article, *Managing Diabetes Across the Lifespan*, is particularly relevant to our theme, discussing the important role diabetes health professionals can play in helping people to manage their diabetes through expected life transitions.

In this edition we are also fortunate to have insight from two people who don't have diabetes themselves but have first-hand experience in the daily challenges that living with diabetes can present. Leanne Mullen, RN CDE, writes about her experiences as a partner of someone with T1DM, reminding us of the important

role that partners and family members play in the lives of people with diabetes, and of their own need for support. Rachelle Ward, JDRF NSW Volunteer of the Year and a consumer representative on MESAC, provides insight into the challenges of navigating the school system when you have a child with T1DM, with some tips on how she feels diabetes educators can help in this setting.

I'd like to take the opportunity to thank our hardworking EAG members – Michelle Robins, Penny Barker, Nicole Duggan and Anne Marks, and to thank Tom Corte, who has decided to stand down from the committee, for his contributions over the past year. In his place, we welcome Kirrily Chambers, a pharmacist CDE and recipient of the 2016 CDE of the Year.

I hope you enjoy reading the March ADE and welcome your feedback on this edition as well as the new online format.

Young adults with type 1 diabetes – The neglected group?

 **Ashley Ng**, PhD Candidate at Deakin University, MDiet, BFS&N(Hons), BHsc
Accredited Practicing Dietitian

Globally, the number of young adults living with type 1 diabetes (T1DM) is on the rise.¹ Within Australia, almost one-quarter of those living with T1DM are aged between 21-39 years.² However, the 2012 Australian Youth Transition Survey found that only 42% of young adult respondents aged between 18-24 years attended a diabetes clinic.³ A loss to clinical follow up is a concern as it is associated with poorer glycaemic control compared to those who maintain regular clinical review contact.⁴

For many young adults living with diabetes, loss of clinical follow up occurs during the transition from paediatric to adult diabetes care and can be linked to a host of barriers unique to emerging adulthood.^{3,5} Major life transitions or turning points young adults experience during this time include living independently, starting new relationships, finishing high school and family planning.⁶ Such turning points may affect diabetes-related decision-making or displace diabetes management and self-care from being a priority, which results in a deterioration in glycaemic control.⁵⁻⁷ As young adults with T1DM progress through major life transitions, they must also learn to adapt the way they live with the condition.⁶

Emerging adulthood is also a period of time where young adults often begin to understand the long-term health benefits that accompany an investment in their diabetes management and self-care.⁷ As such, this time provides a window of opportunity for educational interventions due to an increase in motivation to engage in self-care and diabetes management.⁷ However there are currently limited diabetes education and services in Australia that are specifically catered towards young adults.

Diabetes education programs and services are crucial as they help to promote the health literacy of people with diabetes.^{8,9} Health literacy is a concept that expands beyond traditional literacy and numeracy skills.¹⁰ Rather, the modern health literacy concept revolves around the ability of individuals to source and understand health-related information, having accompanying skills to act upon such information and having adequate support for self-management either through peer support, support from healthcare professionals or family members.¹⁰ Health literacy is vital for people living with diabetes due to the frequent daily decisions required to effectively manage

their condition beyond the clinical setting.¹¹ Recent research also demonstrates that people with diabetes who have poor health literacy are less motivated to engage in diabetes self-management strategies.¹²

With the unequivocal link between self-management and health literacy, patient empowerment is often discussed in line with health literacy. Healthcare education using empowerment as an underpinning principle involves interactive teaching of strategies towards problem solving while drawing from the needs and experiences of patients.¹¹ As a result, individualised care can be provided by involving patients in building problem-solving skills related to their diabetes care while taking into account their own cultural and psychosocial needs.¹¹

In addition to diabetes education and services, opportunities for young adults to meet peers living with diabetes are also important. Peer support provides emotional, appraisal and informational support to young adults with diabetes as they share experiences of living with diabetes.¹³ It also allows them to explore their feelings, provide and receive encouragement, share problem-solving strategies and obtain help with individual goal setting.¹³ As a result, peer support groups can have a positive impact on young adults' self-efficacy and mental health wellbeing, and may subsequently improve overall diabetes self-management.¹⁴

Age-specific diabetes education and services present an opportunity for young adults with diabetes to develop the knowledge and skills necessary for efficient diabetes self-management as they progress through life transitions. However young adults often find that existing diabetes education programs and services are not relevant to their current needs or circumstances or they are unable to access programs

and services due to logistical barriers such as taking time off work or study.¹⁵ One solution to this is the use of online services. Online platforms allow young adults with diabetes to overcome logistical barriers in accessing diabetes education programs or services while maintaining a sense of anonymity.^{16,17} Therefore, integrating online communication with appropriate support and services is one strategy that could enhance health literacy and an individual's sense of empowerment, self-confidence and motivation to engage in self-care, resulting in improved glycaemic control.^{18, 19}

Exploring the feasibility and usability of an online diabetes program developed specifically for Australian young adults (18 to 35 years) living with T1DM is the major focus of my current research as part of my PhD. The first phase of the project involved conducting semi-structured interviews with young adults with T1DM to explore their experiences and determine their needs when it comes to diabetes education programs and services.

From the interviews, participants discussed experiences that can be described as turning points, which impacted on their diabetes management. Such turning points can be categorised into health-related events such as overcoming a significant health scare, traditional turning points such as starting a family, and meeting other people with diabetes. At the cusp of these turning points, participants described an increase in motivation or a 'readiness to change', empowering them to take charge of their health and their diabetes management. Factors which enabled or prevented participants from a successful transition through a turning point were then identified and described as transitional needs from their experiences. These transitional needs were then categorised into themes and included a lack of awareness around existing services, the need for flexible diabetes services, individualised advice, relevant, timely and credible information, and opportunities for peer support. The majority of participants were also supportive of an online platform to receive and access diabetes-related information and peer support opportunities.

The findings from the first phase informed the development of the online diabetes program, which included a website and a moderated online peer support group. The website includes evidenced-based information on popular topics brought up by participants during the interviews such as diet, exercise, emotional wellbeing and updates on the latest diabetes research and technology developments. Information on the website and linked additional resources were sourced from credible websites such as national and state diabetes organisations, government supported websites and sites underpinned by

professional bodies. Nationally recognised clinical experts within the field of diabetes education reviewed relevant sections of the website to ensure that information was evidence-based and up to date. The online peer support group was created as a closed group on Facebook, a commonly used social media platform. As part of the Facebook group, participants were provided with an opportunity to share experiences and provide and receive motivation, encouragement and support to ease the feelings of isolation in a safe environment. Collectively this program is currently being trialed and evaluated among young adults aged 18-35 years with T1DM over a 12-week period.

From this research, I hope to produce a credible resource for young adults living with T1DM, which will improve their health literacy, promote a sense of empowerment and improve emotional wellbeing, in turn encouraging them to take charge of their own diabetes care and make better informed health related decisions.

In summary, there is a lack of diabetes education and support services that are specifically targeted at young adults within Australia. Diabetes education and support services are crucial in promoting health literacy, which ultimately aims to help individuals effectively self-manage their health through having adequate information, skills and support. As young adults navigate through life transitions, they need ongoing support and education to adapt their diabetes management to their changing lifestyle or circumstance. However, many young adults face barriers to access diabetes education support services. These include logistical barriers such as lack of time, and emotional barriers such as feeling judged by their healthcare professional. As such, young adults are often turning to online sources for diabetes-related information, which may not always be credible. My PhD addresses this gap through the development, trial and evaluation of an online diabetes service tailored to the needs of young adults with T1DM within Australia.

How can you help as a healthcare professional?

While my research aims to address the gap in diabetes education and services for young adults with T1DM, it is only a small part of the puzzle. As healthcare professionals, you play an important role in how young adults transition through their turning point.

Participants often placed a high value in healthcare professionals, despite not regularly accessing clinical services. Through the interviews, participants have shared their mix of positive and negative experiences with healthcare professionals and how it helped or hindered their diabetes management. Based on their collective experiences, here are some things for you to consider in your practice. You will probably find that most of these tips would not apply to just young adults with diabetes but to any client or patient you come across.

1. Practice your active listening skills.
 - a. Ask people with diabetes what they are struggling with in regards to their diabetes management and take time to listen to what they are saying.
 - b. Avoid judgmental language when discussing diabetes. For example, telling a person with diabetes that they need to do better at their diabetes management. Please refer to the position statement on language developed by Diabetes Australia for more detail and suggestions.
2. Encourage patient-centered care within your clinic
 - a. Patient-centered care takes a collaborative approach between healthcare professionals and people with diabetes. Acknowledge that people with diabetes are the experts at what will work for them and their diabetes management. Let them lead the way in devising diabetes management strategies while you guide them with your clinical expertise knowledge.
 - b. Invite clients or patients to bring in information they have found elsewhere, which they would like to discuss with you. Teach them to identify credible websites or information.
 - c. Ask people with diabetes what their current priority is and try to address this before addressing other areas of their diabetes management. If clients or patients are not ready for change, any intervention may not be as effective.
3. Share existing resources and offer to refer them to other services if you feel they need them
 - a. You can help break down the stigma of mental health by talking about it and asking how they're coping.

- b. Don't be afraid to dip your toes into social media to find credible resources such as online support groups you can refer to such as the Australian Diabetes Online Community (#OzDOC) on Twitter.
- c. Talk through any changes you are making to their diabetes management. Take time to explain and help them understand the changes.

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The silent sufferers of diabetes

Leanne Mullan, BN, GradCertDiabM, MBA(Health Management), RN CDE
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My alarm goes off at 3am. It's not a beeping sound nor a response to my three year olds nightmare, it's that panic filled groan followed by the words '...I'm low, I'm low, I'm really low, help me'. I provide reassuring words, make a calm brisk move to the kitchen for some cordial, before heading back to the bedroom to be my husband's saviour. I've done it so many times that responding to a night time hypo can generally be done without opening my eyes, in a habitual zombie like fashion.

I'm married to a man with type 1 diabetes (T1DM) and just quietly, despite being a nurse when we married, I was completely naive about what this actually meant. Little did I know how diabetes would at times churn the waters in our relationship. How could I possibly argue and win against a low blood glucose level? How could I feel disappointed if he didn't feel like eating the meal I'd cooked because his blood glucose level had been high all day? How is it possible that my empathy feels tinged with a little resentment and anger, despite knowing the burden he has to deal with every second of his day? How can I even voice my frustrations, fears and feelings about diabetes, when he is the one carrying the weight of it?

I hate diabetes. I don't have diabetes, but I hate it.

In this lies my passion to validate and support those who journey alongside people with diabetes. Research abounds on how diabetes affects those who have it, yet the challenges faced by those who live with and care for someone with diabetes are not discussed as frequently. I wonder whether this is because we don't want people with diabetes to feel responsible or feel worse about their chronic illness and perhaps that's why when I google search 'my husband has diabetes', the forum world overflows with partners looking for support. There's a secret community of people searching for others like them that might just be able to offer understanding, support and connection.

Recently, some validation has been given those who trek this diabetes mountain with their partners. In the second Diabetes Attitudes, Wishes and Needs (DAWN2) study,¹ the experiences of family members of people with diabetes were studied. Over 2000 people participated in surveys assessing, amongst other topics, the impact that diabetes has on family life. Over a third of all respondent family members

perceived a notable burden of diabetes on the family. Almost 40% had a high level of distress related to concerns about their relative with diabetes. Further, 61.3% of respondents were worried about the risk of hypoglycaemia. The greatest negative effect reported by respondent family members was on emotional wellbeing (44.6%). In addition, an effect of diabetes on relationships was noted in one in five (19.8%) respondents. The study also found that more than one-third (37.1%) of respondents felt frustrated that they didn't know how to best help the person they supported with diabetes, yet fewer than a quarter (23.1%) of family members participated in any diabetes educational programs. The DAWN2 study outlined the need for improved psychosocial support for family members and also the need to encourage family involvement in diabetes education programmes.

Supporting this research, a study on the personal and relationship challenges of adults with T1DM found that anxiety, particularly around hypoglycaemia, and fear regarding future complications weigh heavily on partners of people with T1DM and their relationships.²

Interestingly a study into the impact of continuous glucose monitoring (CGM) on diabetes management and marital relationships of adults with T1DM and their spouses, found that CGM may positively impact marital relationships.³ Participants in this study perceived CGM to positively influence hypoglycaemia management through decreasing spouses' anxiety, vigilance and negative experiences. Further, the use of CGM promoted a collaborative diabetes management effort, increasing spousal understanding of diabetes.

A study published by Johnson and Melton, in which 19 partners of people with T1DM were interviewed, identified numerous challenges in the care giving

of their partner.⁴ The study identified that partners struggle with emotional strain from the fear and distress over diabetes symptoms and complications, resulting in care giver burden.

Polonsky, who has published widely on the topic of diabetes burnout, conducted a study on emotional distress in 317 partners of adults with T1DM.⁵ The results of this study indicate that diabetes distress in T1DM partners is common and is closely associated with hypoglycaemia (64.4% of respondents). Further, partners of those with T1DM reported low levels of diabetes-related support from all sources. From this study a 22-item scale was developed comprising of four factors: Hypoglycemia Distress, Emotional Distress, Management Distress, and Role Distress. All scales were significantly correlated with the three criterion variables - depression, general life stress, and diabetes-related relationship satisfaction.

Following on from this research, The Diabetes Empowerment Foundation designed the 'Partner Diabetes Distress Scale (PDDS).⁶ This screening tool is designed to be utilised in clinical practice to assess the level of hypoglycaemia distress, emotional distress, management distress and role distress experienced by partners of those with diabetes. By using this scale to evaluate the level of distress in diabetes partner relationships, the diabetes team may gain insight on how to problem solve and recommend management strategies that will benefit both couples and entire families by improving quality of life.

There is much literature identifying the crucial role that family members play in optimising diabetes management.^{7,8,9} Given this, and in outlining the above research and resources, I hold hope. Hope that the traditional approach to diabetes education and support will quickly evolve to include and address the needs of the partners of those with diabetes. It's hard work, it's exhausting and in acknowledging the emotional burden on the partners, it is anticipated that our holistic care, support and management of the person with diabetes improves. Perhaps we could begin to incorporate such resources as the PDDS into our practice to address the needs of the relevant partner?

So back to reality... last night he rolled over in bed and his pump cannula fell out. The extreme frustration that emanated from what I would see as a minor inconvenience seemed excessive and although not directed at me, it made me cower. I felt like screaming 'HOLD ON, WAIT A MINUTE, I'm an unwilling participant in this battle!' However, given how much I love this man, I held in my feelings, got up out of bed to retrieve a new cannula and helped him get his pump connected again.

The value of the partner – it cannot be understated. Let's be enthusiastic with our praise, encourage and acknowledge their efforts, whilst supporting them in this diabetes roller-coaster ride.

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Managing diabetes across the lifespan

Trisha Dunning AM,

Chair in Nursing, Centre for Quality and Patient Safety Research

Abstract

Diabetes can be diagnosed at any age. Diabetes can affect the social, psychological and spiritual aspects of a person's being and their attitude to and ability to adapt to the diagnosis of diabetes and to integrate diabetes into their life. The way an individual responds to their diagnosis depends on their age at diagnosis, the type of diabetes they have and the reactions of people in their social environment. These factors can also affect the individual's capacity to undertake their usual life tasks across the various life stages.

Life stages are broadly divided into childhood, adolescence, emerging adulthood, middle age and old age. Key studies show maintaining normoglycaemia, the individuals' relationships, including with health professionals, and resilience are essential to good health outcomes. Health professionals must understand the individual's explanatory framework for diabetes and their interpretation of and need for information. Thus, health professionals must have relevant communication skills as well as knowledge to help individuals and their families manage diabetes through the expected life transitions and other changes in their lives. This paper explores diabetes in the broad context of the five main life stages.

Man [and woman] is not worried by things, but by their ideas about things.

When we meet with difficulties, become anxious or troubled, let us not blame others, but rather ourselves, that is our ideas about things.¹

Introduction

It is essential to adopt a proactive life course approach to diabetes care and education. Cultural, economic and social factors impact on life transitions and health outcomes. Research has established that diabetes complications are present some seven years before diagnosis² and that obesity at age 17 is associated with increased mortality.³ Risk of death at an earlier age is increased if the individual has diabetes complications, especially cardiovascular disease. Renal disease affects medicine choice and safety.

Research has also demonstrated the adverse effects of hyperglycaemia and glucose variability on tissues and organs, and long term outcomes, highlighting the importance of maintaining normoglycaemia to prevent the inflammatory processes that lead to complications.^{4,5,6} The risk of complications increases with duration of diabetes and genetic predisposition.^{4,5} Type 2 diabetes (T2DM) is a progressive disease; consequently management often becomes increasingly complex over time.⁴ The chronic progressive nature of T2DM often becomes apparent and the seemingly never-ending new tasks that need to be mastered commonly emerge as function declines. This can be accompanied by grieving and self-questioning that affect self-concept and the capacity to make a successful transition.

Social and psychological factors influence the way individuals respond to diabetes and the turning points/trigger events and transitions they encounter throughout their lives.⁷ Most people make 10-20 major transitions during their lifetime. The term 'life transitions' refers to predictable changes that are associated with discontinuity with the past and the need to face the world anew.⁸ Significantly, the way the individual responds to the trigger event is more important to making a successful transition than the event itself.⁹ Life transitions are crucial opportunities for personal growth and development and are part of an individual's spiritual journey throughout life.

People's experiences of, and reactions to, life transitions are individual, although there are many commonalities.^{10, 11} Erickson¹⁰ regarded adaptation to a trigger event and the following transition as an outcome of interaction among genetic makeup, culture and social influences (nature and nurture). Social influences expand as the child's world expands. Health professionals become part of an individual's social and cultural networks when they develop diabetes. Support from family and health professionals is only helpful if the individual perceives it to be helpful.

Life transitions

Life transitions are well described in scientific publications as well as in art and literature. For example, ancient Greek and Roman philosophers and healers wrote about seven life stages, the hebdomodal system,¹² but life expectancy was generally shorter than today. Shakespeare described the seven 'ages of man': infant, childhood, lover, soldier, justice, old age, dementia characterised by 'sans everything,' and death.¹³

This paper concerns five key life stages or ages (see Table 1):

1. Childhood
2. Adolescence
3. Emerging Adult (previously young adult)
4. Adult to middle age
5. Old age

Table 1: Main life stages and relevant 'tasks' to be mastered and some considerations when planning diabetes care with the individual and or/their families. Note age ranges are broad and not consecutive. Metabolic targets should be individualised and relevant to the individual's needs, risk profile, quality of life and life expectancy at each life stage.

Life stage	'Tasks' to be achieved	Diabetes care considerations
Childhood Early 0-8 years Middle 8-12 years Diabetes can be diagnosed before the child can manage diabetes self-care.	Learn to control biological functions such as toileting, feeding self. Learn to: » Share » Talk » Socialise By age 8 children usually have a basic understanding of some abstract concepts. Independence slowly increases.	The quality of the child/parent attachment is critical and the quality of the relationship can have lasting effects. Type 1 is the most common diabetes in childhood but type 2 is increasingly being diagnosed in childhood. It is important to manage blood glucose, lipids, and blood pressure to prevent/delay long term diabetes complications by providing timely age appropriate education, healthy diet and activity and glucose lowering medicines. These parameters influence the individual at subsequent life stages that is; the plan for old age should begin when the person is young. Prevent/early management of short term complications: hypoglycaemia as well as hyperglycaemia and associated ketoacidosis or hyperosmolar states in type 2. Relevant general health care such as immunisation. Screening for other immune-related disorders such as coeliac and thyroid disease. Managing mental health. Planned transition of self-care from the parents to the child when relevant.

Life stage	'Tasks' to be achieved	Diabetes care considerations
Adolescence 12-18 years May need to move to adult health services before they have managed traditional adult responsibilities Manage competing demands of school and diabetes as well as contribution to family responsibilities	Many physical and mental changes occur as the individual develops autonomy and their self-concept including their sexual identity and where they fit within their peer group.	Plan the transition to adult care. Help parents support autonomy but remain involved in diabetes care. Non-adherence and risk taking is common. Recognise the importance of peer influence, which can be positive and affirming or negative and have undesirable effects. Consider eating disorders. Plan diabetes self-care with the individual. Provide relevant education about sexual health including contraception, alcohol, and drugs and driving. Plan for the transition to adult care.
Emerging adulthood 18-30 years Manage competing demands of work/university and diabetes as well as contribution to family responsibilities	Develop meaningful relationships.	Help the individual plan how to manage their diabetes self-care as they make key transition such as from paediatric to adult care, leaving home, starting university or a job and pregnancy and childbirth.
Middle age 30-50 years Transition less understood than other transitions	Often called the 'generative stage' because people are contributing to society and having children. Life might begin at 40 but middle age can be a very stressful and emotional transition. Menopause can be stressful for women and erectile dysfunction may occur in men. Both these life events can affect diabetes management and self-concept. Generally the 50s and 60s are more settled.	Planned preparation for menopause and including discussion about HRT. Planned preparation for stopping work, however many people continue working till their older age and/or provide a great deal of voluntary work.
Older age Current focus is on Active Ageing and reablement. Focus is on key concepts such as: » Active ageing » Healthy ageing » Productive ageing Successful ageing defined as low probability of disease, high cognitive and physical performance. ²³ Successful ageing depends on health and wellbeing in the preceding life stages. The 'Baby Boomer' Report ²³ highlighted important issues that will shape aged care services in the future.	Accepting the aging process and often changed physical functioning, which affect mental health and quality of life. Older people need to find a balance between stagnation and continuing generativity and engagement. They often examine their lives in relation to their past and current society.	Chronological age is not a good indicator of functional status or diabetes management needs. Optimise opportunities and help the individual realise their potential and the valuable contribution older people make. Avoid ageist and stigmatising language and attitudes. Normalise ageing rather than medicalising it as something to avoid or prevent. Plan diabetes and general health care with the individual and or carers. Focus on what they can and are prepared to do. Conduct age-specific annual assessments. Conduct regular risks assessments such as hypoglycaemia, medicine-related adverse events, falls and pain ²⁰ Ensure general health checks occur and relevant vaccinations are provided. Plan for palliative and end of life care. Discuss the need for home help or admission to a care home when indicated Ensure family carers are informed and have regular health checks.

Individuals are expected to complete various ‘tasks’ during each stage. They need to learn how to balance the demands of diabetes self-care with leading a ‘normal life.’ The way adults construct their sense of self with diabetes is influenced by past experiences, culture and their general and health beliefs and values. Diabetes can make completing these life tasks challenging. A proactive planned approach can help individuals identify trigger events and manage their diabetes as they move through the relevant life stages. It is important that health professionals understand people’s personal meaning of and explanatory model for diabetes and their life and care goals, values and preferences.

Ancient healers understood the need to plan for life stages during early life, i.e. from childhood, through adopting a healthy lifestyle.¹⁴ Modern research confirms the importance of a healthy lifestyle such as not smoking, eating a balanced diet, partaking in regular physical activity, and managing stress, generally and to mitigate genetic predisposition to diabetes and its complications.¹⁵

Signs a person might be entering or is making a life transition are shown in Table 2. Note that many of these signs are also signs of diabetes distress and depression and can be due to physical and cognitive changes that make transitions and self-care difficult.

Table 2: Indications that a person might be encountering a turning point/trigger event or is in a transition.^{25, 26} These transitions need to be considered in the individual’s social context and life span.

Mood changes, disinterest, unhappy, distressed, depressed
Discontent with current situation
Changed interest in things the person usually enjoys such as hobbies
Alcohol and other substance abuse
Not performing usual diabetes self-care e.g. not adhering to medicines or monitoring blood glucose and not keeping appointments
Frequent hyperglycaemia and/or hypoglycaemia
Change in functional and/or cognitive status
Development or exacerbation of a diabetes complication or other comorbidity
Falling in older people

Helping people with diabetes manage transitions

A key aspect of managing diabetes and dealing with life and diabetes-related turning points and transitions is for health professionals to consider and ask about these issues as part of a comprehensive assessment. It is important to consider the diabetes disease trajectory in the context of the person’s life stage. Helping the individual achieve social coherence and build resilience are important care strategies. Other strategies include:

- Following guideline recommendations for managing blood glucose, lipids, blood pressure and complication screening relevant to the life stage. For example, International Society for Paediatric and Adolescent Diabetes,¹⁶ Australian Diabetes in Pregnancy Study Group,¹⁷ Diabetes Australia/Royal Australian College of General Practice 2016-18,¹⁸ American Diabetes Association,^{19, 20} The McKellar Guidelines²¹ and Guidelines for Managing Diabetes at the End of Life.²²
- Pharmacovigilance to ensure medicines are safe and likely to be effective according to the individual’s health status and life expectancy.
- Monitoring the person’s life stage as part of the annual cycle of care to proactively plan for subsequent turning points and life transitions.
- Ensuring general health care needs are addressed as well as diabetes care needs.
- Using teaching/communication strategies that suit the individual’s learning style, health literacy and numeracy, age and information needs.
- Ensuring people know how to recognise and seek help for the conditions that can present with atypical symptoms as the duration of diabetes increases, for example hypoglycaemia, myocardial infarction and infections.
- Helping the person map expected life transitions and proactively plan for these expected transitions.
- Helping them learn how to recognise turning points/trigger events and encourage them to use their experiences to solve problems.
- Helping the person reflect on their personal capabilities and ways to develop skills and/or seek help when needed.

- Ensuring family carers are supported and their health status is monitored, especially older family carers.
- Actively listening and showing empathy and understanding.

Summary

Diabetes management and self-care occurs within complex social and psychological relationships with family, peers and health professionals and within expected life transitions. Health professionals can help people with diabetes and their families prepare for expected life transitions and the changes they bring by proactively considering expected life transitions as part of the diabetes monitoring and management plan.

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Knowledge gaps surrounding insulin use in adults with type 2 diabetes

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Abstract

B **ackground:** Approximately 60 000 Victorian adults use insulin to manage their type 2 diabetes (T2DM), and this number is increasing. Based on enquiries to the Diabetes Victoria Helpline during 2015, many people with T2DM appear to have knowledge gaps around insulin use, particularly in regard to out-of-target glycaemia, carbohydrate intake, illness, exercise and travel.

Aim: To explore insulin-related knowledge and behaviours of adults with T2DM using insulin in order to inform future development of diabetes self-management education programs for this cohort.

Methods: In 2015, Diabetes Victoria members were invited to complete an online survey asking about their insulin use and self-management practices.

Results: A total of 219 people completed the survey: 61% male and 39% female. The mean age was 67 years (range 29-91), 71% had T2DM for more than 10 years and 43% had used insulin for more than 5 years. Findings from the survey showed that whilst 75% of respondents stated they changed their insulin dose for high blood glucose levels (BGLs), only 57% made adjustments for low BGLs. However, 76% of respondents did not have a clear understanding of why their BGLs were high, and 51% could not explain what might have contributed to their low BGLs. Less than half of the respondents stated they adjusted their insulin according to what they were eating (39%) or when they exercised (37%).

The survey findings also show that people with T2DM appear more concerned about high BGLs (70%) than low BGLs (47%). Over half of respondents were also worried about weight gain whilst on insulin. More than 70% of respondents expressed an interest in participating in workshops to learn more about insulin use.

Conclusion: Our findings suggest that people with T2DM who require insulin need specific information and support in regards to insulin and self-management of their diabetes. The responses indicated people were less worried about low BGLs, which is concerning given long-term insulin use increases the risk of severe hypoglycaemia. This suggests that clinicians may need to focus more on managing and minimising hypoglycaemia in this cohort. The findings also demonstrate the need to develop and pilot a structured self-management program for people with T2DM using insulin.

Introduction

According to the National Diabetes Services Scheme (NDSS) database, there are about 255 000 Australians adults with T2DM who use insulin.¹ In Victoria, about 60 000 or 23% of adults living with T2DM use insulin therapy. Over the past 4 years, the greatest increase in insulin users has been people with T2DM aged 60-89. This cohort increased by 29 000 people and now make up 56% of all people with T2DM using insulin.¹

In 2015, more than 3100 members of the general public, including health professionals, contacted the Diabetes Victoria Helpline to speak with a dietitian, diabetes educator or advocacy officer. Anecdotally, when callers with T2DM enquired about insulin use, they were often unsure how to manage out-of-target

BGLs due to food, exercise, illness and infections, travel, missed insulin doses, or what to do when they accidentally took too much insulin.

Previously, the MILES study reported that adults with T2DM who use insulin had poorer overall health compared to adults with type 1 diabetes (T1DM).² They were more likely to experience moderate to severe levels of anxiety and depression, compared to those with T2DM who do not use insulin and to those with T1DM. This cohort was least satisfied with relationships, personal safety and standards of living. They also self-rated experiencing more symptoms of diabetes and reported feeling less in control of their condition compared to those with T1DM or to those with T2DM not using insulin.

Due to the increasing incidence and poorer health outcomes within this cohort, there is an obvious need to provide better diabetes self-management information and support to people with T2DM on insulin. Guided by the topics raised by callers to the Diabetes Victoria Helpline, we conducted an explorative survey which aimed to investigate the insulin knowledge and behaviours in this cohort.

Methods

An invitation to participate in an online survey was promoted to Diabetes Victoria members through our November 2015 Membership newsletter. The survey questions were developed based on the domains identified from the Helpline enquiries, and participation was voluntary.

Results

The respondents

Out of 242 respondents with T2DM, 219 (or 91%) used insulin, and their responses are presented in this paper. Of these 219 respondents, 43% had been using insulin for more than 5 years.

Respondents identified General Practitioners (58%), Endocrinologists (56%) and Diabetes Educators (38%) as the main healthcare professionals who helped them manage their insulin doses. A small group of respondents nominated other health professionals, such as the practice nurse, dietitian and other medical specialists (15%) whilst 8% reported that no-one helped them with adjusting their insulin doses.

BGL adjustments and concerns

Respondents were asked about their insulin use and when they would make changes to their insulin dose. The different situations where respondents stated they would adjust their insulin doses included:

- 75% when having high BGLs
- 57% when having low BGLs
- 39% when eating different foods
- 37% when exercising
- 22% when travelling

Despite the highest number of insulin changes made for above target BGLs, 76% of respondents could not explain why their BGLs were high, and 51% of respondents could not explain why their BGLs were low.

In addition, 70% of respondents stated they were worried about having high BGLs and 47% stated they were worried about having low BGLs.

How carbohydrates affect BGLs

Respondents were asked about their knowledge regarding carbohydrates and the effects on BGLs, and what education they had received in the past. The survey findings showed that:

- 74% were aware that carbohydrates affect BGLs
- 54% of respondents felt they had a good understanding of how carbohydrates affect BGLs
- 44% reported having been taught how to count carbohydrates
- 36% of respondents reported being taught how to spread their carbohydrates across the day
- 26% reported being taught the quantity of carbohydrates to consume per day

Exercise, weight gain and insulin

A good understanding of how exercise affects BGLs was reported by 44% of respondents, however, only 25% of respondents stated they would like to exercise but were worried about low BGLs as a result of exercise. In addition to this, 59% of respondents were also worried about insulin causing weight gain.

Learning more about insulin in different situations

Respondents showed an interest in participating in education on the following:

- 71% thought it would be useful to attend a workshop to learn more about how insulin works for different situations
- 85% wanted to learn more about how food and insulin affected their BGLs

- 72% wanted to learn more about how to manage their insulin with exercise
- 71% wanted to learn more about managing insulin while travelling
- 84% wanted research updates on the above areas

Discussion

There are core areas of diabetes self-management education that are important for people with T2DM. Calls to the Diabetes Victoria Helpline indicated that people with T2DM who progress to insulin treatment may need more comprehensive education to manage the complexities of insulin treatment, particularly in the areas of out-of-target glycaemia, carbohydrate intake, illness, exercise and travel.

The findings from our member survey have identified gaps in knowledge and opportunities for specific targeted education for this cohort.

Insulin adjustments and low BGLs

Interestingly, 75% of adults living with T2DM reported making insulin adjustments for high BGLs whereas 57% reported making insulin adjustments due to low BGLs. Respondents were also less worried about low BGLs compared to high BGLs. Whilst we acknowledge that above-target BGLs increase the risk of various complications, under-target BGLs and hypoglycaemia confer other risks. Hypoglycaemia increases overall mortality and morbidity. The increased risk of cardiovascular events, cardiac arrhythmia, cognitive decline and dementia are well documented.³⁻⁶

Regardless of age, adults with T2DM are more likely to experience hypoglycaemia with a longer duration of diabetes diagnosis or insulin use.⁷ They are also more likely to experience severe hypoglycaemia^{7,8} or have impairment of hypoglycaemia awareness (IAH).^{9,10} Current standards of care recommend avoiding hypoglycaemia, especially in the older population, due to higher risk of falls or poorer memory.⁶ Our findings suggest that this population needs more education to understand the potential risks of hypoglycaemia and address the causes.

Only 25% of respondents indicated being concerned about hypoglycaemia and physical activity. This may indicate that the risk of low BGLs did not discourage people from being physically active, however as we did not ask participants to report their current levels of physical activity and other barriers to this, we are unable to draw this conclusion.

Respondents and their healthcare professionals

Our findings concur with those of The MILES study, which identified that people living with T2DM accessed their General Practitioner the most, followed by their Endocrinologist and Diabetes Educator for diabetes management.² It is encouraging that respondents in our study also report that they access their healthcare professionals for insulin dose advice.

Interpretations and practice implications

Our survey findings indicate that people with insulin-requiring T2DM appear to have limited knowledge about insulin use and related topics, and are keen to learn more. It is very important for all clinicians to routinely discuss all aspects of managing diabetes with insulin. It is also critical that clinicians discuss information about hypoglycaemia, as this was identified as a particular area of concern and gap in knowledge. This education has particular benefits for those who are older, in helping them optimise safety, improve quality of life and preserve independence.

We suggest that a structured education program for adults living with T2DM who use insulin could provide a consistent method of addressing these knowledge gaps. A standardised approach would address hypoglycaemia, insulin adjustment, carbohydrates, exercise and travel.

Limitations and opportunities for further research

This study has highlighted many areas worthy of further investigation, but our survey questions were not specific enough to identify detailed management areas and more complex needs. In particular, our questions about high and low BGLs could not identify whether respondents retrospectively or proactively managed out-of-target BGLs, what actions were taken to help prevent repeat occurrences, and whether such actions involved insulin adjustment or not. Also, knowing more details surrounding physical activity, such as duration and intensity, may be useful to help ascertain if respondents planned for exercise by reducing insulin and / or increasing carbohydrates, before, during or after activity.

A further limitation is that all knowledge-related questions relied on self-report. We were unable to actually assess level of knowledge, for example in relation to impact of carbohydrates or exercise. Focus groups or further surveys may help clarify such needs and identify attitudes around insulin use in adults with T2DM.

Conclusion

Our findings suggest that there are knowledge gaps around insulin use and self-management for people with T2DM requiring insulin, including long-term insulin users. This demonstrates the need to develop and pilot a structured self-management program for people with T2DM who are using insulin.

Given that long-term insulin use increases the risk of severe hypoglycaemia, it was concerning to identify the proportion of respondents less worried about low BGLs than high BGLs. We encourage clinicians to emphasise the importance of managing and minimising hypoglycaemia to clients with insulin-treated T2DM. This should also be a core component of diabetes self-management education in this cohort.

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Back to school

▶ Rachel Ward, BSc, PhD (USyd)

January is a trip to the uniform and shoe shop, check of school bags and the tricky task of matching lunch box containers with lids.

February is a time to squeeze once barefoot little feet into socks and shoes, zip bronzed little bodies into oversized dresses or button-up regulation grey shirts and tame unruly hair.

March is the first school interview to chat about how your child is settling into the new classroom and school routine.

Throw type 1 diabetes (T1DM) into the mix, and preparations, or rather negotiations, begin the year before. I will admit up front that the need for early planning can stem from a parents' anxiety. Facing the uncertainty of school life is a very daunting prospect after more than three years of being safely at home with our child or well supported by our preschool. It exposes the not too distant emotions of fear and worry we had leaving hospital after diagnosis, and the ready exhaustion from having just navigated the diabetes system to match it with the education maze. If only we knew what to expect, when to expect it and what we need to do to give our children the best chance of a smooth time at school.

Our experience at preschool provided a great learning curve. It began by my challenging the eligibility of our child with T1DM to receive additional funding for an extra educator in the classroom. Diabetes is 'just dietary' I was told but being on the preschool committee and having a friend who used to be a preschool director meant I knew that funding was indeed possible. A lengthy internet search, a few phone calls and some paperwork later and I had unwittingly taken my first step on the education advocacy pathway. Annual provision of an information and conversation session by a diabetes educator provided a fantastic platform for open communication between the preschool and our family that continued to develop throughout the whole preschool experience. All of this meant our child (and we) thrived at preschool.

Getting informed

In preparation of our child transitioning to school life I began to read the education department website

only to be startled by the outdated and rabbit warren of information. The uncertainty I was feeling was confirmed as I remained unsure of who does what and when things should happen. When imploring the education department to remedy this issue I was pleased to learn that extensive efforts were being made to review the content and user experience of the website. Schools also welcome a representative from a students' health care team to provide specific education for a health condition that extends upon basic first aid training. There is an assumption that everyone knows this and that it is done, although this is not typically the case.

Our child starting school has also coincided with a fairly volatile diabetes landscape. Our regional Diabetes NSW outlet has closed and Medicare Local has rebadged itself as Primary Health Network thereby removing the two sources of Diabetes Educators that previously provided annual education to preschools and schools in our region. Replacement has been in the form of a webinar and teacher seminars offered mostly in metropolitan areas (Diabetes NSW) and a list of recommended Diabetes Educators (PHN). Local Health Districts could fulfil this gap although NSW Ministry of Health have no policy on this, believing that availability of diabetes educators is determined at a local level and lies under the responsibility of the education department. This means that diabetes education in schools is inconsistent across the state, sometimes provided by a private diabetes educator or not at all. Each option is at odds with the overall objective for health providers to reach and deliver a consistent message to the whole population and the shift towards person-focused care. These outcomes also contradict the desire of preschools and schools to host a representative of the

children's health care team to provide school diabetes education. Again families are left to figure this out and negotiate terms between health and education providers.

Building rapport and routine

Whoever I talk to or whatever I read on the subject, parents are regularly advised that it is crucial for families to develop a good rapport with the school and in particular the classroom teacher. For the sake of diplomacy we can tend to compromise our expectations for safe and good health. We can hesitantly send our kids off to school with a higher than wanted blood glucose level, put careers on hold as we fill the gaps left by the system and hope everything will be ok. So when families raise their voice to negotiate or express concern it is with great trepidation, for fear that we will challenge our immediate relationships. Often this need for assertiveness is not a natural trait and we become overwhelmed by the immensity of the situation. Feedback to those developing policy or documentation is inevitably limited, borne of frustration and of anecdotal nature with the risk that resources developed might miss the actual needs of the T1DM school community. Anecdotes are unlikely to capture the full story, just as my opinion is only one of many that needs to be captured.

As a child is settled into their learning environment and routines are set we are told that everything should be alright. The task of getting settled is not trivial and each family has vastly different experiences based on the barriers they encounter. Establishment of a good system depends on a child's school and health district, the importance and interpretation of various documentation, how proactive the child's parents are and if they have time and skills to help establish and monitor the routines at school. This generalised list of real life barriers can potentially expose children, in their formative years, to the risk of T1DM mismanagement.

Trouble with starting from scratch

No one wants a child to be at risk. The unifying goal of parents, schools and health providers alike is to support children to become young adults who have the confidence and skills to be healthy, capable, critical thinkers. We should all be on the same team, cheering along the next generation. Yet it seems the needs of the child can be secondary and lost to the big picture

debate about who is responsible for what and who pays for it. Individualised (school-speak) or person focused care (health-speak) is fine as long as it comes with a common framework. Without the collective experience and knowledge of families, diabetes educators and schools being distilled into a workable framework we can be sure that mistakes, confusion and duplicity occur.

To give an example, a health care plan is the central document for schools to follow but, depending on the source of information, the task to write an individualised plan can fall to the parent, health care team or school. To some a health care plan is the document placed on the office wall, to others it is a longer document capturing details such as the right to carry a blood glucose monitor or go to the bathroom. When I attempted to create an emergency (or action) health plan based on 4 or so alternative templates sourced from diabetes organisations I managed to miss key hypo symptoms. This experience fortified in my mind the danger and exhaustion of drafting critical health documents from scratch.

Worst of all, the absolute worst, is that children observe all of these negotiations, frustrations and anguish. Even though I am incredibly protective of my children by having phone conversations out of earshot, waking at 5 am to send emails before they wake, and organising play-dates while I attend meetings, they still know what I am up to. If I chat to a teacher I am questioned if it is about diabetes, if there is a staff meeting it is assumed it is about diabetes. If I pause for too long while I gain the strength for another round of assertive conversation, I become fearful that I will lose my capacity and confidence to be a good role model for my children knowing one day I will be passing the advocacy baton to my children.

Awkwardly stuck in the middle

Until children can self-manage and self-advocate without fear of burnout, families have no choice but to be proactive and be parent-advocates. Yet families are not represented in this conversation. Careers have been put on hold with full time work replaced by part-time or no work at all. The cost and sick leave used to attend a multitude of appointments with general practitioners, diabetes educators and schools – many duplicated as we try and negotiate and learn the same things learnt by many families before us. Families anguish as we try to liaise with anyone we can to create the best outcomes we can, thinking all along that it should be easier - it must be easier. Just thinking about it is exhausting and when I multiply

that with 4000+ families in NSW alone it is the mind-numbingly, unnecessary drain on all resources that mean these issues deserve a good, integrated long term solution.

So what do I think would make it easier?

Assurance that all children have access to a similar level of support regardless of who their parents are, which school they go to or where they live. Families need to know exactly what to expect from the time my child sets foot on school grounds until they leave.

Ultimately it is the child and parent who are the conduit and courier of documents between the school and health care team. We need advanced knowledge about the landscape of funding, documentation requirements and timing, school timetable and associated challenges and the practicalities of daily life at school. We need to be able to actually use the resources developed.

When I look up anything to do with T1DM in schools I would like to see three common documents, written with a common terminology and endorsed by all relevant agencies within a state (let's tackle national level another day!). Just one policy and three documents. The policy should provide practical details of the roles and responsibilities of the child, parent/carer, classroom teacher, aide, principal, diabetes educator and other health care provider and be inclusive of any memo of understanding between agencies. The working documents should be a single page emergency plan and a detailed health care plan that can be modified to be fit for the child and school setting. There should be no duplicity, ambiguity or inconsistency across the documents. Just a common, seamless, transparent framework for all tiers of health, education and families to use.

How do I think we achieve this?

Stop working in silos with the distraction of jurisdiction, ideals, power and priorities. Start focusing on the child and mounting independent evidence about what actually happens, what works and doesn't work. Then use this information to develop and execute long term solutions. Recognise the current reality that the child and their families ultimately facilitate negotiations, understand the health requirements and pace of their child's health literacy and fill the gaps left between education and health by engaging their expertise.

What do I think is the role of a CDE in the school environment?

Firstly recognise the amazing knowledge and independence you can bring to the local school setting, and to a broader dialogue. Diabetes educators are in a unique and powerful position to keep our kids safe in school, develop good habits to keep for a lifetime.

In the short term, at a local level:

- You can be the objective voice of families.
- You can organise with your local schools (and possibly supervisors) to provide annual education.
- You can overcome local health-education negotiations to create emergency and health care plan templates for each school in your area.
- You can conduct an audit of schools to ensure that students with T1DM have the appropriate procedures and practical infrastructure in place. This will save duplication of efforts for you and your families.
- You can advise families on processes in your state, and offer resources.

In the medium term, at a state or national level:

- You can contribute to the broader discussion.
- You can gather the necessary evidence to develop recommendations for your area, be it metro, regional or remote, and perhaps a high or low socio economic region.
- You can initiate a research project to uncover best practices to support children with T1DM in schools.

Rachelle Ward is just a mum wanting the best for her children. She was the recipient of the 2016 JDRF NSW Volunteer of the Year and is a consumer representative on MESAC.

Brett Fenton

After 2.5 years on the ADEA Board, Brett Fenton was elected as ADEA's new Vice President.

In this edition we talk with Brett about his new role and his career aspirations.



Q. What made you join the ADEA Board?

A. I wanted to contribute to my professional peak body and learn something along the way. I also wanted to be involved in strategic decision making and planning. The board training has been fantastic and has helped to improve my leadership skills.

Q. What is your role on the Board?

A. Vice President. The Vice President creates the board reports after each meeting and chairs the Complaints Committee.

Q. What is your vision for ADEA during your term as the new Vice President?

A. I'd like to see ADEA to become one of the leading organisations in diabetes education, research and management and that in Australia people with diabetes will receive high quality, timely and accessible diabetes education.

Q. What do you do in your professional life outside your role on the board?

A. I am the Manager of the Diabetes Service at Central Coast Local Health District and I do some private practice work commencing people on insulin pump therapy on weekends.

Q. What sparked your interest in diabetes education?

A. I became interested in diabetes education after helping out at some camps for children with type 1

diabetes (T1DM). I also have T1DM so I guess that provides additional motivation to want to know more about diabetes education and management.

Q. What is something new in diabetes education that is taking your interest at the moment?

A. The work that is being done to develop an artificial pancreas is of great personal and professional interest. This would obviously change so many people's lives.

Q. What is your favourite quote?

A. I know this is not very inspirational but I think "Keep it simple stupid". KISS is very relevant to our work as Diabetes Educators. Diabetes can be so complicated, there is so much information out there and we are often pushed for time, so we need to simplify things for the people and make it easy to understand. I also like "KISS" Keep Insulin Safe and Simple.

Q. Is there anything else you would like to add?

A. I think that one of the biggest challenges we face is staying united as a group of Diabetes Educators. We have a large group of members from different primary disciplines, working in different workplaces, and as a result there is a risk of separation. We need to continue to work together, support each other and enhance communication as a multidisciplinary association. I would encourage members to seek out opportunities to support ADEA whether that's through joining your state branch or program organising committee or a special interest group, and of course the ADEA board.

The Northern Territory Diabetes in Pregnancy Partnership: Improving models of care in remote Australia

Cherie Whitbread, BNursing, Grad. Dip Diab. Ed, MPH, MHSc.(Nurse Practitioner), Credentialed Diabetes Educator, Royal Darwin Hospital, NT, Coordinator NT & FNO Diabetes in Pregnancy Partnership, Menzies School of Health Research, NT

Renae Kirkham, BA(Psych Hon), PhD, Senior Research Officer, Menzies School of Health Research, NT

Evelyn Cheng, MBBS, GP Registrar in Training, Royal Darwin Hospital, NT

Elleni Thorbjornsen, B(Nut. Diet), Nutrition Educator (APD), Healthy Living NT

Louise Maple-Brown, MBBS, FRACP, PhD, Principle Research Fellow, Menzies School of Health Research, NT, Head of Unit, Department of Endocrinology, Royal Darwin Hospital, NT

Diabetes in Pregnancy in the Northern Territory

Diabetes in pregnancy (DIP) poses a number of serious health risks for women and their babies, including developing chronic diseases later in life.¹⁻⁴ The relative risk of developing type 2 diabetes (T2DM) following gestational diabetes mellitus (GDM) is more than seven fold higher than women with normal glucose levels in pregnancy.⁵ However the prevalence of progression from GDM to T2DM has been found to vary depending on a number of factors including population demographics, diagnostic criteria and time since delivery.⁶ The intergenerational impacts of DIP include an increased risk of T2DM and obesity in the offspring at a younger age.^{7, 8}

In Australia the prevalence of DIP among Aboriginal women is disproportionately higher than among non-Aboriginal women (10 times the rate of pre-existing diabetes; and 1.5 times the rate of GDM respectively) (9). In the Northern Territory (NT), rates are also higher among the Aboriginal populations (pre-existing diabetes; 4.1% V 0.6%, gestational diabetes; 15.7% V 10.1%).¹⁰ The high rates of pre-existing T2DM in pregnancy among Aboriginal women can likely be attributed to the younger age of onset of T2DM in this population.^{11, 12} Specifically, rates of T2DM among Aboriginal people under 17 years in Western Australia are four times greater than for the non-Aboriginal population.¹³

Lifestyle factors such as obesity and poor diet also contribute to the onset of diabetes, while smoking contributes to complications of diabetes.¹⁴ Smoking rates among the Aboriginal population in the NT

are the highest in Australia. In 2013, of NT mothers who reported smoking during the first 20 weeks of pregnancy, 52% were Aboriginal and 10% non-Aboriginal.¹⁵ Rates of obesity (29%) and overweight (35%) in NT are aligned with national rates.¹⁶

The management of diabetes-related risks

among this high risk NT population pose significant challenges for health professionals and service delivery providers. These challenges include remoteness, food insecurity, socio-economic disadvantage, lack of infra-structure and varying health literacy levels. Food insecurity is one of the confounding factors associated with remoteness. It includes limited access to affordable fresh foods, and socio-economic disadvantage. The relationship

between socio-economic factors and food purchasing patterns has been reported in local studies in remote regions of the NT. Most foods in remote areas cost more than in urban locations and there are disparities in affordability between healthy fresh foods (fruit, vegetables, lean meats and seafood) and energy dense foods (such as sugar-sweetened carbonated beverages and white bread). Consequently, people with low-incomes tend to make high energy dense food choices.¹⁷ Food insecurity can impact on attempts to achieve optimal glycaemic control, as many women only eat one meal a day and have a diet that has low nutritional value whilst being energy dense.¹⁸

Challenges faced: the NT context

The NT context makes it a unique and challenging place to deliver health care. Despite being the third largest state or territory in Australia, it is the least populated and the reported prevalence of diabetes is double in remote locations compared to major cities. Health service delivery in the NT has been structured to overcome the risks associated with remoteness by the strengthening of primary health care services across all NT regions. Primary health care clinics in the NT are managed by Aboriginal Community Controlled Health Organisations or the NT Department of Health. In addition there are three small regional hospitals and two larger hospitals, one in Alice Springs and one in Darwin. Availability of an experienced workforce remains a significant challenge in remote Australia. For example, health professionals working in the remote context of the NT who have limited training in DIP, report that they lack confidence in providing DIP education and nutrition education for women.¹⁹

Current DIP care

Women who live in urban centres have access to specialist services such as endocrinologists, diabetes educators, dietitians, obstetricians and midwives, in addition to strong primary health care services and Aboriginal Health Practitioners (AHP). In remote areas access to specialist care is limited. In some locations care is provided by remote area medical practitioners, nurses, midwives and AHP's, but in other areas women are required to travel to access specialist care.

For urban Darwin women, access to diabetes in pregnancy care is provided through a weekly multi-disciplinary clinic at the Royal Darwin Hospital (RDH). Women diagnosed with gestational diabetes are referred to diabetes educators and dietitians at

Healthy Living NT (HLNT) for education sessions. Those with pre-existing diabetes access the dietitian services at HLNT when required, but are managed through the RDH multi-disciplinary clinic.

In contrast, in remote settings specialist services are provided through intermittent site visits. Midwives and remote medical practitioners are at times located in remote centres or visit regularly. Otherwise women living in these areas are required to leave their communities for specialist care. This has a number of undesirable consequences, including separation from family for extended periods of time. Travel, at times lengthy, uncomfortable and at the expense of the health system, is a challenge for women and health professionals. Furthermore, the transition between primary and hospital-based health care can be compromised by poor communication and high staff turnover.

The transition of women between remote clinics and hospital visits/admissions has been identified as a risk to continuity of care and effective management. In Darwin, the Midwifery Group Practice (MGP) manages this transition for women from a number of remote communities (not all). Midwives take a pro-active role in this model of continuity of care. They attend hospital visits with the woman and, clearly communicate the woman's transition between tertiary and primary services.

One example of a very successful model of care that aimed to overcome the challenge of remoteness was developed at Alice Springs Hospital approximately 10 years ago under the guidance of Glynis Dent (Credentialled Diabetes Educator). The Diabetes Antenatal Care and Education (DANCE) Clinic is a multi-disciplinary clinic held each Wednesday offering a virtual or clinic review with the woman and all relevant health professionals across Central Australia. Blood glucose levels are faxed to specialists the day before clinic and advice provided.

The NT DIP Partnership: Responding to the diabetes epidemic in a challenging context

The NT DIP Partnership was established in 2011 to address the challenges specific to the NT and improve care for women with diabetes in pregnancy in the NT. The partnership includes representation by clinicians, researchers and policy makers from the NT Department of Health, Menzies School of Health Research, Baker IDI, AMSANT (Aboriginal Medical

Services Alliance of the NT) and HLNT. It has adopted a multi-faceted approach to improve diabetes outcomes in the NT. This involves three main arms: models of care; the establishment of a clinical register (for epidemiological and quality assurance purposes); and a longitudinal research project (Pregnancy and Neonatal Diabetes Outcomes in Remote Australia). See Menzies School of Health Research for further information (http://www.menzies.edu.au//page/Research/Projects/Diabetes/The_Northern_Territory_Diabetes_in_Pregnancy_Partnership_Project/). This manuscript describes how the work of the Partnership has evolved over the past five years to improve models of care for DIP in the challenging context of remote Australia.

The NT DIP Partnership has worked closely with a broad selection of stakeholders (health professionals, researchers, policy makers) from government and non-government health services across the NT to facilitate the translation of evidence based practice into a variety of settings within the models of care arm of the partnership. Meetings are regularly held with stakeholders (including health professionals), health system gaps and challenges continually identified, and strategies developed to improve models of care. This has included the design of interventions to improve access to health care and to improve the capacity of health professionals to appropriately manage delivery of care in their setting. The NT DIP Partnership has since expanded to include the post-partum and inter-pregnancy periods, as well as expanded geographically, to commence similar work in Far North Queensland.

In initial meetings, patient-journey modelling was undertaken to gain an understanding of current practices across the NT. A number of differences between care provided to women in urban and remote locations were identified (as described above). Furthermore, these meetings highlighted evidence-practice gaps which encouraged efforts to increase health professional's awareness of the risks of diabetes in pregnancy and the need for and benefits of early screening with an oral glucose tolerance test.

The NT DIP Partnership has since driven a number of changes to models of care. For example, to avoid issues associated with travel and continuity of care, multi-disciplinary telehealth clinics commenced in 2014 to enable women to receive the appropriate level of care whilst remaining in community. The telehealth clinics also provided support to health professionals working in remote areas, as well as an opportunity for upskilling. Another change to care was made after it was identified that timing of the RDH clinic (Friday afternoon) was a barrier to continuity of care for women. Often women were unable to travel back to

community after review and needed to stay a further two days (over the weekend) in Darwin. Through the commitment of stakeholders involved in the Partnership, the clinic was moved to a more suitable day that facilitated continuity of care and allowed women to return to community in a timely manner.

In order to encourage self-management, the NT DIP Partnership facilitated the provision of glucose monitors to all women with diabetes in pregnancy across the NT (at no cost to the woman). Remote women were also provided with test strips at no cost. Access to these resources has resulted in health professionals teaching women how to monitor and enhancing knowledge around the relevance of blood glucose profiles to appropriate management.

The NT DIP Partnership has facilitated educational activities for health professionals to enhance skills and knowledge relevant to appropriate management of women with DIP. During education sessions, discussions have focused on the evidence associated with the management of diabetes in pregnancy and how it translates in the workplace.

One of the challenges frequently raised in stakeholder meetings and education sessions was the lack of access to dietitians and nutritional resources to assist health professionals working with women with DIP. In response, a session facilitated by dietitians was included in educational activities and the NT Department of Health Nutrition and Physical Activity Strategy Unit allocated funds to develop an educational resource. The NT DIP Partnership worked collaboratively with the working group (including dietitians, AHP's, diabetes educators, midwives and remote medical practitioners) to develop a resource that health professionals could use to discuss nutrition and diabetes in pregnancy with women. It also provided some practical information regarding blood glucose monitoring and medications. Whilst the resource was the outcome of the working group, it also facilitated good working relationships between health professionals from a variety of settings.

To support changes in practice the NT DIP Partnership has also worked with clinicians to develop local clinical guidelines. This includes diagnostic criteria for the diagnosis of GDM and targets for women who are self-blood glucose monitoring, in line with recommendations from Australasian Diabetes in Pregnancy Society (ADIPS).

An evaluation of the Partnership is planned and will involve several elements, including the measurement of clinical outcomes from the Clinical Register and assessment of the impact of the changes on models of care. Specifically, a process evaluation will be

undertaken using both qualitative and quantitative methodologies. Quantitative methods will be employed to analyse health outcome data using the NT DIP Clinical Register, aligned with time-points before and after changes to models of care. Qualitative methodologies will be used to undertake a series of in-depth interviews and focus groups with key stakeholders (including women with DIP, their families and health professionals) to identify contextual issues impacting access to care and health outcomes. Findings will inform future interventions at the health system and individual level.

Conclusion

To address the challenges of delivering care in the NT, the NT DIP Partnership has worked to enhance knowledge around the prevalence of diabetes in pregnancy in the NT and facilitated improvements to models of care. While much of the early work undertaken by the NT DIP Partnership has concentrated on pregnancy, further work will focus on the inter-pregnancy interval with the aim of improving maternal health for women through enhanced models of care across the post-partum and pre-conception periods. Future work is committed to continuing improvements to communication and care-coordination, identifying ways to increase opportunities for staff education and promoting the sustainability of the workforce, and identifying issues relevant to women and their families. This will include a formal evaluation of the Partnership.

Acknowledgements

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New CDEs

Congratulations to the following ADEA members who have recently achieved CDE status, up to 9 March 2017

Gabriela Abrahamson	Antonio Khalil
Kylie Andersen	Pak Kwan Chan
Maree Archer	Carol Lemezs
Eva Ash	Jinyang Lin
Sharon Atkinson-Briggs	Sarah Lindsey
Patricia Baker	Phillipa Low
Andrea Bills	Danielle Marx
Karen Brewster-Kemp	Erin Merks
Sharron Calgaret	Sheryl Moore
Sharon Chambers Blair	Belinda Moore
Daina Coenen	Susan Murray
Sandra Cryer	Rebecca Payne
Thi Do	Sven Pohlsen
Ainsley Doak	Richard Price
Clarissa Dymond	Melanie Pugh
Cherryl Eley	Galina Shapiro
Amber Evans	Daniela Smout
Georgina Faulkner	Casey Thompson
Clare Gartland	Coralie Thomson
Lisa Gibson	Julie Timmers
Glenys Graham	Carolyn Walker
Joanne Hardy	Caroline Webster
Alana Hayes	Sharon Wilesmith
Adham Hnaidi	Ellen Wilson
Amy Horvath	Nicola Witney
Sabrina Imran	Karen Yardley
Mary John Thomas	

Diabetes-Specific Discharge Planning for Older People with Diabetes

2016 ADS ADEA Workshop Summary Report

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Background to the workshop

In Australia in 2014-15 there were 10.2 million hospitalisations, 41% were for people aged 65 and older and 8.9% were directly attributed to diabetes.¹ Older people with diabetes (OPWD) admitted to hospital are at increased risk of re-admission, glucose instability, loss of independence and death. Furthermore, diabetes is associated with increased risk of potentially avoidable hospitalisations and readmission.^{2,3,4} Discharge from the acute to community or other care setting is recognised as a high risk time for unscheduled hospital readmission and serious safety issues for people with diabetes.^{5,6,7,8} Current hospital-based discharge information does not address issues specific to older people such as functional and cognitive decline and may not be appropriate for OPWD.^{9,10} Thus, a study was undertaken to develop and formatively evaluate diabetes-specific discharge planning information for older people with diabetes.

The Managing my Diabetes after being in Hospital – Information for Older People with Diabetes and Families document was co-developed and formatively evaluated by OPWD and family carers, acute care nurses, health professionals and researchers to support the post-discharge needs of OPWD and families. The *Managing Diabetes after being in Hospital – Information for Older People with Diabetes and Families* 'DM Discharge planning' document was presented to conference attendees at a workshop during the 2016 ADS-ADEA Annual Scientific Meeting.

Workshop aims

The interactive workshop was designed to engage with participants and elicit their feedback about the DM Discharge planning document. The specific aims were to:

- Provide an overview about discharge planning for older people with diabetes.
- Introduce the DM Discharge planning study and document.
- Discuss roles and responsibilities about discharge planning for older people with diabetes.
- Trial the DM Discharge planning document using case studies.

Workshop participants and process

In total, eighty diabetes health professionals attended the workshop from disciplines including nursing, pharmacy and acute and community-based diabetes educators. The presenters outlined the need for diabetes-specific discharge planning information for OPWD, detailed the DM Discharge planning study and development process and used two case studies to stimulate discussion with participants about the readability and usefulness of the document and the feasibility of using the document in their care setting.

An overview about discharge planning for Older People with Diabetes

Trisha Dunning provided an overview about and definitions of discharge planning and transitional care and identified key issues concerning discharge planning for OPWD, highlighting how recovery is affected by what happens before, during, and after the hospital admission and the important role of family carers. Significantly, discharge planning is a multidisciplinary activity that relies on good communication and patient/ family carer inclusion. In addition, Trisha proposed the Nine-P discharge model:

1. Personalise - decide with the individual/family.
2. Proactive – assess risks before admission.
3. Plan – e.g. The sick day care plan.
4. Predict risks in hospital e.g. Likelihood of adverse event, deterioration, changes in the disease trajectory and function, readmission.
5. Prevent – put strategies in place to minimise the risk e.g. medicine reconciliation.
6. Psychological considerations.
7. Partners – consult, educate.
8. Practice considerations.
9. Post discharge support.

Managing Diabetes after being in Hospital - Information for Older People with Diabetes and their Families study and document

Nicole Duggan presented an overview of the DM Discharge planning document development process, detailing the study and the significance of convening two advisory groups:

- Older People with Diabetes - to provide their experiences and perspectives about their recent discharge, to review and comment on the draft diabetes-specific discharge planning information to ensure it was readable, usable, and relevant and meet their needs.
- Health Professionals with experience in caring for older people with diabetes and/or discharge planning who contributed to and provided feedback about the literature review and the various drafts of the diabetes-specific discharge planning information as the study progressed.

The study used a mixed methods approach using inter-related phases as illustrated in figure 1.

Key selected study findings included:

1. Prior to developing the DM Discharge planning document a retrospective Medical Record Audit (n=62) was conducted which found:
 - » 48% had changes to their Glucose Lowering Medicines (GLMs).
 - » 74% had changes to their other medicines.
 - » 3% had documented evidence of diabetes information provided on discharge.
2. After acute care nurses had access to the DM Discharge planning document a second online survey of acute care nurses (n=31) found that:
 - » 100% agreed the document was clinically relevant.
 - » 74% found the document easy to follow and suitable for older people with diabetes.
 - » 55% indicated the document helped with the discharge of an older people with diabetes.

3. acute care nurses (n=10) identified some challenges to using the document including:
 - » Nurses need education about the information, about managing older people with diabetes and more time to implement the information.
 - » Older people with diabetes did not know some answers and needed prompting.
 - » It was difficult to complete with an older people with diabetes from non-English speaking background.

The cover page of the final version of the DM Discharge planning document is presented in figure 2.

Two case studies and interactive discussion

Michelle Robins facilitated two interactive case studies. Participants were provided with the DM Discharge planning document and were encouraged to consider the usability, readability and clinical relevance of the document and to explore their perceptions of their role and responsibilities for discharge planning for older people with diabetes.

Figure 1: The mixed methods used in the study to develop the Managing Diabetes after being in Hospital-Information for Older People with Diabetes and their Families document.

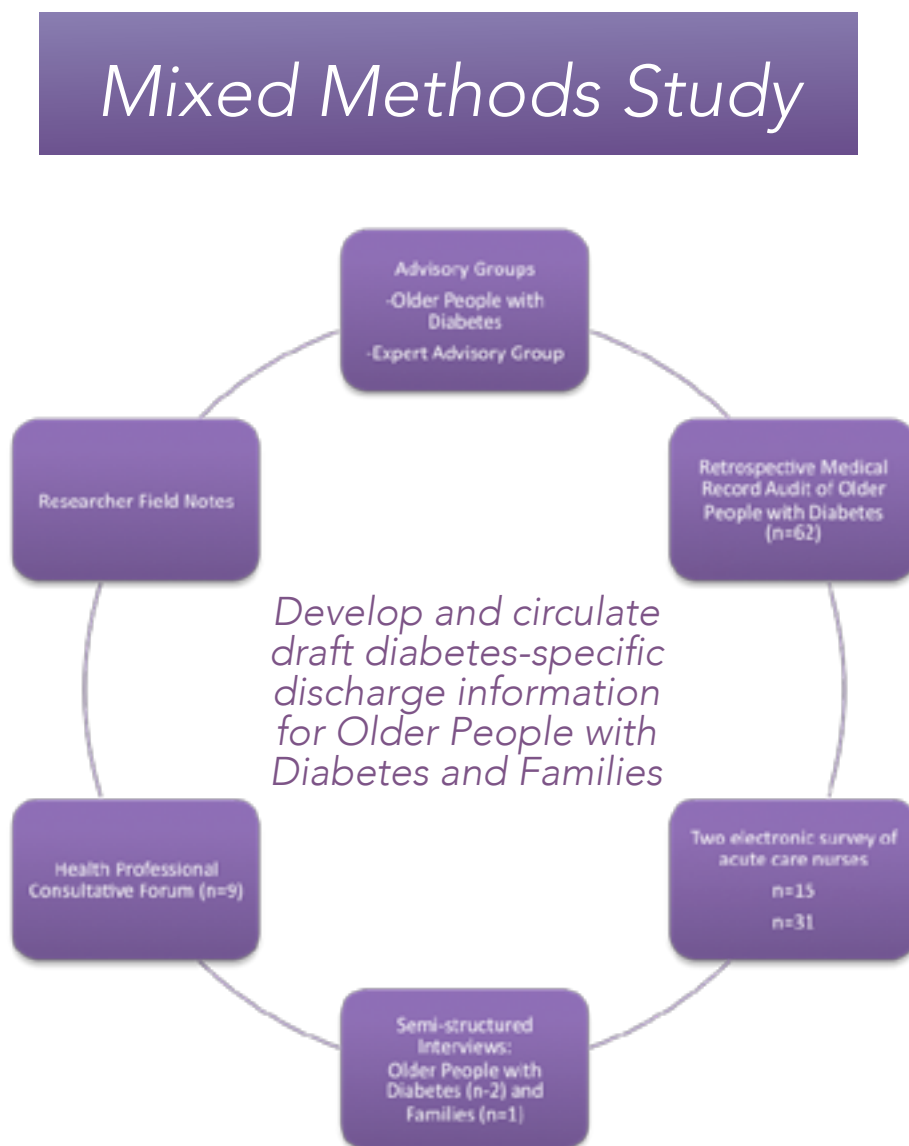
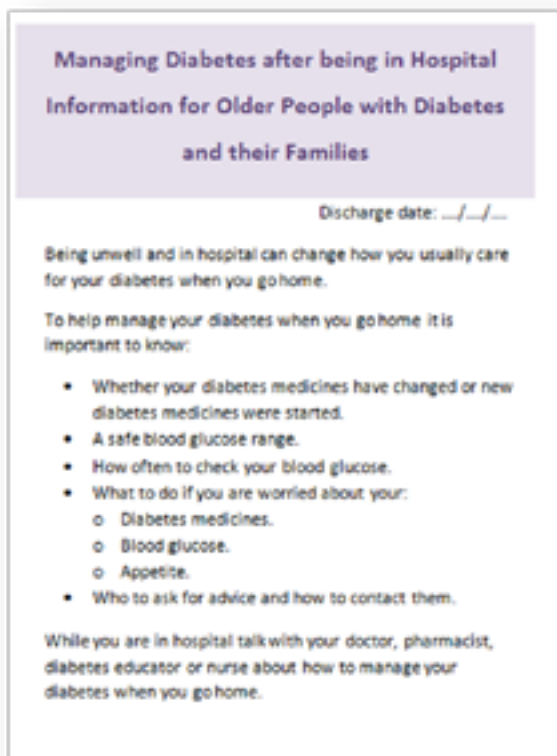


Figure 2: The cover page of the final version of the Managing Diabetes after being in Hospital-Information for Older People with Diabetes and their Families document.



Key workshop discussion themes:

The DM Discharge planning document was well received by workshop participants and the interactive case studies stimulated robust discussion. Four themes emerged from the discussion:

Need for the document

Workshop participants indicated the document is clinically relevant and there is an unmet clinical need for diabetes-specific discharge planning information for all people with diabetes, especially older people. Workshop participants provided some examples of progressing the document for use in clinical practice including creating a colour-coded suite of documents for pre-admission, admission and discharge and expanding to include GDM, other age ranges and people with diabetes from non-English speaking backgrounds.

Content

Workshop participants indicated the content was appropriate, however suggested:

- Modifying the document for older people with low literacy
- Revising the statement about drinking 4 -6 glasses of water
- Adding a section to indicate the person's diabetes diagnosis
- Consider adding a section on signs of infection

Design

Workshop participants indicated the initial design could be enhanced by having the document professionally designed and considering whether some pictures/prompts would be valuable. In addition, more space is needed to write key information in some areas.

Useability

Workshop participants indicated the document was useable beyond its initial plan including being:

- commenced in the community and continued in acute care
- adapted to become a 'pre-admission form' to prevent admission
- a prompt for a Diabetes Educator referral
- provided to pre-op clinics for proactive discharge planning

Next steps

The researchers look forward to working with colleagues to test the feasibility of implementing the DM Discharge planning document into routine clinical practice.

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The Australian Government has recently made changes to the way people with type 2 diabetes who are not using insulin can access blood glucose test strips through the NDSS.

These changes mean that people with type 2 diabetes who are not using insulin are eligible to access subsidised blood glucose test strips over an initial six month period through the NDSS – this six month period commences on the date the person first accesses strips after 1 July 2016. At any time after this initial six months, they will be eligible to access subsidised strips if their doctor, credentialed diabetes educator or nurse practitioner considers it clinically necessary for them to use strips.

People with type 1 diabetes, type 2 diabetes using insulin, women with gestational diabetes and individuals registered through the NDSS as having 'other diabetes' are not subject to these changes.

The initial six month access period will be different for each person, depending on when they first purchased strips after 1 July 2016. For example

- If your patient first accessed blood glucose test strips on 1 August 2017, they will have access until 31 January 2018.
- If your patient first accessed them on 20 January, they will have access until 19 July 2017.

What do you need to do?

If you decide someone with type 2 diabetes who is not using insulin needs to use blood glucose test strips to manage their diabetes, complete the Blood Glucose Test Strip Six Month Approval Form available at www.ndss.com.au/forms.

Once completed, the person with diabetes will need to take the form to their local NDSS Access Point (usually a community pharmacy) to be processed. Any Access Point can also advise the person with diabetes whether their six month access has expired, or will soon expire.

The Government does not expect these changes to affect the frequency of patient visits to healthcare professionals, as people with type 2 diabetes are recommended to undertake HbA1c testing at least every six months and many will also need to visit their health professional to obtain new medication prescriptions every six months.

Why were these changes introduced?

The Government made these changes to the NDSS to ensure people living with diabetes can continue to access the products they need, as well as ensuring the ongoing sustainability of the NDSS.

These changes follow the independent advice of the expert Pharmaceutical Benefits Advisory Committee (PBAC), which recommended changes in access to subsidised blood glucose test strips based on evidence considered through a review of products used in the management of diabetes. A copy of the review report is available at: www.pbs.gov.au/info/reviews/diabetes.

Further information about the changes to the NDSS is available at www.health.gov.au/diabetes-services.

Product Changes:		
Code	Name	Pack Size
New Products – February 1		
305	GE200 Blood Glucose Test Strips	Pack 50
Product Name Changes		
216	Mylife Clickfine Diamond Pen Needle 31G 6mm	Pack 100
217	Mylife Clickfine Diamond Pen Needle 31G 8mm	Pack 100
218	Mylife Clickfine Diamond Pen Needle 29G 10mm	Pack 100
705	MiniMed Reservoir 1.8ml (MMT – 326A)	Pack 10
706	MiniMed Reservoir 3ml (MMT – 332A)	Pack 10
710	Animas 2020 / Vibe 2mL Cartridge (AN100-124-11)	Pack 10
Product Deletions		
704	Minimed Insulin Reservoir 3ml (MMT – 103A)	Pack 10
41	Keto Diabur	Pack 50